

Carnitine Uptake Defect (CUD)

(Sounds like CAR-NE-TEEN UP-TAKE DE-FECT)



What is newborn blood spot screening?

This is a blood test, from a heel poke, that is done a day or 2 after babies are born to test for treatable conditions including carnitine uptake defect (CUD) that you, your doctor, or midwife can't see by just looking at your baby. This screening test is different from those done during pregnancy.



What does it mean if my baby needs more tests for CUD?

A baby needs to have more testing for CUD when their screening test result is abnormal or positive. This doesn't mean your baby has CUD. It means your baby has a higher chance of having the condition and will need more tests to find out if they have CUD or not.

It's normal to feel worried if your baby needs more testing. Your specialists and other healthcare providers are there to support you. They'll explain what will happen and answer your questions.

What is CUD?

CUD is a metabolic condition that affects how your body uses fat from the food you eat to store and make energy. This includes breastmilk and regular formula. Your body breaks down fat into smaller parts called fatty acids. Fatty acids are an important source of energy during times when you don't eat or are ill. With CUD, a substance called carnitine can't be moved into your body's cells. So your body can't use fat to make energy and control sugar. This can cause serious health problems.

What causes CUD?

CUD is genetic. This means babies with CUD are born with a gene from both parents, which has a change in it. This change stops the gene from working properly. CUD isn't caused by anything that happened during pregnancy.

There may be no signs of CUD at birth. It's important to remember that this condition can't be seen by looking at your baby.



What can I expect with more testing?

Everything that will happen with more testing will be explained to you. Your baby may need to have their blood and urine tested to check for CUD.

This testing may be done at a clinic in Edmonton or Calgary that specializes in CUD.

What if more testing shows my baby has CUD?

If testing shows that your baby has CUD a specialized healthcare team will work with you to make a care plan for your baby. You and your baby will get the best care and support possible.

How is CUD treated?

Your doctor at the metabolic clinic will prescribe a carnitine supplement. The specialized healthcare team will give you detailed instructions about how to manage your baby's health. Most babies with CUD have no health problems.



