

Long Chain 3-Hydroxyacyl-CoA Dehydrogenase (LCHAD) Deficiency

(Sounds like LONG CHAIN 3-HIGH-DROX-Y-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 long chain 3-hydroxyacyl-CoA dehydrogenase (LCHAD) 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 LCHAD deficiency?

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

LCHAD deficiency is a metabolic condition that affects how your body uses fat from the food you eat to 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 LCHAD, your body can't use long sized fatty acids to make energy and control sugar. The fatty acids build up in your body and can cause serious health problems.

What are some early signs of LCHAD deficiency?

Your baby may:

- be very sleepy (hard to wake for feedings)
- vomit (more than usual spit-up after feeding)

What causes LCHAD deficiency?

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

There may be no signs of LCHAD 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 LCHAD deficiency.

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

What if more testing shows my baby has LCHAD deficiency?

If testing shows that your baby has LCHAD 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.



Long Chain 3-Hydroxyacyl-CoA Dehydrogenase (LCHAD) Deficiency

What is LCHAD deficiency?

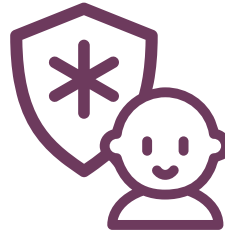
Babies with LCHAD deficiency usually go on a lowfat diet and drink a special formula. Your baby will need to be fed often. They may also need special medicine. The specialized healthcare team will give you detailed instructions about how to manage your baby's health.



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 LCHAD deficiency visit babysfirsttest.org and enter LCHAD 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.



Notes
