

Congenital Adrenal Hyperplasia Fact Sheet for Parents

All babies born in North Carolina are screened at birth for certain medical conditions that can be treated to prevent serious illness. This is called newborn screening. The newborn screening result showed that your baby might have Congenital Adrenal Hyperplasia. Your baby will be referred to a specialist for more testing to know for sure.

There may not be signs of Congenital Adrenal Hyperplasia in some newborns, although it may show up later.

What is Congenital Adrenal Hyperplasia?

The adrenal glands sit above the kidneys and produce several types of hormones (important chemicals in the body) that are important for controlling blood pressure, blood sugar, and the salt and water in the body. These hormones can also affect the appearance of the genitalia.

Babies born with congenital adrenal hyperplasia may not make the right amounts of these hormones. If not treated early, CAH can cause life-threatening illness and affect your baby's development and growth.

What are the symptoms of Congenital Adrenal Hyperplasia?

There are a few types of CAH, and the most serious is the salt-wasting form.

Babies with CAH may have a range of symptoms, or signs of the disease. Symptoms may include:

- Sleeping longer/very tired
- Vomiting
- Poor feeding
- Not typical genitalia or testes that cannot be felt
- Dehydration
- Shock
- Failure to gain back birth weight as expected

What happens next?

Your baby's doctor will examine your baby for symptoms and do a second newborn screening to confirm if your child has CAH. While waiting for the results of these tests, your baby's electrolyte levels (the amount sodium and potassium in their blood) will be monitored every couple of days and additional blood work may be drawn. Your baby may require emergency treatment if they are showing symptoms of CAH or these electrolytes are not normal.

If the second newborn screen also indicates your child has CAH, or if their electrolyte levels indicate there is an issue, a blood sample will be collected and sent to a lab for one final test.

Your doctor will refer you to a specialist to help with your baby's care.

How is Congenital Adrenal Hyperplasia treated?

Babies with CAH will need to take medication all their lives. These medications help keep blood pressure, blood sugar, and salt levels normal.

Where do I go for more information?

Use your smart phone's camera to scan the QR codes below, or click on the provided links.



Baby's First Test: <https://www.babysfirsttest.org/newborn-screening/conditions/congenital-adrenal-hyperplasia>



Cares Foundation: <https://caresfoundation.org/>



Pediatric Endocrine Society: <https://pedsendo.org/wp-content/uploads/2020/06/E-Congenital-adrenal-hyperplasia.pdf>



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