

Be At Risk?



2414 Morris Ave., Suite 110
Union, NJ 07083

www.caresfoundation.org



CONGENITAL ADRENAL HYPERPLASIA



Could Your Family



CAH runs in families. If a family member is affected by CAH, pre-conception genetic counseling should be considered. If both parents carry the CAH gene mutation, their children may be at risk.

The milder form of CAH (non-classic or late onset), may cause symptoms at any time from infancy through adulthood. This form of CAH is more common, especially if your ethnic background is Jewish (Eastern European descent), Hispanic, Croation, or Italian. Its symptoms may include: premature puberty, rapid growth in childhood with adult short stature, hirsutism (excessive hair growth), oily hair and skin, severe cystic acne, polycystic ovary syndrome (unwanted body hair, irregular menstrual periods), and infertility in males and females. Unfortunately, NCAH is often overlooked by physicians as a cause for these problems

If you suspect CAH, you or your family member should be evaluated by a board-certified endocrinologist.

What is Congenital Adrenal Hyperplasia (CAH)

Congenital Adrenal Hyperplasia (CAH) is a family of inherited disorders affecting the adrenal gland. Over 90% of those diagnosed with CAH are affected by 21-hydroxylase deficiency. Inherited in severe, moderate and mild forms, the major types of CAH are:

Classic CAH - The severe form of CAH or Classic CAH can result in life-threatening imbalances in salt and hormone levels. If undetected at birth, Classic CAH can lead to adrenal crisis and death. Frequently, newborn babies show no outward signs of the disorder and are sent home, only to present a few weeks later for urgent medical attention at a time when they are beyond resuscitation. Classic CAH also is the most common cause of atypical genitourinary development in females.

Non-Classic CAH (Late Onset) - The mild form of CAH may cause symptoms at any time from infancy through adulthood. While each individual presents differently, common symptoms include: premature development of body hair, body odor, rapid growth spurt, but ultimately short stature as adult, early puberty, severe acne, anxiety, depression, mood swings, migraines and infertility.

Frequency

The genetic frequency of Classic CAH is approximately 1 in 10-15,000 births. NCAH affects 1 in 100 to 1 in 1000 in the general population, depending upon the ethnic composition of a given community. Its frequency varies in different ethnic groups. For example, it affects one in 27 Ashkenazi Jews, one in 40 Hispanics, one in 53 Croatians, and one in 300 Italians.

Inheritance

CAH affects males and females in equal numbers. For a child to be born with any form of CAH, both parents must carry a gene mutation for the disorder.

Treatment

All forms of CAH may be managed with oral medication that regulates hormone levels and replaces hormones not made by the body.

Long-Term Effects

If not detected or treated, Classic CAH may lead to adrenal crisis and death within a few weeks of life. Non-classic CAH can result in long term quality of life issues, as well as growth problems and early puberty in childhood. However, despite the fact that there is currently no cure for CAH, gene therapy, that may result in a cure, is in clinical trials. With proper treatment those affected by CAH can expect to live normal lives.

What is CARES Foundation?

CARES Foundation, Inc. was established in 2000 to promote education and research for Congenital Adrenal Hyperplasia while providing the resources and the latest information available for managing life and health for people with this disorder. CARES serves the CAH community in every state in the US and over 70 countries outside the US. CARES programs benefit over 8,000 families and medical professionals across the United States and abroad. These programs include:

Research

Since our inception in 2000, CARES Foundation has granted hundreds of thousands of dollars towards medical research. Our goal is to seek better treatment methods for those affected with CAH and to ultimately find a cure.

Education

As the only organization in the United States solely dedicated to CAH, CARES educates individuals, families and healthcare professionals about CAH through our comprehensive website, newsletters, regional conferences and other resources.

Support

Our support groups across the United States and abroad enable individuals and families to meet with each other, share stories and address each other's medical concerns. We also offer one-on-one support to affected individuals and their families through email and telephone communication, as well as occasional face-to-face meetings and social gatherings.



To learn more about CARES Foundation, please visit our website: www.caresfoundation.org, call toll-free: (866) 227-3737, or drop us an email at contact@caresfoundation.org

Comprehensive Care Centers

These CARES-designated centers of excellence include a multi-disciplinary team of healthcare professionals who are experts in the care of CAH. The goal is to provide excellent care to patients with CAH from childhood to adulthood, promote research that will improve patient lives, and educate patients, families and other healthcare providers in CAH and its management. There are a number of Comprehensive Care Centers in the U.S.

Newborn Screening Advocacy

Identifying CAH at birth can save a baby's life. CARES has successfully advocated throughout the US for newborn screening. As of 2008, CAH is included on every state's newborn screening panel. We continue to advocate for newborn screening in other countries in collaboration with other stakeholders and families.

Emergency Medical Service Protocols

Our most recent advocacy effort is to help establish protocols for emergency workers to administer life-saving medication to people in adrenal crisis. Currently, this life-saving medication is not carried on EMS trucks and EMS workers are not allowed, or trained, to administer the life-saving injection in most states. If you would like to become involved in this campaign, please contact CARES.

Ask the Expert Service

Our medical director provides answers to questions about treatments, care and living with CAH to affected individuals and their families through an online service. Available in English and Spanish.

Physician Referral Service

Affected individuals and their families can contact CARES for help locating a physician in their area who has knowledge and experience with CAH.

CAHtalog™

We have partnered with Neurocrine Biosciences to conduct a new type of registry to combine the de-identified medical histories of many volunteers into a single, CAH research database: CAHtalog™. The main purpose of the CAHtalog™ registry is to obtain information about how adults and children with CAH are managed by their doctors in a real-world setting.

PACE App

The PACE app is designed for adrenal insufficient patients and parents/caregivers and features a stress dose calculator, help recognizing signs of adrenal crises, and injection training. This app is available to the CAH community.

How You Can Help

CARES Foundation, Inc. is a 501 (c)(3) tax exempt organization. Contributions are tax deductible. CARES Foundation seeks financial support from many sources, including individuals, foundations and businesses.

In addition, if you would like to join CARES or donate online, you may do so by visiting our website at www.caresfoundation.org or by calling, toll-free, 866-227-3737, or 908-364-0272.

Thank you for contributing to CARES Foundation, Inc. Your tax-deductible contribution will help us continue our work on behalf of individuals and families affected by CAH.

Please mail your contribution to: CARES Foundation, Inc.
2414 Morris Ave., Suite 110
Union, NJ 07083

NAME: _____

ADDRESS: _____

CITY: _____

STATE: _____ ZIP: _____

PHONE: _____

EMAIL: _____

Enclosed is my contribution in the amount of:

\$10,000 \$5,000 \$1,000 \$500 \$250

\$100 \$50 Other \$ _____

Please make checks payable to: CARES Foundation, Inc.

Please charge my contribution to my credit card: MC, VISA, or AMEX

Card # _____

Expiration date: ___/___ Security code: _____

Name (as appears on card): _____