



Overview of the Alberta Newborn Screening Program summary

The Alberta Newborn Screening Program (ANSP) is about healthcare providers working together with parents to screen for 22 treatable conditions.

At the heart of all this is the **newborn blood spot screening pathway**. It ensures all screened infants who may have one of the treatable conditions get clinical assessment, diagnostic testing and early treatment if needed. Timely screening helps find infants with conditions that can be treated early, when the treatment can help the most.

At birth, an infant starts a journey that will last a lifetime. We can help infants on their journeys by making sure they're screened safely, correctly and in a timely manner.




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

-  Walking Along the Newborn Blood Spot Screening Pathway
-  Enhancing the ANSP
-  Getting it Right Every Time

Provider Info

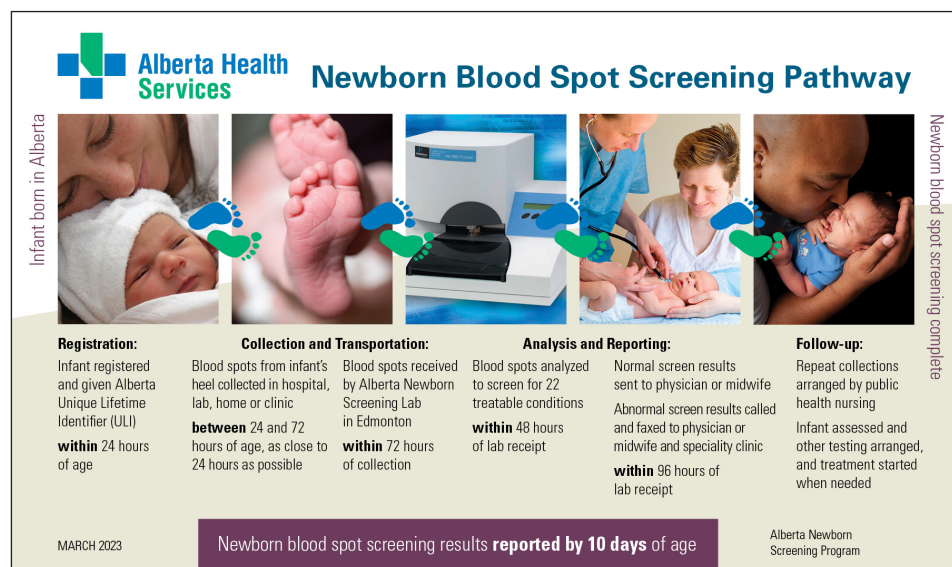
Condition Fact Sheets

Clinical Policy Suite

Newborn Blood Spot Screening Policy, Procedures and Guideline

When we talk about the “newborn blood spot screening pathway”, what do we mean?

We each play our part helping infants at each step along the newborn blood spot screening pathway. But how does the journey start for an infant? And what happens after we've done our part in the newborn blood spot screening pathway? The newborn blood spot screening pathway is a series of steps made up of hundreds of healthcare providers, infants and families across Alberta. The different kinds of healthcare providers bring their own knowledge and background to their step along the pathway.



When does the newborn blood spot screening pathway start?

It's important to have infants start with the newborn blood spot screening pathway as soon as they're born and registered in Alberta*. The next step on the newborn blood spot screening pathway happens when the infant is between 24 and 72 hours old, but as close to 24 hours as possible. This is the best time to collect blood spots for newborn screening.

* Infants born outside Alberta and receiving health care in Alberta may also be screened

Where does the newborn blood spot screening pathway lead?

The newborn blood spot screening pathway takes infants on a journey which ends in one of two ways.

1. There are normal screen results which do not need to be followed up on.
2. There are abnormal screen results and diagnostic testing has been completed to find out if an infant has one of the conditions screened for.



Overview of the Alberta Newborn Screening Program *summary*

The treatable conditions screened for include

- metabolic conditions in which the body can't break down some substances in food like fats, proteins or sugars which it needs to grow (example: phenylketonuria or PKU)
- endocrine conditions in which the body can't make the right amount of hormones (example: congenital hypothyroidism)
- cystic fibrosis (CF), a condition that causes thick, sticky mucus to build up in the lungs, digestive tract and other areas of the body
- sickle cell disease (SCD), which is a group of blood disorders that causes chronic anemia and significant damage to heart, lungs and kidneys
- severe combined immunodeficiency (SCID), a condition that causes little or no immune response making the infant susceptible to infection
- spinal muscular atrophy (SMA), a condition that affects the motor neurons of the brainstem and spinal cord resulting in muscle weakness and muscle wasting (atrophy) throughout the body.

Who contributes to the newborn blood spot screening pathway?

- clerks who register the infants
- nurses, midwives and lab staff who collect the blood spots
- lab staff who transport the blood spot cards
- Alberta Newborn Screening Lab staff who analyze the blood spots and report the results
- genetic counsellors and nurses who consult with physicians and midwives about any clinical assessment and diagnostic testing that might be needed

Each person at each step along the newborn blood spot screening pathway is important and it's also important for each of us to understand the pathway as a whole.

How does the newborn blood spot screening pathway work?

Newborn blood spot screening has several steps

- registering an infant born in Alberta*
- collecting a few drops of blood with a heel poke
- testing the blood spots
- helping the infant get clinical assessment, diagnostic testing and treatment if needed

** Infants born outside Alberta and receiving health care in Alberta may also be screened*

Why does screening every infant, every time matter?

More than 99% of infants born in Alberta have their screen results reported on time. This means about 400 infants are not screened on time each year. Timely screening helps find infants with conditions that can be treated early, when treatment can benefit 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, develop brain damage or even die.

How do we screen every infant, every time?

By following the ANSP timelines about when an infant needs to be registered, when the blood spots need to be collected, transported and analyzed, and when the screen results need to be reported and followed up on, we can improve the quality of newborn blood spot screening for every infant.

What causes delays?

Many little factors can cause delays in an infant's journey along the pathway. Delays can't be blamed on one person or one action. They're usually the result of many different factors – each seemingly harmless on its own – working together to create a real problem and threatening patient safety. For example, one type of delay that is usually preventable is when an infant needs to be poked again. Being poked again may prolong an infant's journey along the pathway.

The most common preventable reasons for needing the blood spots collected again are

- collecting blood spots before an infant is 24 hours old
- poor quality blood spots
- incorrect or illegible information on blood spot cards that often cause delays while staff try to track down the missing pieces of information
- collecting blood spots on an expired blood spot card



Overview of the Alberta Newborn Screening Program *summary*

What are the costs of delays?

It may seem like getting an infant to come back to have the blood spots collected again isn't a big deal. However, the effects can be far-reaching.

Costs to the family

- the discomfort another heel poke causes the baby
- the inconvenience to parents who have to take their baby to a lab to have the blood spots collected again
- the worry of parents thinking their baby is not well
- the financial loss involved in missing work to bring the baby to a lab

Costs to the organization

- the cost of having blood spots collected again
- the added costs of sending and analyzing an additional blood spot card
- the frustration and loss of morale on the part of healthcare providers at not being able to provide the best possible care

What are the most serious consequences of delays?



Rare, but possible, are infants who have one of the treatable conditions and are not screened on time or who need to have the blood spots collected again because of a preventable reason. This could lead to delayed diagnosis and, in turn, treatment beginning later than it could have. If infants aren't treated early, they may have problems growing, develop brain damage or even die.

What can we do?

Improving the quality of care isn't always an easy thing to do. It can be hard to remember that, even in a large organization, you have the power to change things for the better. There are parents of infants who will notice – and appreciate – your efforts to give the best care you can. Little changes can have large effects, like taking the time to destroy a bundle of expired blood spot cards or making sure blood spot cards are filled out correctly so that repeat collections aren't needed.

How do we learn from each other?

Even though we try to get it right every time, the infant's journey along the newborn blood spot screening pathway isn't always as smooth as it could be. You can make it better for the next infant when you learn about how something was missed, how something didn't happen right, or how it didn't happen on time.

When there is a problem, a problem is avoided, or there could be a problem along the newborn blood spot screening pathway, you first need to talk to your supervisor and/or educator and document in the infant's health record (as appropriate). You can also help other staff learn by sharing your experiences through the AHS Reporting & Learning System (RLS). When we learn from problems, we can work together to make it better for the next infant.

When do I submit an RLS report so others can learn?

Submit an RLS report if you identify a problem (adverse event), a problem that was avoided (close call) or a potential problem (hazard) related to newborn blood spot screening. If you're wondering about submitting an RLS report, ask yourself:

- Did something happen, almost happen or could something happen that does not follow the newborn blood spot screening clinical policy suite (policy, procedures and guideline)?
- Do I think other staff could learn from the situation?

If you answered yes to either of the above questions, then go ahead and submit an RLS report, even if you have already talked with your supervisor or didn't collect the infant's newborn blood spot screen. There is no time limit for submitting an RLS report or rules about who must report.

When we work together, we can screen every infant, every time.

