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 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 disorder where the adrenal glands are enlarged (hyperplasia) and do not work normally. These glands are small organs found above the kidneys. Classic CAH can have two types of symptoms, called simple virilizing and salt wasting. Salt wasting is more severe.

A baby with CAH cannot produce certain hormones. These hormones help to maintain blood sugar, salt, and water levels, especially during stress or illness. Too much of a hormone called androgen can also be produced. This can lead to problems with growth and development. Those with salt wasting CAH can have a life-threatening medical emergency.

Is there treatment for CAH?

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

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



Next steps

- Your baby's medical provider will help arrange 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 with more experience 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
 (https://www.babysfirsttest.org). Type "CAH" into the "Find a Condition" Box. Follow the link. For Spanish, click on the top right black box marked "en Español"
- <u>Cares Foundation</u> (caresfoundation.org)





