



Bulletin #76
January 17, 2014

Changes to the Blood Spot Collection Card

Revised blood spot collection cards are now in circulation. Next time you order cards from VWR be sure to take note of the following improvements.

1) New field for arterial method of collection

While the method of choice for newborn screening sample collection is heel stick directly applied, NSO recognizes that this is not always possible. A new field for arterial method of collection has been added to the blood spot collection to provide a space for you to indicate when a sample is collected by this method.

2) Date of transfusion replaced with date of latest transfusion

As you know, packed red blood cell (PRBC) transfusions are known to affect the results of screening for the hemoglobinopathies and galactosemia. For this reason, if an infant has had a PRBC transfusion prior to the newborn screen, a repeat sample should be obtained 4-6 months after their *most recent* transfusion.

It is important for NSO to know the date of an infant's *latest transfusion* in order to determine whether a repeat sample was collected in the appropriate time frame (4-6 months later). The blood spot collection card has been updated accordingly and this change should reduce the number of phone calls you receive from NSO to clarify these cases.

3) Addition of a newborn screening decline/defer form (Appendix 1)

As you know, newborn screening in Ontario is not mandatory but is standard of care for all infants. While most parents choose to have their newborn screened, a very small number of parents choose to decline newborn screening. Others choose to defer the newborn screen (i.e. when they are discharged prior to 24 hours). Results from the NSO submitter survey indicated that the development of a newborn screening decline form would be of value as it will help the documentation of declined newborn screens and simplify the missed screen system that exists to ensure every newborn is offered screening. We have therefore included a decline/defer form as a separate page of the blood spot collection card (Appendix 1).

It is the responsibility of antenatal and newborn care providers at hospitals and midwifery practices to ensure that every infant is offered timely access to newborn screening and that their parents are informed and educated appropriately. Declined or deferred newborn screens should be documented.

While not intended to replace your current method of documenting declined or deferred newborn screens, this form may enhance your practice by:

- improving consistency in documentation of declined/deferred newborn screens,
- reducing the number of communications (phone calls, potential missed newborn screen alerts) from NSO to follow-up on missed newborn screens that have been declined, and
- tracking cases where newborn screening has been deferred by parents.





How to use the NBS decline/defer form to enhance your practice

Key Discussion Points for Parents

- Babies can look normal at birth and still have one of the 29 diseases screened, which can cause mental retardation, growth and health problems, and/or sudden infant death.
- The goal of screening is early detection - so that treatment can be started early and better health achieved.
- Newborn screening samples should ideally be obtained between 24-72 hours of age.
- Some of the diseases on the screening panel, however, can cause severe health problems in the first week of life, and screening is therefore recommended at hospital discharge even if this occurs at <24 hours.
- Newborn screening will be available to the family at any time within the first year of life but the benefits are greatest if the newborn screening tests are done within the first week of life.

Note: The NSO website and new pamphlets can also help!

Parents Decline Newborn Screening

- If, after an informed discussion, parents choose to decline newborn screening for their baby, please ask them to check the appropriate box and sign the decline/defer form portion of the blood spot collection card (Appendix 1).
 - "I choose **NOT** to have my baby's blood taken for newborn screening tests"
- Please complete the entire requisition portion of the blood spot collection card and send it to NSO (without applied blood).
- NSO will send you a decline letter (Appendix 2) for your records. No further follow-up will come from NSO.

Parents Defer Newborn Screening

- If, after an informed discussion, parents choose to defer newborn screening for their baby, please ask them to check the appropriate box and sign the decline/defer form portion of the blood spot collection card (Appendix 1).
 - "My baby is/will be discharged before 24 hours of age and I plan to have my baby screened at a later date"
- Please complete the entire requisition portion of the blood spot collection card and send it to NSO (without applied blood).
- If a sample has not been received after 14 days, NSO will send a reminder letter to the submitter and family (Appendix 3).

Early Discharge

Wherever possible, a newborn screening sample should be collected from all infants prior to discharge when discharge is <24 hours. While unsatisfactory, samples collected <24 hours are still analyzed by NSO and if screen positive for a disease, the infant will be referred to a Regional Treatment Centre for follow-up testing.





NEWBORN SCREENING ONTARIO DÉPISTAGE NÉONATAL ONTARIO

APPENDIX 1 – Sample Decline/Defer form

NEWBORN SCREENING ONTARIO DECLINE/DEFER FORM DÉPISTAGE NÉONATAL ONTARIO – FORMULE DE REFUS OU D'AJOURNEMENT

Please have the form completed and returned to NSO if the parent/ guardian declines or defers newborn screening.

Veuillez remplir ce formulaire et le retourner à DNO si le parent ou tuteur décide de refuser ou de remettre à plus tard le dépistage chez le nouveau-né.

I have been informed that / On m'a expliqué que :

1. Newborn screening for at least 29 treatable diseases is a medical recommendation and considered standard of care for every baby born in Ontario. My baby can look normal and still have one of these diseases that can cause mental retardation, growth and health problems, and/or sudden infant death. The goal of screening is early detection - so that treatment can be started early and better health achieved.

Les médecins recommandent que l'on administre aux nouveau-nés un test de dépistage de 29 maladies qu'il est possible de traiter. Ils considèrent ce test comme une norme de soins de base pour tous les bébés nés en Ontario. Même si mon bébé semble normal, il est possible qu'il soit atteint d'une maladie qui cause un retard du développement mental, des troubles de croissance et de santé ou le syndrome de mort subite du nourrisson. Ce dépistage permet de détecter ces troubles le plus tôt possible afin que l'on puisse tout de suite commencer à traiter le bébé et qu'il jouisse d'une meilleure santé.

2. Newborn screening samples should ideally be obtained between 24-72 hours of age. Some of the diseases on the screening panel, however, can cause severe health problems in the first week of life, and screening is therefore recommended at hospital discharge even if this occurs before 24 hours of age.

Idéalement, il faudrait prendre les prélèvements du dépistage entre 24 et 72 heures après la naissance du bébé. Cependant, certaines des maladies de la liste à tester peuvent causer de graves troubles de santé dès la première semaine de vie du nourrisson. On recommande donc d'effectuer ce dépistage au moment où le nouveau-né sort de l'hôpital, même s'il n'est pas encore âgé de 24 heures.

3. Newborn screening will be available to my baby at any time within the first year of life but the benefits are greatest if the newborn screening tests are done within the first week of life. If I would like my baby screened at a later date, I have been informed that I can speak to my baby's health care provider.

Je pourrai faire administrer ce test de dépistage à mon bébé n'importe quand pendant sa première année. Cependant, ce test est beaucoup plus utile lorsqu'on l'administre pendant la première semaine de vie du nourrisson. On m'a expliqué que si je désire faire tester mon bébé plus tard, je peux en parler au fournisseur de soins de santé de mon bébé.

Please complete the relevant section / Veuillez remplir la section qui vous concerne.

- ☐ I choose **NOT** to have my baby's blood taken for newborn screening tests (either for the original screen or as required for repeat testing in instances of transfusion or unsatisfactory initial samples).

J'ai décidé de ne PAS permettre que l'on prélève du sang de mon bébé pour effectuer les tests de dépistage chez les nouveau-nés (qu'il s'agisse du dépistage initial ou d'un prélèvement pour les tests requis en cas de transfusion ou pour remplacer un échantillon initial non satisfaisant).

OPTIONAL: The reason(s) I have chosen to not have my baby screened is

RÉPONSE OPTIONNELLE : Voici la ou les raisons pour lesquelles je ne permets pas que l'on administre ce test à mon nouveau-né :

OR/OU

- ☐ My baby is/ will be discharged before 24 hours of age and I plan to have my baby screened at a later date.

Mon bébé sortira de l'hôpital avant qu'il ait 24 heures. Je lui ferai administrer le test à une date ultérieure.

Baby's name / Nom du bébé

(Please also complete the Demographic section of the NBS card, including date of birth and health card number. Veuillez aussi remplir la section « Démographie » de la carte NBS, y compris le numéro de la carte-santé et la date de naissance du bébé.)

Parent/guardian: signature
Signature du parent ou tuteur

Parent/guardian: please print
Nom du parent ou tuteur
(en lettres moulées)

Date

Physician/midwife: signature
Signature du médecin ou
de la sage-femme

Physician/midwife: please print
Nom du médecin ou de la
sage-femme (en lettres moulées)

Date



APPENDIX 2 – Sample Submitter Decline Letter



NEWBORN SCREENING ONTARIO
DÉPISTAGE NÉONATAL ONTARIO

Children's Hospital of Eastern Ontario
415 Smyth, Ottawa Ont. K1H 8L1
(613) 738-3222

2014-1-13

Hospital/Midwifery Practice
FAX: 123456789

RE: DOE, Baby Boy

Gender: Male

Health Card Number: 123456789

DOB: 2014/01/07

NSO#: 201301093400

TOB: 13:02

Mother's Name: Doe, Jane

Newborn Screening Ontario (NSO) received notice that the above mentioned baby will not be having a sample collected as the family has declined newborn screening. Newborn screening is still available at any time within the first year of life but the benefits are greatest if the newborn screening tests are done within the first week of life. If the family decides that they would like to have newborn screening in the future, a sample can still be submitted to NSO.

If you have questions or concerns about this notification, or additional information about this baby you would like to share with us, please contact the genetic counsellor with Newborn Screening Ontario at 613-738-3222, option 1.

Sincerely,

Dr. P. Chakraborty, MD, FRCPC, FCCMG
Program Director

Version Date: January 9, 2014





APPENDIX 3 – Deferred Sample Reminder Letter



NEWBORN SCREENING ONTARIO
DÉPISTAGE NÉONATAL ONTARIO

Children's Hospital of Eastern Ontario
415 Smyth, Ottawa Ont. K1H 8L1
(613) 738-3222

Reference #: 201301073400
2014-1-09

Dear Jane Doe
123 Any St, Ottawa, ON

RE: DOE, BABY BOY

Date of Birth: 2014/01/07

Health Card Number: 123456789

We are sending you this letter to make sure you know that we have not received a newborn screening sample for your baby. We have included information about newborn screening with this letter. If you have decided not to have your baby screened, please disregard this letter.

If you are still planning on having your baby screened, please contact your baby's health care provider so they can help arrange for the newborn screen. The newborn screen needs to be taken on a special filter paper that is NOT available at most community blood laboratories. For this reason, most babies will have to go to a hospital to have screening.

If you or your doctor or midwife has questions about this letter or how to arrange for a newborn screen you can contact Newborn Screening Ontario at 1-877-627-8330. Additional information can be found on our website at www.newbornscreening.on.ca.

Sincerely,

Members of Newborn Screening Ontario

cc: HOSPITAL/MIDWIFERY PRACTICE
Family Doctor

Version date: January 9, 2014

