



## **CAH** **(Congenital Adrenal Hyperplasia)**

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### **What is it?**

Congenital adrenal hyperplasia, or CAH for short, affects the way the body makes chemicals called hormones. These hormones are like little messengers that tell the body what to do. In children with CAH, the adrenal glands (2 walnut-sized glands that sit on top of the kidneys) do not make enough cortisol (also known as the stress hormone). Without enough cortisol, the body makes too much male hormone. This can cause growth and development problems. Some children also have a more serious problem called salt-wasting crises. This happens when the body has trouble keeping the right balance of salt.

### **What causes it?**

CAH is inherited when both parents pass an abnormal CAH gene to their child. This means both parents are carriers of CAH. Carriers do not experience any health problems related to CAH. When two carriers of CAH have children together, there is a 1 in 4 (25 percent) chance for each baby to have CAH.

### **How is CAH detected?**

Newborn screening test is done on tiny samples of blood taken from the infant's heel 24-48 hours after birth. After a positive newborn screen, testing at special labs must be done to know for sure if a baby has CAH.

### **What problems can it cause?**

CAH is different for each child. Some female infants have an abnormality of their genitals caused by too much male hormone. Male infants often look normal at birth. If CAH is

not treated, it can cause salt-wasting and electrolyte problems (keeping the right balance of salts in the body), dehydration (not having enough fluid in the body), heart problems, and even death. It is very important to follow the doctor's instructions about caring for a child with CAH.

### **How is it treated?**

CAH can be treated. People with CAH must take daily medication. The medication replaces the missing cortisol and sometimes other hormones that the body is also lacking. The treatment is life-long. Some girls with genital problems may need surgery.

### **CAH in Children?**

The child should have a primary care doctor and a pediatric endocrinologist. These health professionals give the child good medical care and educate the family about CAH.

Treatment for CAH is a life-long, and a child with CAH should see a doctor regularly.

### **Where can I find more information?**

[www.cahsupportforum.com](http://www.cahsupportforum.com)

[www.netnet.net/mums](http://www.netnet.net/mums)  
877.336.5333

[www.magicfoundation.org](http://www.magicfoundation.org)  
708.383.0808

[www.rarediseases.org](http://www.rarediseases.org)  
203.744.0100

### Children's Special Health Services (CSHS)

State Capitol Judicial Wing  
600 E. Boulevard Ave., Department 301  
Bismarck, ND 58505-0269  
Toll Free: 800.755.2714  
701.328.2436  
Relay TDD: 701.328.3975  
CSHS website: [www.ndhealth.gov/CSHS](http://www.ndhealth.gov/CSHS)  
North Dakota Department of Health website:  
[www.ndhealth.gov](http://www.ndhealth.gov)

#### Family support resources available from CSHS:

- Guidelines of Care Info
- Family Support Packet
- Financial Help Packet
- Insurance Fact Sheet

#### *Family Resources*

Family to Family Network  
Center for Rural Health  
University of North Dakota  
School of Medicine and Health Sciences  
P.O. Box 9037  
Grand Forks, ND 58202-9037  
Toll Free: 888.434.7436  
701.777.2359  
Fax: 701.777.2353  
E-mail: [NDF2F@medicine.nodak.edu](mailto:NDF2F@medicine.nodak.edu)  
[www.medicine.nodak.edu/crh](http://www.medicine.nodak.edu/crh)

Pathfinder Services of ND  
Pathfinder Family Center  
1600 2<sup>nd</sup> Ave. SW, Ste. 19  
Minot, ND 58701  
Toll Free: 800.245.5840  
701.837.7500  
Relay TDD: 701.837.7501  
E-mail: [ndpath01@ndak.net](mailto:ndpath01@ndak.net)  
[www.pathfinder.minot.com](http://www.pathfinder.minot.com)

Family Voices of North Dakota, Inc.  
P.O. Box 163  
Edgeley, ND 58433  
Toll Free: 888.522.9654  
701.493.2634  
Fax: 701.493.2635  
[www.geocities.com/ndfv](http://www.geocities.com/ndfv)

\*\*This fact sheet has general information. Every child is different and some of these facts may not apply to your child specifically. Certain treatments may be recommended for some children but not others. All children should be followed by a metabolic doctor in addition to their primary-care provider.

#### **Acknowledgement**

The North Dakota Department of Health Newborn Screening Program thanks Star-G Screening, Technology and Research in Genetics for allowing us to utilize its material.

#### **Disclaimer**

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[www.ndhealth.gov/familyhealth](http://www.ndhealth.gov/familyhealth)