



Organic Acid Disorder

What is newborn screening?

Newborn screening is a blood test to check for conditions that might be hidden at birth. To do the screening, a nurse takes a few drops of blood from your baby's heel soon after birth.



Newborn screening is not the same as diagnostic testing. A screening test is used to learn which children would benefit from diagnostic testing. Diagnostic test can tell with more certainty whether or not a

child has a condition. This means that many children with an out-of-range screening result are healthy. When a child with an out-of-range newborn screening result has follow-up testing or diagnostic test results within the normal range, then the newborn screen result is sometimes called a "false positive."

What if my baby needs more testing?

When a baby needs follow-up testing, it does not necessarily mean that they will be diagnosed with a metabolic disorder. An out of range result might happen if:

- The sample was too small
- The sample was collected too early
- The sample was collected too close to a feeding
- The baby was born too early or had a low birth weight

Most babies who have follow up testing for organic acid disorders are healthy, and will not have a metabolic disorder. However, out of range screening results CAN indicate a disorder, so it is important to follow your doctor's advice and to get your baby tested with the recommended diagnostic testing quickly.

KEY POINTS:

- You have just heard that your baby may have an organic acid disorder. Please understand that the newborn screening is just that: a screening test. Other tests are needed to confirm or rule out a diagnosis.
- Most babies who have out of range newborn screens are healthy, and will not be diagnosed with an organic acid disorder.
- If treated early, children with organic acid disorders can have healthy growth and development.

What is an organic acid disorder?

Organic acid disorders are a group of rare conditions that affect a body's metabolism. Metabolism is the way your body changes food into energy. Babies with organic acid disorders cannot break down protein properly. This causes harmful substances to build up in their blood and urine. These substances can affect health, growth and learning.



What does this mean?

Although these conditions cannot be cured, they can be treated. If further testing finds that your baby has an organic acid disorder, he or she may need to be on a special diet. Sometimes, a doctor will recommend medication or supplements. If treated early, children with organic acid disorders can have healthy growth and development.

What happens next?

Your baby's doctor may ask for the newborn screen (heelstick) to be repeated or, for your baby to have more testing (blood and/or urine tests). You will want to have these follow up tests done as soon as possible. In some cases, you may be asked to visit a specialist and/or dietician.

What are the signs and symptoms of organic acid disorders?

Some babies with organic acid disorders never have serious signs or symptoms. Sometimes signs and symptoms may not happen until later in life. Each disorder has different signs and symptoms, but they often include: drowsiness, fussiness, not eating well or having trouble gaining weight, nausea, diarrhea, vomiting, illness, or infection. If you become concerned about your baby's growth, feeding or activity, please talk to your child's pediatrician.

What if I still have questions?

We understand that this can be an overwhelming and emotional process. Many families have questions and concerns. The Connecticut newborn Diagnosis and Treatment Network (the Network) is available to put you in touch with the best resource. To reach the Network, you can call 860-837-7870, Monday-Friday, 8:30am-4:30pm. We also recommend the website www.babysfirsttest.org as an accurate and informative resource.

**This fact sheet was written for information purposes only.
It should not replace medical advice, diagnosis or treatment.**