



CONGENITAL ADRENAL HYPERPLASIA (CAH)

FAMILY FACT SHEET

What is a positive newborn screen?

Newborn screening is done on tiny samples of blood taken from your baby's heel 24 to 36 hours after birth. The blood is tested 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.

You will be notified by your primary care provider or the newborn screening program to arrange for additional testing.

What is CAH?

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

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

CAH is a genetic disorder that is passed on (inherited) from parents to a child. The mother and father of an affected child carry a gene change that can cause CAH. Parents usually do not have signs or symptoms, or even know they carry the gene change.

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
- Non-salt wasting CAH
- Non-classic 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 non-salt wasting CAH is not treated, a child might develop:

- Rapid growth in childhood
- Early puberty

Individuals with non-classic CAH have milder problems that don't start until later in childhood. It is very important to follow the doctor's instructions for testing and treatment.

What is the treatment for CAH?

CAH can be treated. Treatment is life-long and can include:

- Daily medications to replace missing hormones.

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

Prompt and careful treatment helps children with CAH live the healthiest lives possible.

Michigan Resources and Support

Michigan Newborn Screening

Nurse Consultant

Toll-free: 1-866-673-9939

newbornscreening@michigan.gov

Newborn Screening Endocrine Follow-up Program (EFUP) at

Michigan Medicine

1-734-647-8938

Children's Special Health Care Services

Toll-free: 1-800-359-3722