

How to Talk About Your Child's Congenital Adrenal Hyperplasia (classic, salt-wasting)

To Healthcare Providers: My child has salt-wasting congenital adrenal hyperplasia (CAH) and is adrenal insufficient and steroid dependent. When s/he is ill, s/he will need to have additional doses, or stress doses, of hydrocortisone. If s/he cannot take medications orally or if signs of adrenal crisis are present, s/he will need an intramuscular injection of hydrocortisone or intravenous hydrocortisone immediately. It might also be necessary that s/he for fluids to be given intravenously, likely normal saline.

My child's daily medicines include:

To People in Your Social Network (teachers, family, friends, coaches, babysitters): My child has an inherited condition called congenital adrenal hyperplasia, CAH for short. Basically, his/her adrenal glands don't function properly and are unable to produce cortisol, a steroid hormone, which is necessary for life. Cortisol helps regulate important body functions such as glucose levels and blood pressure. Because of this, s/he takes steroids every day to replace what s/he can't make on his/her own. This is not something s/he will outgrow. People without CAH produce up to ten times the amount of cortisol when they are sick, but my child cannot do this. So when s/he is sick with a fever or stomach illness or experiences some sort of trauma, like a broken bone, s/he will need extra steroids quickly—either by mouth, or if s/he can't take medicines by mouth because he is throwing up or unconscious, an injection in his/her muscle (usually thigh) of hydrocortisone. Most of the time, s/he acts and behaves like all other children and has a great quality of life with no significant restrictions, including dietary. However, when s/he is sick, s/he will need these additional steroids quickly and will need to be watched closer than other children. I am happy to talk with you more about my child's CAH if you are interested.

OPTIONAL TALKING POINTS:

- *S/He also cannot produce aldosterone, which helps regulate the body's regulation of salt.*
- *Possible to add any special instructions such as allowing child to have unrestricted access to water and the bathroom.*
- *Boys and girls born with CAH are born with very high levels of testosterone. This corrects as they begin steroid treatment. Boys don't show any outward symptoms of high testosterone at birth, but sometimes girls are born with non-*

typical genitalia that may or may not be corrected surgically at some point in their lives.

Watch training video.

How a Child Can Talk to Another Child about CAH

Middle/High School Aged Child:

What is CAH? It's a condition that I was born with. My adrenal glands, which sit on top of my kidneys, don't work like they should so I have to take medicine to replace the steroids that my adrenal glands can't make. As long as I take my medicine every day, I am just like every other kid and feel fine. If I get sick with a fever or I throw up, I will need extra medicine until I feel better.

Why do you have to take medicine every day? I take medicine every day to replace the steroids that my body can't make on its own because my adrenal glands don't work like they are supposed to.

Why do you wear a medical bracelet? I have a condition called CAH and when I feel sick I need an adult to know that I have to get extra medicine. Sometimes I might need a shot if I am really sick.

Elementary School Aged Child:

What is CAH? I was born with it. I have to take medicine every day (or one time/two times/three times a day). If I get sick, like with a fever, I need extra medicine. I can still eat what I want and do what other kids do that don't have CAH. I wear this bracelet (or necklace or shoe tag) so that if I felt really sick, an adult would know that I need extra medicine.