

Newborns with Non-Typical Genital Appearance

Information for Parents

What made my baby look this way?

At birth it may not be possible to tell, but testing is done to identify the cause. It did not happen because of something you did or did not do. During very early development, boys and girls start out down the same pathway of genital development. Both boys and girls have identical structures that will become either testicles or ovaries, a penis or clitoris, and internal organs that can become the uterus and vagina. In boys, a "Y" chromosome normally causes testicles to form. A normal testicle makes a substance that causes the early uterus and vagina to almost completely disappear, such as in a normal male. If the substance is not made, the uterus and vagina remain present and grow, such as in a normal female.

What is gender?

Person's feelings about themselves as male or female constitute their gender identity. Many factors contribute to a person's gender identity. These factors include a child's brain development before and after birth, hormones, body image (including the genitals- "private parts"), and the child's culture/environment. The appropriate gender role or sex-of-rearing is, in most babies, a very easy choice. When the genitals do not appear typical for a male or female, there must be testing and careful consideration before this choice is made.

How do hormones affect a fetus?

Masculinizing hormones (called "androgens") normally make the clitoris and penis grow. Both the testicle and the adrenal gland of a baby can make androgens. Also, androgens from the mother can cross the placenta and cause a masculinizing effect. When there is an abnormality in the baby's adrenal glands (called "Congenital Adrenal Hyperplasia"), they may make too much androgen and not enough of other hormones. With androgens the clitoris can grow large enough to look like a penis. If there are not enough androgens or they aren't working well the penis can be small enough to look like a clitoris. Likewise, too much androgen in a girl can cause the opening of the vagina to close, and too little androgens in a boy can cause the urinary opening to be near where a vagina normally opens.

Why couldn't the doctors tell if my baby was a boy or a girl when he/she was born?

Since many factors are involved in determining a child's gender, when the genitals don't look typical it is best to perform some tests before a gender decision is made. You can and should have input into all decision-making processes in involving your child's care.

What tests are done and how soon do you know the results?

Specialists are from the fields of medicine, including neonatology, endocrinology, urology, genetics, and psychology may be involved. They examine your baby, recommend some blood tests (looking at hormone levels and chromosomes), and often obtain an ultrasound or x-ray studies. The results of the blood tests usually take at least 72 hours. The team will review the results of all the tests and explain the results to you as well as make a recommendation about your baby's gender. The team will also discuss with you their recommendations for medical or surgical treatment if needed. Sometimes, further tests are needed that take longer.

What should people be told when they ask if the baby is a boy or girl or other questions about our baby?

That is, of course, a very personal choice. You may not wish to share the details. One possible explanation could be that sometimes there can be swelling or abnormal structure that developed in the genital region so more information was needed. It is important to remember that as a parent your baby's medical information is confidential. People often feel an obligation to share medical information about their baby with the public. However, your child has as much right to private, confidential medical care as any person. At a later time you can share the medical information with your child, who can then choose how much information he or she wants to disclose for public knowledge, if any.

For more information, or for specialist in your immediate area, contact MAGIC Foundation.

Text was adapted from one produced by the Gender Issues Management Team at the University of Iowa

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The MAGIC Foundation is a national nonprofit organization created to provide support services for the families of children afflicted with a wide variety of chronic and/or critical disorders, syndromes and diseases that affect a child's growth. Some of the diagnoses are quite common while others are very rare.

MAGIC continues and develops through membership fees, corporate sponsorship, private donations and fundraising.

"Not an illusion or magical, but the caring for children and their families"

* * * * Dedicated to the growth and overall development of children * * * *

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