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. In some states, the state newborn screening will bill your insurance company for this screening. In other states, you will need to pay for this screening, but you may be able to get reimbursed by your insurance company. Your state newborn screening program can tell you what the rules are for your state.

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 may 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?

○ **Not thought about it**
○ **Thinking about it**
○ **Close to choosing**
○ **Made a choice**

This guide was made in collaboration with several state newborn screening programs and several midwives.

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 their 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 your baby		Most children won't have one of these conditions	
TOTAL SCORE	0		0

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 for myself after hearing the views of . . . ○ Somebody else decides. . .

3. Identify Your Decision-Making Needs			
Knowledge	Do you know the benefits and risks of each option?	○ **Yes**	○ **No**
Values	Are you clear about which benefits and risks matter most to you?	○ **Yes**	○ **No**
Support	Do you have enough support and advice to make a choice?	○ **Yes**	○ **No**
Certainty	Do you feel sure about the best choice for you?	○ **Yes**	○ **No**

If you answer "no" to any of these questions, 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	☐	Find out more about the options and the chances of the benefits and risks.
If you feel you do NOT have enough facts	☐	List your questions. Look at the FAQs and concerns in step **5**.
	☐	List where you could find the answers (e.g. midwife, pediatrician, OB).
Values	☐	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	☐	Find people who know what it is like to experience the benefits and risks.
	☐	Talk to others who have made the decision.
	☐	Read stories of what mattered most to others you trust.
	☐	Discuss with others what matters most to you.
Support	☐	Discuss your options with a trusted person (birth provider, pediatrician, friends, family).
If you feel you do NOT have enough support	☐	Find help to support your choice.
If you feel PRESSURE from other to make a specific choice	☐	Focus on the views of others who matter the most to you.
	☐	Share your guide with others.
	☐	Ask others to fill in this guide (See where you agree. If you disagree on the 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.)
	☐	Find a person to help you.
Certainty	☐	Work through steps **2** and **4**, focusing on your needs.
If you feel UNSURE about the best choice for you	☐	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:***

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

Concern/Question	***Points to Consider***
"These diseases are so rare—why screen?"	• While rare, the conditions screened for can cause serious harm, including death, if untreated. Screening can identify conditions early and prevent life-altering outcomes in the few babies affected. • You can see what your state screens for here (https://www.babysfirsttest.org/newborn-screening/states)
"We've never had children with these disorders before."	• 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.
"I don't want to hurt my baby."	• 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. • It is like a finger prick to check blood sugar for diabetics. • 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."	• 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?"	• In many regions, specimens are stored securely and may be used for research if parents' consent. The specimens can also be used for retesting if a health concern arises later that the family is interested in looking into. You can look here for your state's rules. (https://www.newsteps.org/data-resources/reports/dbs-retention-report)
"Birth is a natural process. Our ancestors did not need newborn screening, why does my child?"	• 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 safe for my baby to have a newborn screen?"	• Yes, 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?"	• 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.