



# Parent Information quick reference

Alberta's Newborn Metabolic Screening (NMS) Program parent information helps provide accessible, current and standardized key messages to parents and guardians.

Parent information effectively gives parents and guardians the opportunity to understand the valuable benefits of newborn blood spot screening for their baby.

## What is NMS Program parent information?

NMS Program parent information is a collection of useful resources for parents and guardians about newborn blood spot screening that is presented in four parent information sheets.

It is

- based on informed practices
- parent-friendly in terminology, language and format
- easily-accessible and understandable

## Why is NMS Program parent information important?

NMS Program parent information resources are important to facilitate consent discussions and answer general questions that expecting and new parents and guardians may have regarding newborn blood spot screening. The information covers:

- nature and purpose of newborn blood spot screening
- risks and benefits of screening
- information about the program
- consequences of not undertaking newborn blood spot screening

## How is NMS Program parent information used?

Health care providers use NMS Program parent information to guide newborn blood spot screening discussions with parents and guardians before and after birth. This gives parents and guardians the opportunity to discuss, ask questions and understand the benefits that are available for their baby through newborn blood spot screening.

## What does NMS Program parent information cover?

NMS Program parent information is broken down into four separate information sheets

- *Why does my baby need to be screened?* (discussed with parents and guardians before the blood spots are collected the first time) has information about
  - the who, what, why, when, where and how of newborn blood spot screening
  - the nature, purpose and benefits of screening, and the consequences of not screening
  - privacy for parent or guardian and baby
- *Additional Information for Parents* (discussed with parents and guardians on an as-needed basis) has information about
  - privacy and having personal information removed from the NMS Application
  - what happens to the blood spot card, other purposes for the card and getting the card back



- what might happen if parents and guardians choose to not have the newborn blood spot screen done
- additional screening requests or concerns about other conditions in the family
- *Why does my baby need to be screened again?* (discussed with parents and guardians before the blood spots are collected again) has information about
  - possible reasons why a newborn blood spot screen may need to be done again
  - what happens when the newborn blood spot screen needs to be done again
  - what the results may be and how parents and guardians will find out their baby's screen results
- *Making Sense of Abnormal Results* (discussed with parents and guardians with the condition fact sheet after an abnormal screen result) has information about
  - what an abnormal screen result means
  - the conditions that newborn blood spot screening looks for
  - what happens next when the results show a baby has one of the treatable conditions

### How is NMS Program parent information accessed?

Health care providers can access NMS Program parent information sheets in three ways.

- all parent information sheets can be accessed and printed through [www.ahs.ca/newbornscreening](http://www.ahs.ca/newbornscreening)
- all parent information sheets can be ordered online through [www.ahs.ca/newbornscreening](http://www.ahs.ca/newbornscreening)
- the *Making Sense of Abnormal Results* parent information sheet is faxed to physicians and midwives who have an infant in their care that has an abnormal screen result

Parents and guardians can access NMS Program parent information in three ways.

- parent information sheets can be accessed through and printed from [MyHealth.Alberta.ca](http://MyHealth.Alberta.ca) and [www.ahs.ca/newbornscreening](http://www.ahs.ca/newbornscreening)
- parent information sheets are available from health care providers
- NMS Program parent information key messages are included in provincial prenatal and new parent resources

