Very Long Chain Acyl-CoA Dehydrogenase (VLCAD) Deficiency

(Sounds like VERY LONG CHAIN A-SIL-CO-A DE-HIGH-DRAW-GEN-ASE DE-FISH-IN-SEA)

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 very long chain acyl-CoA dehydrogenase (VLCAD) deficiency 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 VLCAD deficiency?

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

VLCAD deficiency 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. With a deficiency, or not enough VLCAD, your body can't use very long-sized fatty acids to make energy and control sugar. These fatty acids build up in your body and can cause serious health problems.

What are some early signs of VLCAD deficiency?

Your baby may:

- find it hard to feed well and gain weight
- be very sleepy (hard to wake for feedings)

What causes VLCAD deficiency?

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

There may be no signs of VLCAD deficiency 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 VLCAD deficiency.

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

What if more testing shows my baby has VLCAD deficiency?

If testing shows that your baby has VLCAD deficiency 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.

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How is VLCAD deficiency treated?

Babies with VLCAD deficiency usually go on a low-fat diet and drink a special formula. Babies need to be fed often. They may also need special medicine. The specialized healthcare team will give you detailed instructions about how to manage your baby's health.

Be careful when you search for information on the Internet. Get information from trusted sources and learn where to find reliable information.

If you're ever concerned about your baby's health or need support for you or your family, speak with your family doctor, the specialized healthcare team, or call Health Link at 811.

To learn more about VLCAD deficiency visit babysfirsttest.org and enter enter VLCAD into Find a Condition, or scan this QR code.

Newborn blood spot screening is provided through the Alberta Newborn Screening Program (ANSP) within Alberta Health Services (AHS). The program helps your baby have the best start in life. Early screening for certain conditions makes sure your baby gets treatment when it can help the most.

To learn more about newborn screening visit ahs.ca/newbornscreening or scan this QR code.

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