

Very Long-Chain Acyl-CoA Dehydrogenase Deficiency

VLCAD

(very long chain ay-sill-co-A dee-hi-drodge-in-ace 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 a disorder called VLCAD (vee-ell-cad).

A positive newborn screen does not mean your baby has VLCAD, 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 VLCAD.

What is VLCAD?

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

A person with VLCAD doesn't have enough enzyme to break down fat into energy. Using stored fat for energy is especially important between meals.

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

What problems can VLCAD cause?

VLCAD is different for each child. Some children with VLCAD have few health problems, while other children may have very serious complications.

If VLCAD is not treated, a child might develop:

- Low blood sugar
- Sleepiness
- Behavior changes (such as crying for no reason)
- Feeding problems
- Seizures

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

What is the treatment for VLCAD?

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

- Frequent meals/snacks and a low fat high carb diet - a dietician will help you learn what foods can be eaten
- Medications to help the body make energy and get rid of harmful toxins
- Careful treatment of routine illnesses

Children with VLCAD should see their regular doctor, a doctor who specializes in VLCAD, and a dietician.

Children with VLCAD can benefit from prompt and careful treatment.

Resources for parents

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

Fatty Acid Oxidation Support
www.fodsupport.org

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

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