Newborn Blood Spot Screening

Consent and Declination Form

This form is provided by your midwife to support an informed decision about newborn blood spot screening. It includes information about the conditions screened for, the importance of early detection, and common concerns.

What is Newborn Screening?

Newborn blood spot screening is a public health program that tests for rare but serious health conditions. A few drops of blood are taken from your baby's heel within the first days after birth and tested for a panel of genetic, metabolic, hormonal, and blood disorders. Most of these conditions do not show symptoms right away, but early detection and treatment can prevent serious and permanent harm.

Importance of Early Detection

The conditions screened for are rare but serious. Screening allows early treatment to begin—often before symptoms appear—which can prevent severe disability or even death.

- Approximately 1 in every 300–500 babies are found to have a condition through newborn screening.[1]
- Most conditions are not apparent at birth, and many babies with these disorders are born to families with no history of the condition.

Some of the Serious Conditions Detected by Newborn Screening

While each jurisdiction may screen for a different panel of conditions, the following are among the most common and/or serious:

1. Congenital Hypothyroidism (CH): Affects about 1 in 2,000 to 4,000 newborns. Left untreated, it can lead to irreversible cognitive impairment and poor growth. With early detection and treatment (daily thyroid hormone), children typically develop normally.[2]
2. Phenylketonuria (PKU): Affects about 1 in 10,000 to 15,000 babies. Without dietary treatment, PKU can cause irreversible, severe intellectual disability. Early detection allows for dietary management that prevents these outcomes.[3]
3. Medium-chain acyl-CoA dehydrogenase deficiency (MCADD): Affects about 1 in 10,000 to 20,000 babies. Babies with MCADD cannot break down certain fats for energy. Without treatment, it can lead to sudden death. Treatment involves frequent feeding and avoiding fasting.[4]
4. Severe Combined Immunodeficiency (SCID): Rare (approx. 1 in 58,000 births) but fatal without treatment. Early diagnosis allows for bone marrow transplantation before infections occur.[5]

Frequently Asked Questions or Concerns Around Newborn Screening

"These diseases are so rare - why screen for them?"
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.

"We've never had children with these disorders before."
Each baby is genetically unique and the risk of having a condition is the same for each child. Most babies with conditions found on newborn screening are born into families with no known history. Screening helps identify these unexpected cases early.

"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 can hold your baby, sing to your baby, or breastfeed to make you and your baby feel better.

"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 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. Parents may be able to opt out of long-term storage or request destruction after testing. 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. Also, in nature there is a certain amount of loss expected.

"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.

"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.

Your Decision

Please select one of the following options:

◯ I accept newborn screening for my newborn.

◯ I affirm that I have been informed about the importance of newborn screening for my baby. Despite this, I decline newborn screening for my newborn.

Parent(s) Name(s): _____

Signature(s): _____

Date: _____

Midwife Name: _____

Midwife Signature: _____

Date: _____

References:

1. CDC – 'Newborn Screening Saves Lives' https://www.cdc.gov/newborn-screening/
2. Rastogi, M. & LaFranci, S.H. Congenital hypothyroidism. (2010). *Orphanet Journal of Rare Diseases, 5, 17, https://doi.org/10.1186/1750-1172-5-17.*
3. van Spronsen FJ, Blau N, Harding C, Burlina A, Longo N, Bosch AM. Phenylketonuria. Nat Rev Dis Primers. 2021 May 20;7(1):36. doi: 10.1038/s41572-021-00267-0. PMID: 34017006; PMCID: PMC8591558.
4. MD Searchlight Medium-Chain Acyl-CoA Dehydrogenase Deficiency - https://mdsearchlight.com/genetic-disorders/medium-chain-acyl-coa-dehydrogenase-deficiency/
5. Kwan et al. (2014). 'Newborn Screening for Severe Combined Immunodeficiency in 11 Screening Programs in the United States'. JAMA.