VERY-LONG CHAIN ACYL-CoA DEHYDROGENASE DEFICIENCY (VLCAD)

FAMILY FACT SHEET

What is a positive newborn screen?

Newborn screening is done on tiny samples of blood taken from your baby's heel 24 to 36 hours after birth. The blood is tested 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.

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

You will be notified by your primary care provider or the newborn screening program to arrange for additional testing.

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 in between meals when the body is not getting new energy from eating food.

VLCAD is a genetic disorder that is passed on (inherited) from parents to a child. The mother and father of an affected child carry a gene change that can cause VLCAD. Parents usually do not have signs or symptoms, or even know they carry the gene change.

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)
- Vomiting
- Seizures
- Coma

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

What is the treatment for VLCAD?

VLCAD can be treated. Treatment is life-long and can include:

- Frequent meals/snacks and a low fat/high carbohydrate diet – a dietitian will help you learn what foods can be eaten.
- Medications to help the body make energy and get rid of harmful toxins.
- Special approaches to routine illnesses.

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

Prompt and careful treatment helps children with VLCAD live the healthiest lives possible.

Michigan Resources and Support

Michigan Newborn Screening
Nurse Consultant
Toll-free: 1-866-673-9939
newbornscreening@michigan.gov

Michigan Metabolic Coordinating Center
C.S. Mott Children's Hospital, Michigan Medicine:
1-734-764-0579

Children's Special Health Care Services
Toll-free: 1-800-359-3722

MDHHS Michigan Department of Health & Human Services | Michigan Newborn Screening

Phone 1-866-673-9939
www.michigan.gov/newbornscreening

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