

## Newborn Screening Ontario Biliary Atresia Screening Pathway

This document provides an overview of the Newborn Screening Ontario (NSO) biliary atresia (BA) screening pathway. It describes the responsibilities of NSO, birth hospitals and midwifery practices (submitters), and pediatric academic health sciences centres (PAHSCs) at each stage of the pathway.

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

### Biliary atresia screening

BA screening through home stool colour monitoring using an Infant Stool Colour Card (ISCC) is the standard of care for all newborns in Ontario. Parents monitor their infant's stool colour for the first month of life (for infants born at 37 weeks or more), or for 4 weeks past their due date (for infants born <37 weeks gestation).

The purpose of BA screening is to:

- Detect pale stool, which is one of the early signs of BA, at an early stage to prevent irreversible liver damage and improve patient outcomes

An ISCC is a visual reference tool that differentiates pale versus normal stool colours and provides instructions on how to proceed if pale stool is identified. It is distributed to parents by newborn care providers shortly after the birth of their newborn and is used by parents to screen for pale stool colour at home. If parents identify pale stool, instructions on the ISCC guiding them to contact NSO. A telephone triage assessment will be conducted within one business day and infants who are deemed to be 'screen positive' will be referred by NSO to a gastroenterologist at a PAHSC for an outpatient conjugated/direct bilirubin measurement, and further testing/treatment as required.

Find out more about [BA screening](#) on our website.

### BA screening pathway: Infants screened at home

#### 1. ISCC SUPPLY AND DISTRIBUTION FOR HOME SCREENING

These requirements relate to ensuring that ISCC are available, explained, and distributed to the parents/caregivers of every infant born in Ontario.

Birth hospital and midwifery care providers will:

- Maintain a robust supply of ISCCs proportional to the number of births they expect each month
- Develop a process for ordering new ISCCs from NSO's distributor, VWR; ISCCs can be ordered along with dried blood spot (DBS) cards using the same [ordering process](#)
- Distribute an ISCC to parents/caregivers shortly after the birth of their infant and/or in the first few days of life
- Provide parents/caregivers with a simple explanation about the purpose and importance of the screening program, the ISCC, and instructions for its use, while showing the physical copy of the ISCC.
- Direct parents/caregivers to educational content and [translated versions of the ISCC](#) on the NSO website.
- Document the distribution of the ISCC and the education provided in the patient chart and on the screening card

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NSO will:

- Ensure adequate ISCC supply is available for submitter ordering through our distributor

## 2. IN-HOME ISCC SCREENING (IDENTIFY PALE STOOL)

These requirements relate to the process of in-home screening of newborn stool colour by parents/caregivers using the ISCC.

Parents/caregivers will:

- Use the ISCC to monitor their infant for pale stool colour daily for the first month of life
- Contact NSO through our web portal, email, or phone line if pale stool is identified
- Submit photos of their infant's stool, as requested by NSO, to either the NSO BA email or web portal

NSO will:

- Provide education about the BA screening program to healthcare providers and the public through [NSO website resources](#), webinars, online presentations, and professional organization publications
- Contact parents who notify NSO about their infant's pale stool concern within one business day to perform a telephone triage assessment
- Follow infants, via email or telephone, who have indeterminate (not yet determined to be screen positive or negative) stool pictures until a screen determination is made
- Refer infants who have pale stool identified using the ISCC (screen positive) to a pediatric gastroenterologist at a PAHSC for further investigation and treatment as needed (see Appendix A)
- Provide a mailed telephone triage summary letter to parents who reach out to NSO, and the infant's primary care provider, about their infant's pale stool

PAHSC gastroenterology teams will:

- Confirm receipt of the faxed referral form with NSO within 6 hours (same business day) of the referral

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### 3. LABORATORY CONFIRMATION OF CHOLESTASIS FOR INFANTS SCREENED AT HOME

These requirements relate to the process of following up on screen positive results to confirm if the pale stool is due to cholestasis. A direct or conjugated bilirubin measurement is required for all infants who have pale stool identified using the ISCC.

Parents/caregivers will:

- Bring their infant to a community or hospital laboratory, as requested by their referred PAHSC, for blood work to measure direct or conjugated bilirubin level
- Bring their infant for any follow up investigations and treatment as requested by their referred PAHSC

PAHSC gastroenterology teams will:

- Contact parents of infants who are screen positive within 24h of receiving the referral form from NSO to instruct them about arrangements to get a direct/conjugated bilirubin level measured
- Arrange for infants to have a direct/conjugated bilirubin test performed at a community or hospital laboratory within 48h of referral
- Follow up on and interpret bilirubin lab results and arrange for further investigations and treatment as needed
- Notify parents of the bilirubin lab results and any further repeat lab tests if needed
- Provide NSO with information about screen positive infants via the [Diagnostic Evaluation Report Form](#) (DERF)

NSO will:

- Follow up on direct/conjugated bilirubin lab results for infants identified and referred as 'screen positive' through EPIC or OLIS within 72h of referral to a PAHSC to confirm completion of this test.
- Collect information about screen positive infants from the PAHSC from the DERF

### 4. DIAGNOSTIC INVESTIGATIONS TO DETERMINE CAUSE OF CHOLESTASIS

If the result of the bilirubin measurement indicates cholestasis is present, the infant will need further investigations to determine if BA is the cause of the cholestasis.

Parents/caregivers will:

- Bring their infant for any follow-up investigations as requested by their referred PAHSC

NSO will:

- Collect information about screen positive infants from the PAHSC on the DERF

PAHSC gastroenterology teams will:

- Arrange for screen positive infants with cholestasis to have timely diagnostic testing to determine if BA is the cause
- Provide NSO with information about screen positive infants via the DERF

## BA screening pathway: Infants screened while in hospital

For infants admitted to hospital, NICU/SCN/pediatric ward care providers assume the role of the primary screener until the infant is discharged. During the hospital stay, care providers are responsible for ensuring that ISCC screening is carried out at each diaper change, that an ISCC is available at the bedside, and that any pale stool concerns are promptly acted upon. Care providers are also responsible for educating parents/caregivers prior to discharge about the purpose and importance of biliary atresia screening, how to use the ISCC at home, and where to access additional educational resources, including translated materials. Distribution of the ISCC and parent education provided must be documented in the patient record in accordance with institutional policies.

## Symptomatic presentation of BA

This section outlines required actions when an infant presents directly to a PAHSC gastroenterology team with pale stool (outside of the BA screening program), and it is determined the infant has BA.

PAHSC gastroenterology teams will:

- Notify NSO about these infants, and obtain consent from the parents/caregivers for this notification to NSO, using the [Symptomatic Diagnostic Report Form \(SDRF\) or SDRF webform](#)

NSO will:

- Obtain information from the PAHSC about these infants so an SDRF can be completed
- Follow up on any concerns identified through the SDRF case with submitter sites

## Appendix A

# BILIARY ATRESIA SCREEN POSITIVE CRITERIA AND FOLLOW UP

### Screen Positive Considerations

- 2 or more pale stools (1-6) for at least 24h duration
- any pale stool (1-6), even if only for <24h, and if > 2weeks old with persistent jaundice and/or dark urine
- any pale stool if > 3 weeks old

*Note: infants 2-3 weeks old with very infrequent stooling but only 1 pale stool may also need to be referred for a bilirubin measurement*

