# Congenital Adrenal Hyperplasia (CAH)

(Sounds like CON-GEN-IT-AL A-DREE-NULL HIGH-PER-PLAY-Z-A)



## 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 congenital adrenal hyperplasia (CAH) 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 CAH?

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

Congenital (meaning "born with") adrenal hyperplasia ("hyper" meaning "too much") is an endocrine condition that affects how your body makes special chemicals called hormones. Your adrenal glands are a pair of walnut-shaped organs that sit on top of each kidney. Adrenal glands make various hormones. These hormones control how your body reacts to stress and how it controls salts in your body. With CAH, your adrenal glands make too many androgen hormones. They also can't make enough of the hormone cortisol and sometimes the hormone aldosterone. This can cause problems for health, growth, and development.

#### What are some early signs of CAH?

Your baby may:

- find it hard to feed well and gain weight
- be very sleepy (hard to wake for feeding)
- have a loss of energy

#### What causes CAH?

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

There may be no signs of CAH 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 will need to have their blood tested to check for CAH.

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

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

If testing shows that your baby has CAH 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.





### Congenital Adrenal Hyperplasia (CAH)

#### How is CAH treated?

Babies affected by CAH will need to take a hormone called cortisol as a medicine. In most cases, your baby will also need to take another hormone called aldosterone as a medicine as well. A 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 CAH visit <u>babysfirsttest.org</u> and enter CAH 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			

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