

# Newborn Screening

## Follow-up to Newborn Screening: A Guide for Parents



### For more information:

- Talk to your pediatrician.
- Call your State's Department of Public Health and ask about their Newborn Screening Program.
- Visit the New England Consortium of Metabolic Program's website at:  
[www.newenglandconsortium.org](http://www.newenglandconsortium.org)



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## Newborn Screening Follow-up

For newborn screening, a nurse takes a few drops of blood from your baby's heel soon after birth. This blood sample is required from ALL babies in order to screen for metabolic and other disorders. A follow-up test for newborn screening occurs whenever there is the slightest reason for concern.

## Expanded Newborn Screening

Some states offer additional, optional tests. These tests do not require any extra blood from your baby. In Massachusetts, all newborn babies are required to be screened for 10 disorders. There are 19 additional metabolic disorders that can also be screened for with the same blood specimen.

## Metabolic Disorders

Metabolism is the process by which the body breaks down, stores and transforms food into energy for use within the body. A metabolic disorder can lead to abnormal levels of chemicals in the body because this metabolic process is not working properly.



## Why Newborn Screening is Important

If a metabolic disorder is not detected and treated early on, it can lead to significant health problems. Often early testing is the only way to detect a disorder before it harms the infant. This is why follow-up testing should occur whenever there is any concern. These disorders are treatable and therefore proper diagnosis and treatment early on allows infants to develop into healthy children.

## The Cost of Newborn Screening

Both newborn screening and follow-up testing for metabolic disorders should not cost you anything.

## Follow-up Testing: Just in Case

If your doctor calls and says that your baby needs follow-up testing, it does not necessarily mean your baby is at risk. The blood sample may have been too small, or it may have been taken too early. Abnormal results are often due to premature birth and/or low birth weight. It is estimated that only 1 in 12 babies who have follow-up testing actually have a disorder. However, abnormal screening results can indicate a disorder so it is important to follow your doctor's advice and get your baby tested quickly so that final results can be confirmed.

## Positive Diagnosis

If additional tests show that your baby has a metabolic disorder, your doctor will refer you to a metabolic center. At the center you will be told more about your baby's disorder and your baby will be provided with medical treatment that can prevent serious consequences.

