



NEWBORN SCREENING ONTARIO  
DÉPISTAGE NÉONATAL ONTARIO



# Ontario Newborn Screening for Critical Congenital Heart Disease (CCHD)


## Documentation and Follow-Up



# *NSO CCHD Screening Program*



## *Objectives*

- ♥ How to fill out the newborn screening card with  CCHD screening results page
- ♥ What to expect with a Screen Positive result



Documentation



# *Documentation Responsibilities*



- ♥ Documenting CCHD results, including saturation values and screen evaluation in the patients chart or health record and the CCHD page of the newborn screening card
- ♥ Providing NSO with follow-up information for screen positive infants



# Demographic Details (top of card)



## CRITICAL CONGENITAL HEART DISEASE (CCHD) SCREENING RESULTS SHEET

**INFANT**

Last Name

First Name

Health Card Number

Submitter Unique Number

Multiple Birth: N/A A B C

Sex:  M  F  Ambiguous

Date of Birth: Y Y M M D D

Time of Birth: H H M M  AM  PM

**LABEL**

**SUBMITTING HEALTH CARE PROVIDER**

Hospital/Midwifery Practice Name

Address

City

Screen Performed By: Last Name

First Name

♥ Identifiable with a bar code; shares an ID number with the blood spot portion

♥ Ensure the information is complete

- Label (if applicable), date and time of birth, date of screen, etc.

*\*\* especially important for patient identification when the CCHD page is separated from the blood spot portion*

# Screening Details (bottom of card)



**Initial screen** Evaluate screening result with NSO CCHD screening algorithm or evaluation chart

Y Y M M D D Date of CCHD screen	R Hand: _____%	<input type="checkbox"/> Pass
H H M M Time of screen	Foot: _____%	<input type="checkbox"/> Repeat
	Difference: _____%	<input type="checkbox"/> Refer *

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**First repeat (if applicable)**

H H M M Time of screen	R Hand: _____%	<input type="checkbox"/> Pass
	Foot: _____%	<input type="checkbox"/> Repeat
	Difference: _____%	<input type="checkbox"/> Refer *

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**Second repeat (if applicable)**

H H M M Time of screen	R Hand: _____%	<input type="checkbox"/> Pass
	Foot: _____%	<input type="checkbox"/> Refer *
	Difference: _____%	

\* URGENT physician assessment required at time of screen

**Reason screen not done (check box that applies)**

- Decline/deferred (complete form on back of page)
- Infant in or is expected to be in NICU/SCN/PICU over 7 days
- Infant diagnosed prenatally with heart defect
- Infant diagnosed with heart defect by physical exam
- Other (ex. limb anomaly). Specify: \_\_\_\_\_

Screen results go here

If the screen is not completed, indicate why here

Forward to **Newborn Screening Ontario** once the CCHD screening results page is filled out. Follow your usual card submission process.

# CCHD Decline/Defer Portion



♥ Declined/Deferred screens should be documented

♥ While not intended to replace your current method of documenting declined/deferred screen, the back of the CCHD page provides an option for this if needed



## NEWBORN SCREENING ONTARIO DECLINE/DEFER FORM FOR CRITICAL CONGENITAL HEART DISEASE (CCHD) SCREENING — FORMULAIRE DE REFUS/REPORT DU DÉPISTAGE DE LA CARDIOPATHIE CONGÉNITALE CRITIQUE (CCC) DE DÉPISTAGE NÉONATAL ONTARIO

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

Veuillez remplir ce formulaire et le retourner au DNO si le parent/tuteur refuse ou reporte le dépistage néonatal de la CCC.

I have been informed that / J'ai été informé que :

1. Newborn screening for CCHD is a medical recommendation and is considered standard of care for every baby born in Ontario. My baby can look normal and still have CCHD, which can cause severe health problems and/or sudden infant death. The goal of CCHD screening is early detection- so that treatment can be started early and better health achieved.

Le dépistage néonatal de la CCC est une recommandation médicale et est considéré comme une norme de soins pour tous les bébés nés en Ontario. Mon bébé peut sembler normal et être tout de même atteint de la CCC, qui peut causer de graves problèmes de santé et/ou la mort subite du nourrisson. Le dépistage a pour objectif la détection précoce de la CCC afin de pouvoir administrer le traitement rapidement et assurer une meilleure santé pour votre bébé.

2. It is best to do newborn screening for CCHD between 24-48 hours of age. If my baby leaves hospital before 24 hours of age, my health care provider should make arrangements to have the CCHD screen done when my baby is 24-48 hours of age.

Idéalement, le dépistage néonatal de la CCC se fait entre 24 et 48 heures après la naissance. Si mon bébé quitte l'hôpital moins de 24 heures après sa naissance, mon fournisseur de soins de santé devrait prendre les dispositions nécessaires pour que le dépistage de la CCC soit effectué lorsque mon bébé aura 24 à 48 heures.

3. My baby's CCHD screening results and screen positive follow-up information are collected by NSO to ensure he or she has been effectively screened. NSO will also use this information to maintain and improve the quality of the CCHD newborn screening program. NSO is committed to keeping my baby's information safe and confidential. NSO meets or exceeds all the requirements set out in Ontario's *Personal Health Information Protection Act, 2004*, for the protection of personal health information.

Les résultats du dépistage de la CCC de mon bébé et l'information du suivi associé à un dépistage positif sont recueillis par le DNO pour s'assurer que mon bébé a effectivement fait le test de dépistage. Le DNO utilisera également cette information pour maintenir et améliorer la qualité du programme de dépistage néonatal de la CCC. Le DNO respecte et dépasse toutes les exigences en matière de protection des renseignements personnels édictées dans la Loi sur la protection des renseignements personnels sur la santé de l'Ontario de 2004.

4. This form will be sent to NSO to document that CCHD screening was offered to me, and if I have declined to make sure I am not contacted about this.

Ce formulaire sera envoyé au DNO pour confirmer que le dépistage de la CCC m'a été offert et, si j'ai refusé ce dépistage, que je ne serai pas contacté à ce sujet.

Please complete the relevant section / Veuillez remplir la section pertinente.

I choose NOT to have my baby's CCHD screening done.

Je choisis que mon bébé NE fasse PAS le dépistage de la CCC.

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

FACULTATIF : Raison(s) pour laquelle ou lesquelles j'ai choisi que mon bébé ne fasse pas le dépistage de la CCC :

OR/OU

My baby is/will be discharged before 24 hours of age and I plan to have my baby screened for CCHD, optimally by 48 hours of age.

Mon bébé obtient/obtiendra son congé moins de 24 heures après sa naissance et je prévois que mon bébé fera le dépistage de la CCC, idéalement dans les premières 48 heures de vie.

Baby's name/Nom du bébé

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

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



# *Collected Screening Results*



- ♥ Screening results are collected by NSO and entered into an information system, with built-in algorithm evaluation (double check in place 😊)
- ♥ Any risks are identified and an alert is created (incomplete data, incorrect interpretation, missed screen, etc.)
- ♥ NSO will call the organization involved to follow up on the alert

# Screen Positive Results



- ♥ Newborn Screening Ontario will follow up on all screen positives with a phone call
- ♥ You will be asked to assist in the completion of the *Diagnostic Evaluation Report Form (DERF)*.
- ♥ NSO will inquire about the screen results and baby's course in hospital

# *DERF Information Collected*



- **Screen Results**

- Confirmation of screening results submitted

- **Diagnostic Evaluation**

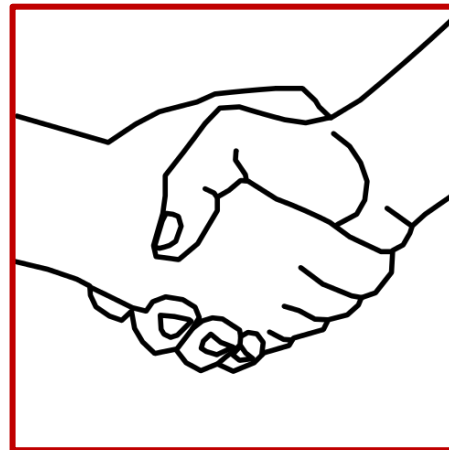
- Who was referral made to? Date/time of referral? Date/time of assessment?
- Was an echocardiogram completed? (date/time)
- Was a decision made to transfer patient? To where? How? (By what method? Transport team?)
- What supportive interventions were necessary? (Prostaglandins? Intubation and ventilation?)

- **Definitive Diagnosis**

- Was there a definitive diagnosis made? Please specify.
- Comments (can add value to the case if there was anything noteworthy)



***Collaboration between NSO, hospitals,  
midwives and newborn care providers is  
essential to ensure quality CCHD  
screening by pulse oximetry for all babies  
of Ontario***



# Questions?



***Thank you for your front line  
commitment to promoting  
healthy starts for Ontario's  
babies!***

# References



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