



# Talking with Parents summary

Involving parents as part of the process is the best way to protect an infant's health.

For this to happen, parents need to know two things – they need to know why we're poking their baby's heel and how they can help their baby while it happens.

The process of newborn blood spot screening can be a stressful time full of questions for a parent. Give them the most accurate information about their baby's health in a way that's easy to understand.







## Documenting

Document according to your local practices and professional guidelines. Some examples for important points to document are included in each *essentials* resource.

## For more information

Patient & Family Centred Care on Insite visit [www.ahs.ca/newbornscreening](http://www.ahs.ca/newbornscreening)

### Staff Education

-  Using the Parent Information Sheets
-  Special Situations when Talking with Parents
-  Parent Refusal
-  Filling out the Blood Spot Card
-  Collecting the Blood Spots
-  Getting Great Blood Spots

### Parent Info

Why does my baby need to be screened?  
Additional Information for Parents

### Clinical Policy Suite

Newborn Blood Spot Screening Sample Collection Procedure

## Parents as part of the process

Including parents in the newborn blood spot screen seems like an obvious step however, sometimes we can go on “autopilot” and forget. This can leave parents out of an important step in their baby's health care. Remember, there is a wide spectrum of how families may feel about the screen (from indifference to fear). Tailor your discussion with the family to look at things from the parent's perspective.

To help make parents part of the process, it's important to keep in mind

- what a parent may not know
- common questions a parent might have
- the core concepts of patient and family centred care

## What a parent may not know

Clinical terminology is a way for us to easily express complex ideas, but a parent may not know terms like

- “screening”
- “borderline results”
- “endocrine conditions”
- “metabolic conditions”

However, they may have a general understanding of the meaning of these terms. Remember to use words the parent will know and understand. The Alberta Newborn Screening Program (ANSP) parent information sheets can help you with parent friendly language.

## Common parent questions

Parents may ask

- why is my baby being screened again? Is this normal?
- what is a borderline screening result?
- how is my baby's privacy protected?

The ANSP parent information sheets can help you with answering these questions for parents.

## How to use the parent information sheets

The ANSP parent information sheets are to help guide your conversation with the parent about newborn blood spot screening, to give answers to questions parents might have and to obtain verbal consent.



If you're not sure about how to use the parent information sheets, follow these simple guidelines

- go through the parent information sheets with the parent
- ask the parent questions to see if they understand the information on the sheets
- use the vocabulary on the parent information sheets when talking to the parent
- use words the parent will know and understand
- don't assume that by just giving the parent the parent information sheets that you have explained newborn blood spot screening


## Talking with parents about collecting the blood spots (informed consent process)

The most responsible health practitioner (MRHP)\*, usually a nurse, needs to talk with the parent before collecting the blood spots the first time or collecting the blood spots again. Use the ANSP parent information sheet *Why does my baby need to be screened?* to describe

- what are the screened conditions
- what is newborn blood spot screening
- what are the risks and benefits of newborn screening
- what are the next steps after getting the screen done
- how to comfort the baby during the heel poke

The ANSP parent information sheet *Why does my baby need to be screened?*



Ask if the parent has any further questions about newborn blood spot screening. Answer any questions the parent might have using the ANSP parent information sheet *Additional Information for Parents*. Ask the parent if it's okay to collect their baby's blood spots (parent gives express consent verbally). If the parent refuses to have the newborn blood spot screen done, see the *Parent Refusal essentials*. 

\* The MRHP is the health practitioner who has responsibility and accountability for treatments and procedures provided to an infant.

## After talking with parents

After the parent agrees to proceed with the screening, the blood spots can be collected. Document in the infant's health record that you talked with the parent about the newborn blood spot screen or the repeat newborn blood spot screen.

For more information, see the ANSP essentials



If the blood spots are not collected before an infant goes home from the birth facility, do not give the blood spot card to the parent. If the blood spot card has already been filled out, destroy it. Inform zone public health nursing services and mark the "Not Collected" box in the "Blood Spot Screen" field in the notice of birth ( if you have the notice of birth).

## Special situations



A new parent may have concerns about **privacy**. If the parent has concerns about privacy, see the *Special Situations when Talking with Parents essentials*.

Including parents as part of the process is an important step toward screening **every infant, every time**.

