



Parent Refusal essentials

Remember

- Some parents may have concerns about newborn blood spot screening. However, if an infant is not screened and has one of the treatable conditions, the condition may not be found early when treatment can help the infant the most.
- Parents can refuse initial collection or any repeat collection. It is important to ask if it is okay to collect their baby's blood spots (parent gives express consent verbally) before each collection.

For more information

visit www.ahs.ca/newbornscreening

Staff Education



Talking with Parents



Using the Parent Information Sheets

Parent Info

Additional Information for Parents

Clinical Policy Suite

Newborn Blood Spot Screening Sample
Collection Procedure

First steps

- go over the *Additional Information for Parents* parent information sheet with the parent and explain the risks and consequences of not having the newborn blood spot screen done IF the *Why does my baby need to be screened?* parent information sheet doesn't answer all the parent's questions
- ask the parent if they still want to refuse the newborn blood spot screen
- if the parent decides to have the newborn blood spot screen done, arrange to collect the blood spots as usual
- if the parent still decides **not** to have the newborn blood spot screen done, see the "Parent refusal checklist"



Parent refusal checklist

- get the *Refusal for Newborn Blood Spot Screen* form found through www.ahs.ca/newbornscreening (click on *Information for Health Professionals*, then *Collection Resources*)
 - if you have access to Connect Care use the Consent Withdrawal/Refusal form. In the "Withdrawal or Refusal of Consent for" field, type "ANSP" to customize the form and follow the instructions in the "Additional Comments" section
- review the form with the parent and ask the parent to sign the refusal form (if the parent refuses to sign the form, write "parent refused to sign" on the refusal form)
- if the parent refuses the newborn blood spot screen over the telephone, review the form with the parent. A second healthcare provider needs to listen to the phone call in which the parent verbally refuses
- fill out the blood spot card as much as possible and write "PARENT REFUSAL" on the blood spot card
- send the blood spot card to the Alberta Newborn Screening Lab
- let the infant's physician or midwife know the parent refused the newborn blood spot screen
- document in the infant's health record that the parent refused the newborn blood spot screen (including their refusal to sign the form, if applicable)
- fill out the "Health Professional Use Only" section (if using the paper *Refusal for Newborn Blood Spot Screen* form)
- fax the filled out refusal form to the Alberta Newborn Screening Program at 403-476-8782 (if you used the paper *Refusal for Newborn Blood Spot Screen* form)
- write "parent refused" in the "Blood Spot Screen" field on the notice of birth (if you have the notice of birth)

