



Ottawa Personal Decision Guide Edited to Help Discuss Newborn Bloodspot Screening with Expecting Families

This is a tool to help families determine if newborn screening is appropriate for their newborn.

1. Overview of the Decision

The decision: Within 24-48 hours of birth your child can receive a newborn screen. It is important that this screening is done in this time frame because there are conditions that can seriously harm your baby within the first days of life. This screening is designed to identify if your newborn has a condition that is not evident by looking at them but could be harmful. All conditions that are screened for can be treated or managed if caught early. The charges for newborn screening will either be billed to your insurance company or you will need to submit payment for this screening directly to the Iowa laboratory, but you may be able to get reimbursed by your insurance company.

What are your reasons for making this decision? Newborn screening is offered to all babies born in the United States. You get to choose if you want your baby to be screened.

The screening will identify babies who need treatment.

When do you need to make a choice? The screening is most beneficial when it is performed 24-48 hours after your baby has been born and delivered to the newborn screening lab within a few days of life.

How far along are you with making this choice?

- | | |
|---|--|
| <input type="checkbox"/> Not thought about it | <input type="checkbox"/> Close to choosing |
| <input type="checkbox"/> Thinking about it | <input type="checkbox"/> Made a choice |

This guide was made in collaboration with several state newborn screening programs and several midwives and was edited to reflect North Dakota.



2. Explore your decision

Knowledge	Values	Certainty
Below are some considerations around newborn screening. Please add your own to the list.	Rate each consideration using numbers to show how much each one matters to you.	Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

Reasons to Consider Newborn Screening	How important is this to you? Score of 1 (not important) to 5 (very important)	Reasons You May Be Hesitant about Newborn Screening	How important is this to you? Score of 1 (not important) to 5 (very important)
Peace of mind that child was screened		You may have to pay out of pocket for the screening	
Identify if your child is at risk for having a treatable condition if caught early		Temporary pain and discomfort for baby	
Your child would be connected to early treatment that could decrease chance of death or severe impairment		Doing this may not fit with your personal beliefs	
Even if other members in your family do not have a condition, it does not mean there is no risk for baby		Most children won't have one of these conditions	
TOTAL SCORE			

Which option do you prefer?

☐ Do the screening
 ☐ Don't do the screening
 ☐ **Unsure** (continue)

Support

Who else is involved?

Which option do they prefer?

Is this person pressuring you?

☐ Yes

☐ No

How can they support you?

What role do you prefer in making the choice?

- ☐ Share the decision with . . .
☐ Decide myself after hearing the views of . . .
☐ Somebody else decides. . .

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3. Identify your decision-making needs

Knowledge	Do you know the benefits and risks of each option?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Values	Are you clear about which benefits and risks matter most to you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Support	Do you have enough support and advice to make a choice?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Certainty	Do you feel sure about the best choice for you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

If you answer “no” to any question, you can work through steps **two** and **four**, focusing on your needs or look at step **five** which has frequently asked questions. (People who answer “No” to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes).

4. Plan the next steps based on your needs

Decision making needs	✓ Things you could try
Knowledge	<input type="checkbox"/> Find out more about the options and the chances of the benefits and risks.
If you feel you do NOT have enough facts	<input type="checkbox"/> List your questions. Look at the FAQs and concerns in step 5 . <input type="checkbox"/> List where to find the answers (e.g. midwife, pediatrician, OB).
Values	<input type="checkbox"/> Review the scores in step 2 to see what matters most to you.
If you are NOT sure which benefits and risks matter most to you	<input type="checkbox"/> Find people who know what it is like to experience the benefits and risks. <input type="checkbox"/> Talk to others who have made the decision. <input type="checkbox"/> Read stories of what mattered most to others. <input type="checkbox"/> Discuss with others what matters most to you.
Support	<input type="checkbox"/> Discuss your options with a trusted person (birth provider, pediatrician, friends, family).
If you feel you do NOT have enough support	<input type="checkbox"/> Find help to support your choice (e.g. funds).
If you feel PRESSURE from other to make a specific choice	<input type="checkbox"/> Focus on the views of others who matter the most. <input type="checkbox"/> Share your guide with others. <input type="checkbox"/> Ask others to fill in this guide (See where you agree. If you disagree on facts, get more information. If you disagree on what matters most, consider the other person’s views. Take turns to listen to what the other person says matters most to them.) <input type="checkbox"/> Find a person to help you.
Certainty	<input type="checkbox"/> Work through steps 2 and 4 , focusing on your needs.
If you feel UNSURE about the best choice for you	<input type="checkbox"/> Look at the frequently asked questions/concerns in step 5 to see if that helps.
Other factors making the decision difficult	List anything else you could try:

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5. Understand the Frequently Asked Questions or Concerns Around Newborn Screening

Concern/Question	Points to Consider
“These diseases are so rare—why screen?”	<ul style="list-style-type: none"> While rare, the conditions screened for can cause serious harm, including death, if untreated. Screening can prevent life-altering outcomes in the few babies affected. Over the past 10 years, there have been about 450 children identified in North Dakota. You can see what your state screens for here.
“We’ve never had children with these disorders before.”	<ul style="list-style-type: none"> Most babies with these conditions are born into families with no history. Screening helps identify these unexpected cases early. Genetics reset with each child. Each baby is genetically unique and the risk of having a condition is the same for each child. In our state there have been families whose subsequent child did have a condition that the older children did not.
“I don’t want to hurt my baby”	<ul style="list-style-type: none"> After the initial nick, which is like a papercut, it is not painful. Your baby is more likely upset that we are holding their foot. You may want to hold your baby on your shoulder, sing to your baby, or breastfeed while we do this to make you and your baby feel better. Nursing has been shown to increase comfort. The short-term discomfort can prevent long-term harm like cognitive impairment or death.
“I had genetic testing when I was pregnant so I know it is all okay. I don’t need a newborn screen.”	<ul style="list-style-type: none"> The prenatal genetic screening only tests for a few of the conditions on the newborn screen; it is not as comprehensive. The newborn screening looks for conditions that can be mitigated with early identification. “Prenatal carrier screening does not replace newborn screening, nor does newborn screening diminish the potential benefit of prenatal carrier screening” – American College of Obstetricians and Gynecologists (Committee Opinion, Number 609, Reaffirmed 2020)
“The state stores my baby’s blood spot. Why? How long? What do they do with them?”	<ul style="list-style-type: none"> In North Dakota, specimens are destroyed after 30 days. No research is done on the blood spot specimens prior to destruction. You can view the North Dakota law on the destruction of newborn screen bloodspots - here.
“Birth is a natural process. Our ancestors did not need newborn screening, why does my child?”	<ul style="list-style-type: none"> Newborn screening only looks for conditions where there is treatment available and early identification saves lives. In nature there is a certain amount of loss expected. Unexpected outcomes, including death, are human experiences that deserve respect. If something unexpected were to happen, would that have changed your decisions leading up to that point? If yes, then that is worth more curiosity between you and your partner.
“If I choose not to do Vitamin K, is it dangerous for my baby to have a newborn screen?”	<ul style="list-style-type: none"> No, your child can still undergo the newborn screen even if you choose to decline vitamin K. The newborn screen only involves a small nick and is unlikely to cause harm.
“Can I do the newborn screen at a later visit? Why do I have to do this 24-48 hours after birth?”	<ul style="list-style-type: none"> Newborn screening aims to identify conditions that can be life-threatening or cause serious health problems if not detected and treated early within the first week of life. Collecting the blood specimen within two days of life allows time for it to be tested and reported so babies get the immediate care they need.

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