

Family Action Sheet for Congenital Adrenal Hyperplasia (CAH)

If a newborn blood screening result shows that your baby could have a serious condition called congenital adrenal hyperplasia (CAH). This result does not mean that your baby has this condition, but that more tests are needed.

All babies born in California have a routine blood screen shortly after birth. The goal of this newborn screening is to find those at risk for serious medical conditions. Babies can look healthy at birth and still have one of these conditions. Babies with these conditions benefit from early diagnosis and treatment.

What is congenital adrenal hyperplasia or CAH?

Congenital adrenal hyperplasia (CAH) is a condition where the adrenal glands are enlarged (hyperplasia) and do not work properly. These glands are small organs found above the kidneys. Babies with CAH cannot make certain hormones that maintain blood sugar, salt, and/or water levels, especially during stress or illness. Too much of a hormone called androgen may also be produced. This can lead to problems with growth and development.

Classic CAH can cause two types of symptoms, called simple-virilizing and salt-wasting. Salt-wasting is more severe and can cause a life-threatening medical emergency called an adrenal crisis. Signs of CAH include poor feeding, vomiting, and low energy.

Is there treatment for CAH?

Yes, there are treatments for CAH, including steroids. Starting treatment early is better.

Newborn screening takes blood from a baby's heel to screen for medical conditions



Next steps

1. Your baby's medical provider will help arrange for more testing as soon as possible.

These tests will let you know if your baby has CAH.

2. Work closely with your baby's medical provider and follow recommendations.

Your baby's medical provider may give advice on how to keep your baby safe. The provider may also refer your baby to a doctor who specializes in CAH. It is important that you keep all appointments and start treatment if instructed.

Where can I get more information?

Your baby's medical provider or CAH doctor is the best person to teach you about CAH. Find more information at these websites:

• Baby's First Test

(www.babysfirsttest.org). Type "CAH" into the "Find a Condition" box and follow the link. For Spanish, click on the top right black box marked "en Español"

• Cares Foundation (caresfoundation.org)

