

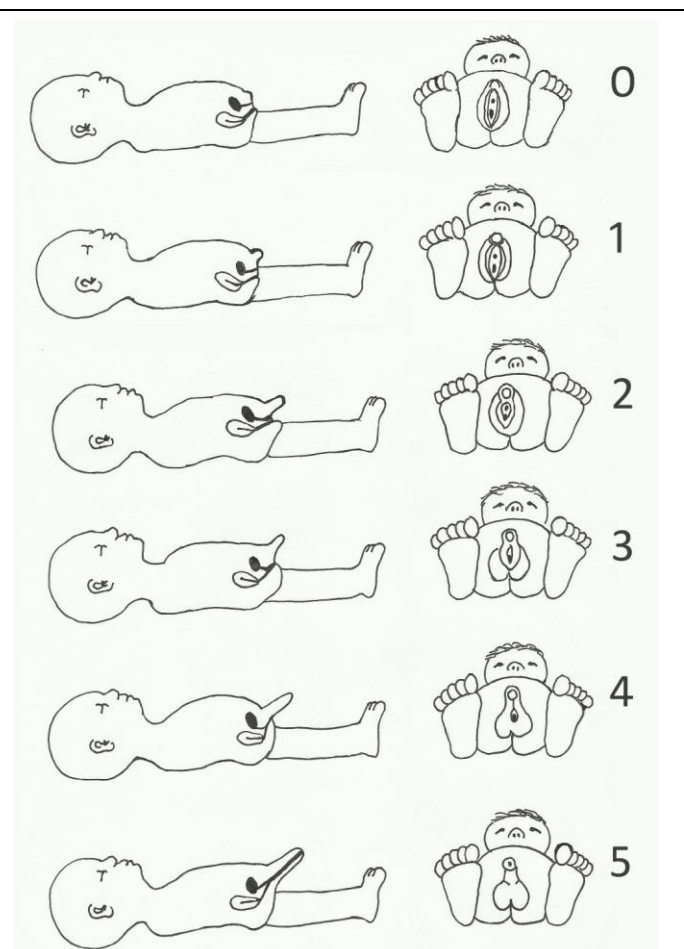
Congenital Adrenal Hyperplasia (CAH) 46XX CONTINUED

Living with Congenital Adrenal Hyperplasia - CONTINUED

Doctors and parents may choose to allow the child to grow up without surgery until the child is old enough to decide for themselves whether they want help in altering their body to be more masculine or to be more feminine. Historically, adults have often made a choice for the newborn with CAH, and have started surgical reconstruction before the child could participate in the decision. Sometimes the decisions made for the child adversely affected the individual, and forced them to live with consequences they did not want.

At birth, some individuals with CAH have genitals that look more female than male. Other individuals with CAH have genitals that look more male than female. The extent to which the infant's body is masculinized depends on how early in the development of the fetus the adrenal glands started to make excess testosterone. The earlier that the high testosterone is present, the more masculine the baby's body will be. One way of communicating the extent of masculinization of the XX body by testosterone is to use a scale called the Prader scale. On this scale a zero refers to genitalia consistent with a typical female, and a five on this scale refers to external genitalia that are indistinguishable from a typical male.

Although parents and doctors can see what effect testosterone has had on the baby's genitals, it is not possible to see what effect the testosterone has had on the baby's brain and on their gender identity. That is why it is wise to wait for the individual living with CAH to grow up enough to be able to inform their doctors and parents about the nature of their own gender identity.



Prader Scale

0 = normal female

1 = clitoris is enlarged
no fusion of the labia

2 = clitoris is enlarged
labia are only partly fused

3 = clitoris enlargement more noticeable
single opening shared by urethra + vagina
almost complete fusion of labia

4 = clitoris very similar to a penis
urethra-like opening at base of clitoris
complete labial fusion

5 = clitoris looks like a penis
urethra opens at tip of penis
labia have become scrotum (but do not
contain gonads)