

Congenital Adrenal Hyperplasia

Series N. 6



Patient's Guide

Easy Readability Leaflet

Congenital Adrenal Hyperplasia - Series 6 (Revised August 2006)

This leaflet was produced by Fernando Vera MSc and Prof Gary Butler at the Institute of Health Sciences, University of Reading, Reading, UK (August, 2006). Some portions of the text were extracted or modified from the Growth and Growth Disorders Booklet Series (Third edition, 2000)* and may be used in conjunction with these as they provide a choice of leaflets providing the same information, but for people of different ages and reading abilities. The numbering sequence in each series is the same for easy cross-reference. The original leaflet series can be also obtained from the links given at the end.

All illustrations were created and produced by Fernando Vera MSc.

This leaflet is part of the Hormone Disorders Leaflet Series. The following are also available:

- Series N 3.** Puberty and the Growth Hormone Deficient Child.
- Series N 4.** Precocious Puberty
- Series N 5.** Emergency Information for Children with Cortisol and GH Deficiencies and those Experiencing Recurrent Hypoglycaemia.
- Series N 6.** Congenital Adrenal Hyperplasia
- Series N 7.** Growth Hormone Deficiency in Young Adults.
- Series N 10.** Constitutional delay of growth and puberty
- Series N 11.** Multiple Pituitary Hormone Deficiency
- Series N 12.** Diabetes Insipidus
- Series N 13.** Craniopharyngioma
- Series N 14.** Intrauterine Growth Retardation or Small Gestational Age
- Series N 15.a.** Hyperthyroidism
- Series N 15.b.** Hypothyroidism
- Series N. 16.** Type 2 Diabetes and Obesity

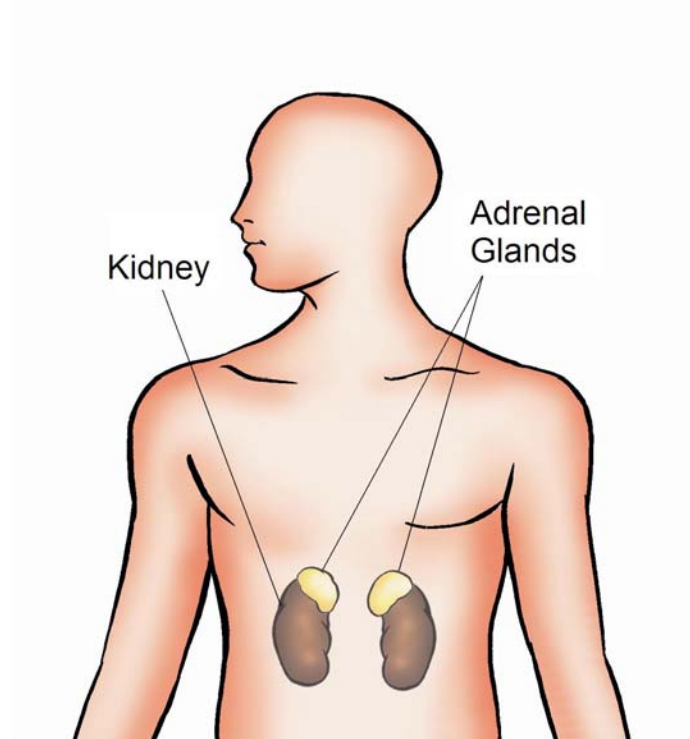
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Hello!

Today we'll tell you about **congenital adrenal hyperplasia** or **CAH**. You may think that it sounds a bit difficult, but do not worry! We'll tell you what it means, why it happens and how doctors treat it.

Let's start by first talking about some organs in your body called the **adrenal glands**. These glands are quite small and lie above the kidneys.

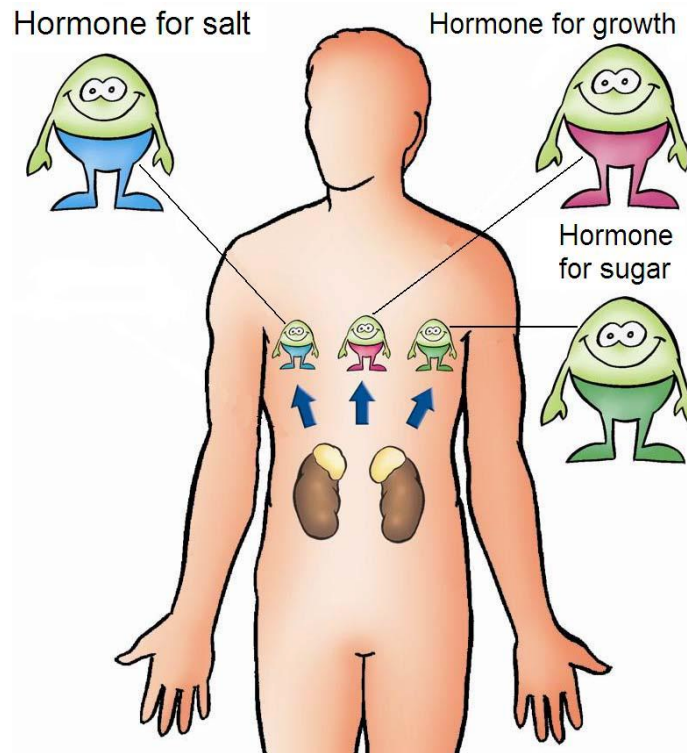


The adrenal glands act like the “**boss**” by telling the rest of the organs to do 3 things:

1. To keep the right amount of sugar in your blood.
2. To keep the right amount of salt in your body.
3. To help your body grow.

The adrenal glands order the rest of the organs by sending special messengers to them. These messengers are called **hormones** and tell the organs when and how much to work.

For each of these 3 jobs only **one type** of hormone is sent. This means that there is one hormone for controlling the sugar in your blood, one to control the salt in your body, and one to help your body grow.



What is CAH?

CAH is where the adrenal glands send too many hormones for body growth and not enough hormones for sugar and salt control!

This means that your body will start growing faster than normal. You may not have enough sugar in your blood and feel more tired. Some boys and girls may lose too much salt in their urine.

How does CAH affect boys and girls?

As you already know, CAH occurs because the adrenal glands are sending too many hormones for body growth. This will make all children grow faster than normal. There are also other things which will affect boys and girls in different ways:

- **In boys:** early muscle development, a bigger penis and hair in the armpits and around the penis.
- **In girls:** hair in the armpits and between the legs, too much hair on the rest of the body and a deeper voice

How is CAH treated?

Doctors can treat CAH with special medicines. These medicines correct the amount of hormones produced by your adrenal glands. As a result, you will have the right amount of hormones to grow normally. This will also help your body to stop losing salt and to keep the right amount of sugar in the blood.



This medicine is given in tablets and you may need to take them everyday for all your life. The amount of medicine that you need will depend on your body size. Your doctor will tell you how much is needed and how to take it.

What tests are needed during treatment?

It is very important that your body receives the right amount of medicines. To make sure this is the case, sometimes tests can be done. Test can be done on blood, finger-prick bloodspots, urine and saliva (spit).

For the blood test, the doctor will take a bit of your blood by using a needle. You may get some special cream on your skin, so it won't hurt so much!

Bloodspots are made by pricking your finger and putting drops of blood on a special paper.

For the urine test, you will have to go to the toilet and fill a small plastic cup with urine.

Saliva tests are done by filling small plastic tubes with spit.

Is an operation needed for CAH treatment?

In some girls but not boys, operations may be needed. If you need these operations, the doctor will talk about this with your mum or dad.

Congratulations!

Now you know about CAH, why it happens and how it's treated. If you have not understood some things in this leaflet, don't feel shy to ask your doctor or other friendly people in the hospital. They will happily explain these or any other doubts you may have.

