

How to Obtain the Expanded Newborn Screening Blood Test Information for Parents

What is Newborn Screening?

- A small amount of blood is taken from the baby's heel and tested for many different disorders.
- All states have a Newborn Screening Program. The state's laws determine the disorders screened for by the program.
- The state program makes sure all babies in the state get screened. They also make sure that all babies with abnormal newborn screening test results are referred for follow-up care. Finally, they educate parents and doctors about newborn screening.
- Most newborn screening is done through state programs.

What is the Expanded Newborn Screening Blood Test?

- The *expanded* newborn screening blood test uses a new method to test for over 24 rare disorders. This method is called Tandem Mass Spectrometry.
- Not all states are able to provide expanded newborn screening at this time.

How Can My Baby Get the Expanded Newborn Screening Blood Test?

- Check with your doctor to see if your state program is already doing this expanded screening.
- If your state program does not do the expanded newborn screening, you or your doctor may contact one of the four labs offering expanded newborn screening:



Baylor Institute for Metabolic Disease

(800) 422-6436

www.baylorhealth.com/medicalspecialties/metabolic/newbornscreening.htm



Mayo Medical Laboratories

(800) 533-1710

www.mayoreferenceservices.org/mml/mml-sns-intro.asp



Pediatrix Screening

(866) 463-6436

www.pediatrixscreening.com



UCHSC Biochemical Genetics Laboratory

(303) 724-3826

www.uchsc.edu/newbornscreening

What Will Happen When My Doctor or I Call the Labs?

- The labs will explain their testing to you or your doctor, including the cost of the test.
- The labs will also mail information about their expanded newborn screening test to you or your doctor.

How Will My Baby Be Tested?

- Once you decide that you want your baby to have the expanded newborn screening blood test, you or your doctor should ask one of the labs for a screening packet.
- It may be helpful to get this screening packet *before you deliver* and to *bring the packet to the hospital* with you when you deliver.
- The screening packet should include instructions on how the hospital can collect your baby's blood and information for you and your doctor.
- A nurse will obtain a few drops of blood from your baby's heel to put on a card to be sent to the laboratory.
- Besides being tested for the expanded newborn screening blood test, your baby will also receive the required newborn screening by your state program.

Who Will Get the Results of My Baby's Test?

- The results of your baby's expanded newborn screening blood test should go to your baby's pediatrician. A copy may also be sent to you.
- Make sure that the lab that tests your baby knows the name, phone number, and address of your baby's pediatrician.
- Make sure to ask your baby's pediatrician for the results of the expanded newborn screening blood test.
- Your baby's pediatrician should follow up on any questionable results.
- Your state Newborn Screening Program *will not* automatically get a copy of your baby's expanded newborn screening test results. The program *will not* follow up on your baby's expanded newborn screening test results.

Disclaimer: The information provided is not an endorsement of the laboratories listed above. The information is provided purely as a service for new and expecting parents.

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