

# Congenital Adrenal Hyperplasia (CAH)

(kuhn-jen-i-til uh-dreen-l hi-purr-play-she-uh)

## FAMILY FACT SHEET POSITIVE NEWBORN SCREEN

### What is a positive newborn screen?

Newborn screening is done on tiny samples of blood taken from your baby's heel 24 to 48 hours after birth. Newborn screening tests for rare, hidden disorders that may affect your baby's health and development. The newborn screen suggests your baby might have a disorder called CAH.

**A positive newborn screen does not mean your baby has CAH, but it does mean your baby needs more testing to know for sure.**

Your baby's doctor will help arrange for more testing for CAH.

### What is CAH?

CAH affects the way the body makes chemicals called hormones. Hormones help the body work and grow properly.

A person with CAH doesn't make enough of a hormone called cortisol (also known as the "stress hormone"). Without enough cortisol, the body can have problems growing and developing. Some children may also have trouble keeping the right amount of salt in the body. The wrong amount of salt can cause the body to stop working properly.

CAH is a disorder that is passed on, or inherited, from a child's mother and father. Because CAH is a genetic disease, family members are at risk of having CAH too, even if no one in the family has had it before.

### What problems can CAH cause?

CAH is different for each child and affects females and males in different ways. Girls with CAH can have problems with their genitals, while boys with CAH don't. There are three main types of CAH:

- Salt-wasting CAH
- Simple virulizing CAH
- Nonclassic CAH

If **salt-wasting CAH** is not treated, a child might develop:

- Poor feeding and weight gain
- Sleepiness
- Dehydration (not enough fluid)
- Life-threatening salt-wasting crises

If **simple virulizing CAH** is not treated, a child might develop:

- Rapid growth in childhood
- Early puberty

Individuals with **nonclassic CAH** have milder problems that don't start until childhood, or even adulthood.

It is very important to follow the doctor's instructions for testing and treatment.

### What is the treatment for CAH?

CAH can be treated. The treatment is life-long. Treatment for children with CAH includes:

- Daily medications to replace missing hormones

Children with CAH should see their regular doctor and a pediatric endocrinologist (hormone specialist).

With prompt and careful treatment, children with CAH can live a healthy, normal life.

### Resources for parents

#### Genetics Home Reference

<http://ghr.nlm.nih.gov>

#### Congenital Adrenal Hyperplasia Network

[www.congenitaladrenalyperplasia.org](http://www.congenitaladrenalyperplasia.org)

#### MN Children & Youth with Special Health Needs

(651) 201-3650 or (800) 728-5420

#### MN Newborn Screening Program

[www.health.state.mn.us/newbornscreening](http://www.health.state.mn.us/newbornscreening)

