CONVERSATIONS IN CARE

A Practical Guide for CHWs and Care Teams Rooted in Trust and Respect

Newborn Bloodspot Screening

Why It Matters

Welcoming a new baby is a joyful and life-changing experience for families. In the first few days, babies receive several routine health checks to make sure they are healthy and thriving. One of these is the **newborn bloodspot screening**.

Helping parents or caregivers understand what to expect and how to prepare can help them feel confident during the process. Knowing the importance of early screening, being aware of your baby's results, and following up if needed ensures each baby gets the best start possible.

This conversation guide aims to support providers in delivering information with compassion, creating a safe and respectful environment, and connecting families to the resources and support they need as they begin to navigate their journey.

Before the conversation

- Create a safe, respectful environment.
- Ask about what the family already knows or believes.
- Acknowledge that some words, beliefs, or traditions may be different, and that it is okay.
- At first, listen more than speak.

Questions	Answers
What is the newborn bloodspot screening?	Newborn bloodspot screening is a simple test done in the first days after birth. A few drops of blood are taken from the baby's heel and tested for rare, but serious, health conditions that may not be visible at birth. The goal is to find these conditions early so babies can get the care and treatment they need right away. Early detection gives each baby the best possible start. In Maine, this screening is required by law, and all healthcare providers must complete it for newborns.

Tip: Families may feel nervous about the heel prick. You can reassure them it is quick, safe, and an important step in protecting their baby's health.

How is the screening done?	A healthcare professional pricks the baby's heel to collect a few drops of blood (the 'heel prick'). The blood is placed on special paper and sent to a lab for testing.

Tip: Prepare families by describing the procedure and how brief it is. Reinforce that the procedure is safe and routine.

When should the screening be completed?	The newborn bloodspot screening should be completed when the baby is between 24- and 48-hours old.

Tip: Help families plan for timing if they are leaving the hospital early. Remind families that completing the screening within this window is important for accurate results.

Questions	Answers
Do parents have the right to refuse the newborn bloodspot screening?	Yes. Families do have the right to refuse the newborn bloodspot screening and any follow-up testing. In the instance of parental refusal of the screening tests on religious grounds, the parental refusal must be stated in writing and added to the infant's medical record. There are no legal consequences for refusing.

Tip: Respect their decision. Explain why it is recommended, and share that early detection can prevent serious health problems. Offer resources if they have questions.

What conditions are being tested for?	Tests vary by state, but generally babies are screened for conditions in these groups: • **Metabolic conditions**: affects how the body processes food. • **Endocrine conditions**: affects hormone levels. • **Hemoglobin conditions**: affects blood, which can cause anemia, infections, or other problems. • **Pulmonary conditions**: affects lungs and growth. • **Immune conditions**: affects how the body fights infections.

Tip: Emphasize that the test screens for conditions that may not be visible at birth. Encourage families to ask questions about any conditions they don't understand.

How will we know the results?	The baby's doctor will contact the family if results suggest a possible condition. They will explain the results and next steps. It is also helpful for families to **ask the doctor about the screening results** at the newborn checkup.

Tip: Encourage families to take notes or bring a list of questions to appointments. Remind families that it is okay to ask the doctor to explain results in plain language.

Questions	Answers
What does it mean if my baby needs a repeat or follow-up test?	A repeat test does **not always** mean the baby has a condition. Retesting may be needed if: • The first sample was taken before 24 hours of age. • There was an issue with the first blood sample. • The first test showed a possible condition that needs confirmation. The baby's doctor will contact the family if a retest is needed. It is important to complete follow-up tests promptly.

Tip: Reassure families that a repeat test is common and often routine. Explain why timely follow-up is important for the baby's health. Support families in scheduling and attending follow-up appointments.

How are these conditions treated?	Treatment depends on the condition and may include: • Special diet • Hormone therapy • Stem cell transplants • Enzyme replacement • Medications If a screening shows a possible condition, families will be connected to a specialist to guide them. Families are not alone; support is available every step of the way.

Tip: Emphasize that treatments are available and effective when started early. Reassure families that specialists and support systems will guide them through next steps. Validate feelings of worry, and offer emotional support.

Questions	Answers
What happens to my baby's blood samples after testing?	In Maine, the blood samples are sent to a laboratory in Massachusetts for testing. After the lab completes the tests, the samples are stored. Specimens may be destroyed at the request of an individual and parent or guardian of a child. Written requests for specimen destruction must be submitted in writing using the Request for Destruction of Residual Filter Paper Specimen Form provided by the Maine Center for Disease Control and Prevention (Maine CDC). To contact the Newborn Screening Program, call 1-207-287-5357 or email MCH.CDC@maine.gov.

Tip: Explain the storage process in simple, clear language. Respect families' wishes if they request destruction of the sample. Let families know they can contact the Maine CDC for the proper steps to have the sample destroyed. Reassure them that requesting destruction does not affect their baby's care.

Note: These questions and responses were gathered from community members and developed with their voices and cultural insight. For more information or resources, visit MCD's Strengthening Patient Care webpage: mcd.org/technical-assistance-training/strengthening-patient-care