Understanding and Communicating Newborn Screening Results

A toolkit from:

baby's first test

A PROGRAM OF EXPECTING HEALTH

Table of Contents

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Receiving an abnormal, positive, or out-of-range newborn screening result can be a challenging and stressful experience for parents. Similarly, communicating these results can be a complex multistep process for health professionals. This toolkit provides resources for you and others to learn more about what newborn screening results mean and how to support families through the process of receiving their child's results.

What do Newborn Screening Results Mean?

The next thing a family will likely want to know is what their child's results mean and what their next steps are.

Key Points to Share:

- Newborn screening is used to find babies with **a higher risk of having certain medical conditions.**

- An abnormal (positive or out-of-range) result **does not** mean that the baby has a condition. It **does** mean that the baby will need follow-up tests, which can include repeat screening and/or diagnostic testing.

- Diagnostic testing is needed to **confirm** if the baby has a condition or not.

- All follow-up testing should be completed quickly.

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Video: Navigating an Abnormal Newborn Screening Result

Watch and share this video from the [Newborn Screening Family Education Program](#) about a family's journey through their newborn son's abnormal (positive or out-of-range) newborn screening result and the follow-up testing process.

View the video [here](#) on Expecting Health's YouTube Channel.

Newborn Screening Test Results One-Pager

Understanding Your Baby's Newborn Screening Results

While most babies are born healthy, some infants are born with serious, but treatable medical conditions. Newborn screening is a public health program that helps healthcare providers identify these conditions before they make a baby sick. Newborn screening usually happens 24-48 hours after your baby is born and can lead to treatment within the first few days of life. There are three parts to newborn screening – the heel stick to collect a small blood sample, a pulse oximetry to monitor the amount of oxygen in your baby's blood, and a hearing screen. Every baby born in the U.S. receives newborn screening and it's important to ask your doctor about your baby's newborn screening results.

A negative, normal, or in-range result means that the blood test **did not** show any signs of the conditions included on the newborn screening panel and no follow-up is needed.

A positive, abnormal, or out-of-range result means your baby's screening **did** show signs that they may be at higher risk of having a condition included on the newborn screening panel. If your baby receives a positive result, you will be notified immediately and follow-up testing will be conducted.

While needing more follow-up does not mean that your baby has a condition, it's important to follow your baby's healthcare provider's instructions quickly and carefully.

How can I access a copy of my baby's newborn screening results?

You will be notified of positive results within two weeks of when the test was performed, and the results will be part of your baby's medical records. Ask your baby's doctor or healthcare provider to get a copy of the results. If the healthcare provider doesn't have the results, you can get in touch with your state's newborn screening program. Find your state's contact information <u>here</u>.

Could the results of the screening be wrong?

The purpose of a screening test is to catch all babies that **may** have a condition. It does not confirm a diagnosis - it simply alerts doctors that further testing is required. The results of a newborn screening test can be a false positive, meaning that your baby does not have the condition that was suggested by the first screen. However, if you continue to have concerns, contact your baby's healthcare provider.

You have the right to see your baby's newborn screening results. Whether your baby's newborn screening results are positive or negative, every result should be taken seriously. If you would like to receive information about your baby's newborn screening results, contact your baby's healthcare provider.

For more newborn screening information and resources, visit BabysFirstTest.org.

This resource can be shared with parents of a child with an abnormal (positive or out-of-range) newborn screening result to help them understand what that result means.

View and download this resource <u>here</u>.

Additional Information about Results

There are several possible outcomes of an initial abnormal (positive or out-of-range) newborn screening result including:

- True Positive - the baby **does** have a condition

- False Positive – the baby **does not** have a condition

- Carrier Identification – the baby **is a genetic carrier** for a condition

Learn more about these screening outcomes here.

What is Newborn Screening and Why is it Important?

Often, the first time a new parent learns about newborn screening or finds out that their child had this screening is when they receive an abnormal (positive or out-of-range) result. This means parents may also need resources to help them understand what newborn screening is and why it is important at that time.

Key Points to Share:
Newborn screening is a test that screens babies for certain serious medical conditions 24-48 hours after birth.

Newborn screening can help determine if a baby *may* have certain medical conditions before there are signs and symptoms.

Early detection of a newborn screening condition allows for early treatment, which can improve the baby's health.
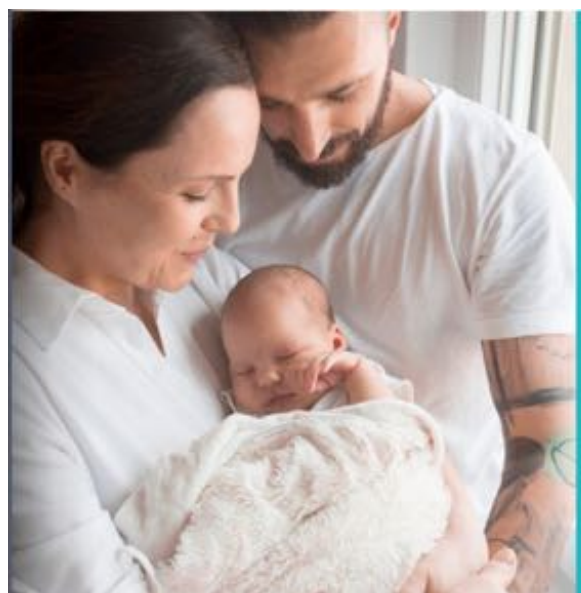

Each year, 12,500 babies with serious but treatable conditions grow up healthy.

Thanks to newborn screening.

baby's

Resources from the Newborn Screening Family Education Program

The [Newborn Screening Family Education Program](#) is dedicated to developing opportunities for all families to learn about newborn screening and creating educational and training resources that build confidence in families to become leaders in the newborn screening system.

NAVIGATE NEWBORN SCREENING

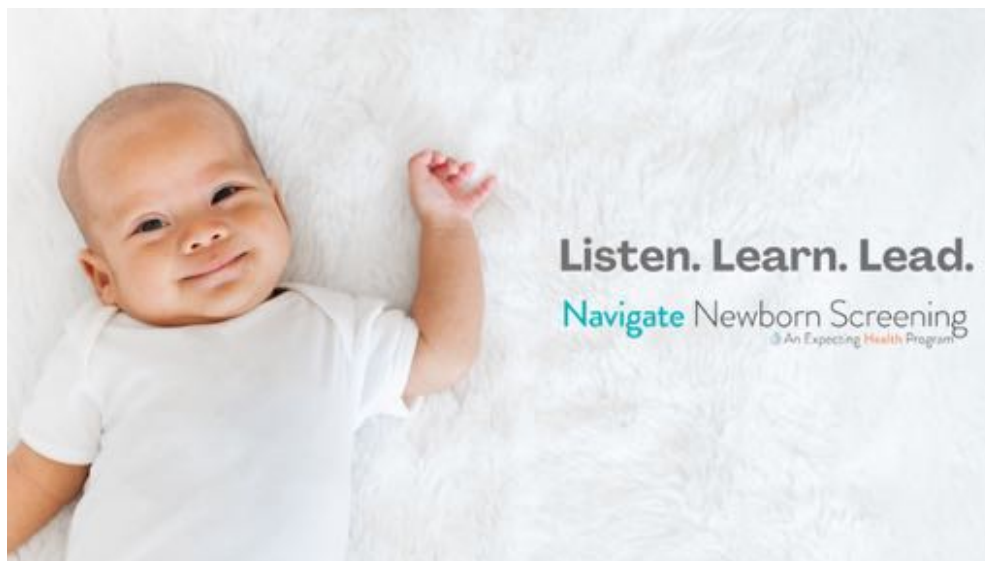A learning book created by the Newborn Screening Family Education Program

Newborn Screening Learning Book

This educational book can be shared with families so that they can learn more about newborn screening.

View or download the book [here](#).

Navigate Newborn Screening

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Online Learning Modules about Newborn Screening

The Newborn Screening Family Education Program also provides a series of online educational videos about newborn screening for families called Navigate Newborn Screening. The best part? This information is easy to access, FREE, and available to view at your convenience safely from the comfort of your home.

Register for Navigate Newborn Screening here.

Looking for More Information? Connect with us!

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