

KNOW YOUR LABS

A guide to your numbers and why they matter

Together with how you feel and what signs and symptoms you're experiencing, lab values are what doctors use to make decisions about your care.

Labs are a valuable tool for you, too. They can help you better understand why you feel the way you feel and can help you get more out of conversations with your doctors.



Essential bloodwork for people with congenital adrenal hyperplasia (CAH)

Blood test	What it measures	Why it's important	Understanding your results
Androstenedione (A4)	Levels of the hormone androstenedione, which is an ingredient the body uses to make different androgens. Sometimes abbreviated A4, it also has slight testosterone-like effects in the body.	<ul style="list-style-type: none"> An indicator of androgen control Lower levels are associated with better CAH management Higher levels are associated with acne, early puberty, and fertility issues, and may be treated with a CRF₁ antagonist or an increased steroid dose 	<ul style="list-style-type: none"> Your target range depends on a number of factors including age and gender For men, the target range for androstenedione is optimally less than half the level of testosterone. Your doctor may refer to this as the "A4 to T ratio"
17-OHP	Levels of 17-OHP, also called 17-hydroxyprogesterone, a hormone that the adrenal glands use to make androgens.	<ul style="list-style-type: none"> Together with androstenedione, 17-OHP is an indirect measure of how well androgen levels are managed Lower levels are associated with better CAH management Higher levels may be treated with a CRF₁ antagonist or an increased steroid dose 	<ul style="list-style-type: none"> Target range is based on a number of factors. If CAH is treated with steroids alone, values in the "normal" range of your lab report may suggest that steroid doses are too high During pregnancy, 17-OHP testing is not useful for managing CAH
Testosterone (T)	Levels of the hormone testosterone, an androgen.	<ul style="list-style-type: none"> Testosterone helps support muscle and bone mass. High levels are associated with facial hair growth and acne and can cause early puberty in children High levels in women are associated with poor CAH management and can cause deepening of the voice and other symptoms 	<ul style="list-style-type: none"> In females, total testosterone higher than the upper limit of normal indicates poor CAH management In males, the ratio of androstenedione to testosterone (A4 to T, or A4/T) helps determine whether CAH is well managed
Plasma renin activity (PRA)	Levels of renin, which the body releases into the bloodstream when electrolyte (salt) levels are too low or you are dehydrated.	<ul style="list-style-type: none"> Helps measure whether you are getting enough salt and mineralocorticoid (fludrocortisone) Renin helps maintain a healthy blood pressure and prevent levels of electrolytes that are too low 	<ul style="list-style-type: none"> Target range is low to normal unless you have high blood pressure Elevated renin levels suggest that salt and/or mineralocorticoid (fludrocortisone) doses, or water intake, may be too low Low, or suppressed, renin suggests that the dose of salt and/or fludrocortisone may be too high

OTHER LABS... AND BEYOND

For women



Progesterone

Progesterone levels vary based on where a person is in their menstrual cycle. Levels that are too high may affect fertility or cause irregular periods.

Estradiol

Low estradiol can mean that androgen levels are too high. Low estradiol can cause irregular periods and may impact fertility.

Labs for hormones that affect fertility

Your doctor may also order other blood tests to evaluate how well your treatment is addressing your goals. Because these labs can measure levels of hormones that affect fertility, they are especially important if you or your partner see starting a family in your future.

For men



FSH

High levels of FSH (a gonadotropin) can be a sign of possible sustained testicular damage from testicular adrenal rest tumors (TARTs).

Luteinizing hormone (LH)

Low levels of LH (a gonadotropin) can impact fertility in adulthood. These imbalances can appear as early as childhood.

Inhibin B

Low levels of inhibin B can impact fertility in adulthood. These imbalances can appear as early as childhood.

More than labs: looking at the big picture

A holistic approach to managing CAH can include monitoring for risks of high-dose steroids and the symptoms of high ACTH and androgens. Your doctor may order other tests such as bone age and bone density scans. Talk to your doctor about screening for these risks.

Mental health

Living with a chronic condition can present mental health challenges at any age. For people with CAH, the risk can be even higher because high androgens and high-dose steroids may affect mental health. Experts recommend seeking help when in doubt. It's good to find support for even minor changes in the way you feel, mentally and emotionally.

Consistency is key

Having your labs done at consistent times of day can help create a more accurate measure of CAH management. Ask your doctor about what time of day your labs should be done and how to time them with your steroid doses.

ACTH=adrenocorticotrophic hormone.

High ACTH and androgens

Some symptoms of high androgens are easy to spot, like acne, early puberty, or irregular periods. However, in men, TARTs—a consequence of high ACTH—require routine monitoring. Ultrasound screenings for TARTs should start in adolescence for boys and happen at least every 1 to 2 years.

High-dose steroids

People who take high-dose steroids, especially for long periods of time, may be at increased risk for health concerns including:

Obesity	High blood pressure
Diabetes	Low bone density
High cholesterol	Mental health challenges, including depression and anxiety

Don't underestimate the importance of how you're feeling, too

And one more thing: Sometimes the best information doesn't come from a lab report. It will help your doctor to hear about changes, even small ones, in how you feel. For example, changes in energy level, weight gain, and menstrual cycles—all those will be useful for evaluating updates to your CAH treatment. Talk to your doctor about anything new you are experiencing.

