# Isovaleric Acidemia (IVA)

(Sounds like I-SO-VAL-AIR-IC ACID-E-MIA)



### 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 isovaleric acidemia (IVA) 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 IVA?

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

IVA is a metabolic condition that affects how your body uses protein from the food you eat to make energy. This includes breastmilk and regular formula. With IVA, your body can't break down a building block of protein called leucine. Certain substances then build up in your body and can cause serious health problems.

#### What causes IVA?

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

There may be no signs of IVA 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 IVA.

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

### What if more testing shows my baby has IVA?

If testing shows that your baby has IVA 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.

#### How is IVA treated?

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





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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 IVA visit <u>babysfirsttest.org</u> and enter IVA 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 <u>ahs.ca/newbornscreening</u> or scan this QR code.



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### Notes