



Biliary Atresia In-Home Screening Protocol

Purpose:

- To ensure a consistent and effective methodology for in-home screening for biliary atresia (BA).

Scope or Principle:

This protocol outlines the Newborn Screening Ontario (NSO) guidelines for in-home biliary atresia screening.

Background:

BA screening using an Infant Stool Colour Card (ISCC) can assist in the early identification and treatment of biliary atresia, resulting in better outcomes for affected babies.

Responsibility:

HCPs caring for newborns during the first weeks of life, including but not limited to nurses and midwives, should be familiar with the protocol, distribute the ISCC and provide education to parents/families in order to facilitate in-home screening for BA.

Definitions/Acronyms:

- NSO = Newborn Screening Ontario
- BA = Biliary Atresia
- HCP = Health Care Provider
- ISCC = Infant Stool Colour Card **Appendix A**
- NICU/SCN/PICU = Neonatal Intensive Care Unit/Special Care Nursery/Paediatric Intensive Care Unit
- DBS card = Dried Blood Spot card

Related Documentation:

- Frontline Education Script **Appendix B**
- Newborn Screening Ontario Biliary Atresia – Newborns Admitted To Hospital Protocol
- How to Screen for Biliary Atresia – Step by Step

Distribution of Infant Stool Colour Cards Suggested Procedure:

1. Caregivers of all newborns in Ontario should receive an ISCC shortly after the birth of their baby for biliary atresia screening.
2. Hand out the ISCC either at the time of discharge, or ideally while performing the newborn screening dried blood spot or CCHD screening. A brief instruction from the frontline care provider distributing the card should follow. Please refer to the Frontline Education Script (Appendix B) for recommended discussion points.
3. It is strongly recommended to document the distribution and teaching in your discharge checklist/patient medical record, as per organization documentation standard.

Special Considerations:

Please consider associated protocols for screening in the following circumstances:

- Admitted Newborn and Biliary Atresia Screening





Appendix A:

BILIARY ATRESIA INFANT STOOL COLOUR CARD:



Infant Stool Colour Card
Carte colorimétrique des selles du bébé

ABNORMAL Stool Colours Couleurs des selles ANORMALES		
1	2	3
4	5	6
Consult the physical version of this card for greater colour accuracy. Consultez la carte en papier pour une plus grande précision des couleurs.		
NORMAL Stool Colours Couleurs des selles NORMALES		
7	8	9

INSTRUCTIONS

Check your baby's stool (poop) colour every day for the first month after birth to screen for biliary atresia.

If your baby has an abnormal stool colour (see above colours 1,2,3,4,5,6), please contact Newborn Screening Ontario by phone or email or by scanning the QR code below.

INSTRUCTIONS

Vérifiez la couleur des selles (cacas) de votre bébé chaque jour durant le premier mois de vie pour dépister l'atrésie des voies biliaires.

Si les selles de votre bébé ont une couleur anormale (voir couleurs ci-dessus 1,2,3,4,5,6), veuillez contacter Dépistage Néonatal Ontario par téléphone, par courriel, ou en scannant le code QR ci-dessous.

Phone / Téléphone : **1-833-POOP-CHK**
(1-833-766-7245)

Online / En ligne : www.newbornscreening.on.ca/poop

Email / Courriel : [NSOBA@cheo.on.ca](mailto:nsoba@cheo.on.ca)



When identification and treatment start early, babies with biliary atresia can have a better chance to grow and develop normally.

What is biliary atresia?

Biliary atresia (BA) is a rare but serious disease where bile cannot get from the liver to the stool (poop). Babies with BA usually seem well but they can develop **pale yellow or whitish coloured stools** in the first month of life. Along with the pale poop, these babies can have yellow skin and eyes (**jaundice**) **lasting longer than the first two weeks of life**. Without treatment, babies with BA will develop life-threatening liver damage. Treatment is most effective when babies are identified before they are one month old.

How can you screen for biliary atresia?

You can screen for BA by comparing your baby's stool (poop) colour to the numbered pictures on the front of this card, for the first month after birth. Screening for abnormal stool colour can help to identify problems with the liver earlier. Keep this card close by when you change your baby's diaper.

Who do I contact and when?

If at any time during the screening you notice that your baby has an abnormal stool colour (number 1,2,3,4,5, or 6), please contact Newborn Screening Ontario using the information on the front of this card.

Please have available the baby's name, birth date, and health card number. If you also choose to see your doctor, please take this card with you.

What happens next?

First, don't be alarmed. This is a screening tool and not a diagnostic test. A clinical team member from Newborn Screening Ontario will return your call by the next business day to discuss your concern and begin next steps. Your privacy and health information is protected. Learn more: www.newbornscreening.on.ca/privacy

If you have concerns about your baby **other than stool colour**, please contact your health care provider. For more information about biliary atresia, visit our website or scan the QR code on the front of the card.

Information is available in other languages. / Ces informations sont aussi disponibles dans d'autres langues.
www.newbornscreening.on.ca/poopcard

Le dépistage précoce et le traitement sans délai chez les bébés atteints de l'atrésie des voies biliaires peuvent les aider à grandir et se développer normalement.

Qu'est-ce que l'atrésie des voies biliaires?

L'atrésie des voies biliaires (AVB) est une maladie rare et grave dans laquelle la bile ne passe pas du foie aux selles (cacas). Les bébés atteints de l'AVB semblent être en bonne santé, mais leur selles peuvent être de couleur **jaune pâle ou blanchâtre** au cours du premier mois de leur vie. En plus d'avoir des selles pâles, les bébés peuvent avoir une coloration jaune de la peau et des yeux (**jaunisse**) qui dure **plus longtemps que les deux premiers semaines de vie**. Sans traitement, les bébés atteints de l'AVB développeront de sérieux dommages au foie, potentiellement mortels. Le traitement est plus efficace quand les bébés sont identifiés avant l'âge d'un mois.

Comment puis-je dépister l'atrésie des voies biliaires?

Pour dépister l'AVB, il suffit de comparer la couleur des selles (cacas) de votre bébé aux images numérotées au recto de cette carte pendant le premier mois suivant la naissance. Le dépistage d'une couleur anormale des selles peut aider à identifier plus tôt les problèmes liés au foie. Gardez cette carte près de l'endroit où vous changez la couche de votre bébé.

Qui devrais-je contacter, et quand?

Si, à tout moment pendant le dépistage, vous remarquez que les selles de votre bébé ont une couleur anormale (numéro 1, 2, 3, 4, 5 ou 6), veuillez communiquer avec le Dépistage Néonatal Ontario en utilisant les renseignements au recto de la carte.

Veuillez avoir à portée de main le nom du bébé, sa date de naissance et son numéro de carte santé. Si vous choisissez également de consulter votre médecin, veuillez apporter cette carte avec vous.

Que se passe-t-il ensuite?

D'abord, ne vous inquiétez pas. Il s'agit d'un outil de dépistage et non d'un test diagnostique. Un membre de l'équipe clinique de Dépistage Néonatal Ontario vous rappellera d'ici le prochain jour ouvrable pour discuter de vos préoccupations et amorcer les prochaines étapes. Votre vie privée est protégée et vos renseignements médicaux sont confidentiels. Pour en savoir plus : www.newbornscreening.on.ca/fr/vie-privee

Si vous avez des préoccupations concernant votre bébé **autres que la couleur des selles**, veuillez communiquer avec votre fournisseur de soins de santé. Pour en savoir plus sur l'atrésie des voies biliaires, consultez notre site web ou scannez le code QR au recto de la carte.

We thank / Nous remercions
Heeh Promotion Administration, Ministry of Health and Welfare, Taiwan, and Professor Aili Hsueh Chang, National Taiwan University, College of Medicine
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Version: 2022.1 415 Smyth Road, Ottawa, ON K1H 8M8 Phone: 1-833-766-7245
DOI: WELB www.newbornscreening.on.ca - NSOBA@cheo.on.ca - @NBS_Ontario
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Appendix B:

Education for Families Script:

Frontline Script for Biliary Atresia Screening

- ✓ Ensure parents/families have an Infant Stool Colour Card (ISCC) to screen at home.

Explain the following at time of discharge to parents/families:

1. Biliary atresia (BA) is a rare but serious disease where bile cannot get from the liver to the stool (poop). Babies with BA can seem well at first but can develop pale coloured poop as one of the first signs of this problem. We can screen for this liver problem by watching for any pale poop and reporting it if it occurs. Without treatment, babies with BA will develop life-threatening liver damage. Treatment is most effective when babies are identified before they are 1 month old.
2. It is important to check your baby's poop every day for the first month of life. You can do this by comparing your baby's poop colour to the numbered pictures on the infant stool colour card that you will take home with you. Please note that it is normal for newborn poop to transition from very dark meconium to greenish then to yellow colour towards the end of the first week of life.

Screening Advice for Preterm Infants: If baby is born before 37 weeks of age, continue screening until 1 month post due date. Babies born preterm have a higher chance of developing BA and may develop symptoms later. We recommend screening their poop for longer than babies born full term.

3. If your baby's poop colour is closest to picture numbers 7, 8, or 9 on the ISCC:
 - This is normal; keep screening for your baby's first month of life.
4. If your baby's poop colour is closest to picture numbers 1, 2, 3, 4, 5, or 6 on the ISCC:
 - These are abnormal colours and might mean there is a problem.
 - Don't be alarmed. Please remember this is a screening tool and not a diagnostic test.
 - Contact Newborn Screening Ontario using the contact information on the card:

Phone – or – Email – or – Website – or – QR code

- A clinical team member from Newborn Screening Ontario will contact you by the next business day to discuss your concern and determine if any next steps need to be taken.
- The Newborn Screening Ontario clinical team member will only be able to assist with concerns you have about the pale colour of your baby's poop. If you have any concerns other than poop colour about your baby, you should contact your family doctor or pediatrician.
- In addition to calling Newborn Screening Ontario, if you also decide to go see your baby's doctor about this problem, please bring this card with you to the visit.
- We recommend screening for 1 month after birth, but if you notice pale stools after this time, please feel free to still contact NSO.

More information about Biliary Atresia and screening (if needed) can be found at:

<https://www.newbornscreening.on.ca/poop>

When identification and treatment start early, babies with biliary atresia can have a better chance to grow and develop normally.

Thank you for your frontline contribution to newborn screening in Ontario.

(see reverse)





Frontline Script for Biliary Atresia Screening

NEWBORNS ADMITTED TO HOSPITAL

All newborns should be screened for biliary atresia regardless of whether they are in-hospital or at home!

DURING HOSPITALIZATION:

- ✓ Ensure Infant Stool Colour Card (ISCC) is at bedside/accessible for screening.

Explain the following to parents/families:

1. We are monitoring the baby's stool (poop) colour. Pale coloured poop can be an early sign of biliary atresia.
2. Biliary atresia (BA) is a rare but serious liver disease where bile cannot get from the liver to the poop. Babies with BA can seem well at first but can develop pale coloured poop as one of the first signs of this problem. We can screen for this liver problem by watching for any pale poop. Treatment is most effective when babies are identified before they are 1 month old (1 month past due date).

Important: If pale poop is detected while the baby is hospitalized, please notify NSO about this 'screen positive' case for documentation and facilitation of referral to pediatric gastroenterology.

AT DISCHARGE:

BILIARY ATRESIA SCREENING WINDOW

Term (37 weeks or more): Screen for the first month of life

Pre-term (36 weeks + 6 days or less): Screen until one month past the baby's due date

If baby is still within the screening window as described above:

- ✓ Ensure parents/families have an Infant Stool Colour Card (ISCC) to screen at home.
- ✓ Refer to the other side of this script for information to be communicated to parents/families at discharge.

(see reverse)

