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Recognized by CARES Foundation as a Center of Excellence in CAH

Our mission is to provide the best care possible, promote research, and offer education in CAH to patients, families and healthcare providers.

Fact Sheet:

Non-Classical Congenital Adrenal Hyperplasia (NC-CAH): Adolescents and Adults

Congenital Adrenal Hyperplasia (CAH) is a family of inherited disorders affecting the adrenal glands. 21-hydroxylase deficiency is the most common form of CAH. The disorder is divided into classical (severe) form of CAH (further divided into salt-wasting and simple-virilizing types) and the mild form known as non-classical CAH.

Non-classical CAH is a mild form of CAH where 21-hydroxylase, an enzyme responsible for proper control of many adrenal hormones, is partially deficient. Unlike classical 21-hydroxylase deficiency form of CAH, the disorder is not life-threatening, but can cause symptoms anytime from early childhood to adulthood. While girls with classical CAH are born with abnormalities of the genitalia, patients with NC-CAH have normal genitals. Certain ethnic groups, such as patients of Ashkenazi Jewish and Italian ancestry, are genetically more predisposed to the condition. It has been reported that 1 in 3 Ashkenazi Jews is a carrier of a mutation responsible for non-classical CAH, and 1 in 27 is affected with the disease.

Non-classical CAH can manifest itself in a number of ways in the adolescent and adult population. Women may develop irregular menstrual periods, acne, excess body hair (called hirsutism), loss of hair on the scalp, and infertility. Some women may also develop polycystic ovarian syndrome (PCOS). Men may experience acne, decreased libido and in rare cases infertility. Some patients are shorter than other members of the family as adults. The number of symptoms and their severity are different in everyone; some patients may have all the symptoms while others have none of the symptoms and are diagnosed with the disorder incidentally on genetic testing.

Symptoms of non-classical CAH can affect your quality of life physically and psychologically; however, treatment of the disorder has been well-established. Dexamethasone once daily or hydrocortisone twice daily is the treatment of choice. Once the adrenal hormones have normalized, many of the symptoms improve quickly. Medication doses are adjusted to achieve proper control of adrenal hormones. Adjuvant treatments, when necessary, are utilized as well to target PCOS, acne, hirsutism, and

hair loss on the scalp. If necessary, a referral is made to a fertility specialist.

Our team is here to help you every step of the way:

- Our team of physicians will see you frequently in the beginning; once your adrenal hormones have been well-controlled and symptoms have improved, visits can take place every 6 months.

- Our nutritionist will work with you on a proper diet aimed at helping you control your weight.

- Our psychologist, who has years of experience with patients and families living with a chronic illness, can provide ongoing psychological support.

- When necessary, our team can refer you to The Cornell Institute of Reproductive Medicine, an internationally recognized reproductive center.