

Carnitine Uptake/Transport Deficiency (CUD/CTD)**(car-na-teen up-take/tran-sport de-fish-in-sea)****What is a positive newborn screen?**

Newborn screening is done on tiny samples of blood taken from your baby's heel 24 to 48 hours after birth. Newborn screening tests for rare, hidden disorders that may affect your baby's health and development. The newborn screen suggests your baby might have CUD/CTD (cee-you-dee/cee-tee-dee).

A positive newborn screen does not mean your baby has CUD/CTD, but it does mean your baby needs more testing to know for sure.

Your baby's doctor will help arrange for more testing by specialists in disorders like CUD/CTD. Sometimes, a baby has a positive screen because the mother has a hidden form of CUD/CTD. Mothers of babies with positive newborn screens also need testing.

What is CUD/CTD?

CUD/CTD affects an enzyme needed to break down fats in the food we eat, so they can be used for energy and growth. In CUD/CTD, an enzyme used to break down fats into energy is missing or not working properly.

A person with CUD/CTD doesn't have enough enzyme to break down fat into carnitine. Carnitine helps the body make energy from fats and also helps the body use stored fat.

CUD/CTD is a disorder that is passed on, or inherited, from a child's mother and father. Because CUD/CTD is a genetic disease, family members are at risk of having CUD/CTD too, even if no one in the family has had it before.

What problems can CUD/CTD cause?

CUD/CTD is different for each child. Some children with CUD/CTD do not have any health problems, while other children may have very serious complications.

If CUD/CTD is not treated, a child might develop:

- Sleepiness
- Behavior changes (such as crying for no reason)
- Feeding problems
- Seizures
- Coma

It is very important to follow the doctor's instructions for testing and treatment.

Some people with CUD/CTD have no obvious problems, so they don't even know they have it. This is why mothers of babies with positive screens need testing.

What is the treatment for CUD/CTD?

CUD/CTD can be treated. The treatment is life-long. Treatment for children with CUD/CTD can include:

- Carnitine to help the body make energy and get rid of harmful toxins
- Frequent meals/snacks - a dietician will help you set up the best diet for your child
- Low fat/High carb diet - a dietician will help you learn what foods can be eaten

Children with CUD/CTD should see their regular doctor, a doctor who specializes in CUD/CTD, and a dietician.

Children with CUD/CTD can benefit from prompt and careful treatment.

Resources for parents

Genetics Home Reference
<http://ghr.nlm.nih.gov>

MN Newborn Screening Program
www.health.state.mn.us/newbornscreening

MN Children & Youth with Special Health Needs
(651) 201-3650 or (800) 728-5420

Fatty Acid Oxidation Support
www.fodsupport.org