Alberta Health Services
Alberta Newborn Screening

Information for Health Professionals

Following Up summary

What happens after an infant's blood spots are collected, transported and analyzed?

Once the Alberta Newborn Screening Lab looks at the infant's personal information and analyzes the blood spots, a series of steps by many different staff members begins that makes sure we screen every infant, every time.

Different kinds of situations involving newborn blood spot screening within the Alberta Newborn Screening Program (ANSP) are followed up on in different ways. Infants may need to have blood spots collected, have their data investigated, or be referred for clinical assessment and diagnostic testing.

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

visit www.ahs.ca/newbornscreening

Staff Education

- Parent Refusal
- Special Situations when Collecting
- NICU
- Finding the Family
- Following Up on Infants
- Special Situations when Following Up

Clinical Policy Suite

Newborn Blood Spot Screening Policy

Newborn Blood Spot Screening Follow-up Procedure

Why do we follow up?

We follow up on **every infant, every time** because it is our responsibility to make sure every infant in Alberta is screened.

Following up is a series of steps we take to make sure

- every infant gets the newborn blood spot screen
- every infant's personal information is correct and up-to-date
- every infant who needs to have the blood spots collected again gets them collected again
- every infant who needs clinical assessment or diagnostic testing gets it

Why is following up important?

Following up on infants is important to make sure each one has a chance at early screening. Early screening helps find conditions that can be treated early, when the treatment can help the infant the most. A delayed screen can lead to delayed diagnostic tests and delayed treatment. If an infant with one of the screened conditions is not treated early, they may have problems growing, have brain damage or even die.

Who follows up on infants?

- ANSP coordination team
- Alberta Newborn Screening Lab staff
- zone public health nursing services
- neonatal intensive care unit
- midwives
- physicians
- First Nations communities
- genetic counsellors
- specialty clinics

How do we follow up?

When we need to follow up on an infant

- the ANSP Application, a database that monitors and tracks infants who have been screened or need to be screened, generates an "alert" which draws attention to the situation
- the ANSP coordination team gets information about the situation from the ANSP Application and sends it to zone public health nursing services or First Nations communities
- the Alberta Newborn Screening Lab gets information about the situation from the ANSP Application

- actions are taken by different people to resolve the situation such as
  - checking and correcting the infant's personal information
  - checking that the infant was registered correctly
  - checking that the infant got his or her newborn blood spot screen
  - arranging to collect the infant's blood spots or collect the blood spots again
  - referring the infant for clinical assessment and diagnostic testing, and making sure the infant's physician is told
  - informing physicians of infant's sickle cell trait carrier status

When do we follow up?

We need to follow up on situations where

- there are **abnormal results** (major alert), meaning the infant may have one of the screened conditions and needs clinical assessment and diagnostic testing to confirm whether the infant has the condition or not
- there are **borderline results** (minor alert), meaning the blood spots need to be collected again because the screen results did not give a clear answer
- there are **inadequate results** (collection alert), meaning the blood spots need to be collected again because
  - there is a problem with the infant's blood spots such as not enough blood or blood not being put on the blood spot card (requisition) correctly
  - the date and time that the blood spots were collected is missing, illegible or incorrect on the blood spot card
  - the blood spots were collected when the infant may have been less than 24 hours old
- the infant weighed less than 2000 grams at birth (low birth weight), to support the detection of congenital hypothyroidism and congenital adrenal hyperplasia
- the infant is less than 37 weeks gestational age at birth (preterm), to support the detection of severe combined immunodeficiency and sickle cell disease
  - this is **not** needed for all preterm infants; **if** follow up is required a notification will be sent to collect the blood spots again
- the infant is a sickle cell trait carrier, meaning the Alberta Newborn Screening Lab will notify the infant's healthcare provider
- there is missing, illegible or incorrect personal information on the blood spot card (invalid data alert – IDA)
- the infant's first blood spot card wasn't received by the Alberta Newborn Screening Lab by the time the infant was 10 days old (missing screen event – MSE)
- the Alberta Newborn Screening Lab received a blood spot card for an infant with a registration circumstance (i.e., out of province registrations, registration information errors or temporary identifier used) that needs to be investigated (missing birth event – MBE)

When do we need to investigate an infant's data?

- if there was missing, illegible or incorrect personal information on the blood spot card (other than the date and time of collection), the infant's data needs to be investigated (data investigation)
- if the infant's first screen wasn't received by the Alberta Newborn Screening Lab by the time the infant was 10 days old, we need to find out whether the blood spots were collected
- for information about how to investigate an infant's data, see the *Following Up on Infants essentials*

Finding the family

It can be hard to track down an infant after they leave the birth facility.

To make sure we've done all we can to find the family, please see the *Finding the Family essentials.*

Following Up summary

Which infants need to have blood spots collected again?

- the infant has an inadequate result, meaning
  - there was a problem with the infant's blood spots such as not enough blood or blood not being put on the blood spot card correctly
  - the date and time of collection is missing, illegible or incorrect on the blood spot card
- the infant's results could not be interpreted accurately
  - the exact age of the infant (in hours) is important for accurately interpreting results
  - the blood spots were collected when the infant was less than 24 hours old
- the infant has a borderline result
  - if the infant with borderline result is one of a multiple birth set, collect the blood spots again from all infants in the birth set
- the infant weighed less than 2000 grams at birth
- the infant is less than 37 weeks gestational age at birth (preterm), if follow up is required a notification will be sent to collect the blood spots again
- the infant's blood spot card didn't get to the Alberta Newborn Screening Lab

For information about how to find out if an infant needs to have blood spots collected and how to arrange it, see the *Following Up on Infants essentials* and the *Special Situations when Following Up essentials.*

When are we finished following up?

- the infant has normal, adequate screen results reported (except for certain situations in neonatal intensive care units)
- the infant is diagnosed with a screened condition
- the reason for not collecting an infant's blood spots is documented in the infant's health record and the infant's physician or midwife is told why the blood spots weren't collected. Reasons for not collecting an infant's blood spots might be
  - neonatal death
  - the parent refused the newborn blood spot screen
  - the physician does not allow the blood spots to be collected for specific clinical reasons (i.e., medically unstable)
  - the infant's blood spots were collected using a different name or Unique Lifetime Identifier number for the infant
  - the infant moved out of Alberta or we can't find the family

Special situations

Life circumstances for new parents can be very complex. For information about how to handle special situations that might come up (for example, cannot find the family, family moved out of province, etc.), see the *Special Situations when Following Up essentials.*