



# Additional Information for Parents

## Alberta Newborn Screening Program

**Newborn blood spot screening is a blood test that is done a day or 2 after babies are born.** Screening helps your doctor or midwife find out if your baby is at risk of having certain conditions that can't be seen by just looking at your baby. **These conditions are treatable.** When your baby is treated early, it can prevent health problems, improve your baby's health, and maybe even save your baby's life. This screening test is different from those done during pregnancy.

### How is my baby's privacy protected within the Alberta Newborn Screening Program (ANSP)?

- The ANSP respects you and your baby's confidentiality and privacy.
- Health information is collected, used and shared (disclosed) by following Alberta's *Health Information Act*.
- Your baby's health information is protected in a secure, private and confidential place as required by the *Health Information Act*.

### Can I have personal information removed from the ANSP Application?

Yes, personal information that identifies you and your baby may be removed from the ANSP Application, after newborn blood spot screening is complete. Call Health Link for more information.

### What happens to the blood spot card after the screening is complete?

The blood spot card is securely stored according to Alberta Health Services guidelines.

### What other purposes can blood spot cards be used for?

- Blood spot cards may be used to develop better screening tests for the treatable conditions.
- Alberta Health Services may use blood spot cards for approved research.
- If your baby's blood spot card is used for research, you and your baby's privacy will be protected under the *Health Information Act*.

### Can I get my baby's blood spot card back?

Yes, you can get your baby's blood spot card back after newborn blood spot screening is complete. Talk to your doctor or midwife, or call Health Link.

### Can I choose to not have my baby screened?

Yes, having your baby screened is your decision. It is important to talk to your doctor or midwife if you are thinking about not having the screening done.

Medical experts strongly recommend having your baby screened. Screening is the best way to tell if your baby is at risk of having certain treatable conditions that you or your doctor, or midwife can't see by just looking at your baby.

### What might happen to my baby if he or she is not screened?

If your baby is not screened and has one of the treatable conditions, the condition may not be found early when the treatment could help your baby the most. By the time you notice that your baby has problems, it may be too late to prevent permanent damage.

If your baby is not treated early, he or she may have health problems or even die.

### Can I choose which treatable conditions my baby is screened for?

No, you can't choose which treatable conditions your baby is screened for. All treatable conditions are screened for at the same time.

If you would like your baby to have more screening or have concerns about other conditions in your family, talk to your doctor or midwife.

### What if I have more questions?

- Talk to your public health nurse, doctor or midwife if you have any questions about your baby's health or newborn blood spot screening.
- Call Health Link at 811 to talk to a registered nurse 24 hours a day.

