

Atypical Genitalia

What is atypical genitalia?

Atypical genitalia, previously known as ambiguous genitalia, is a condition in which a baby's external genitals are not typically formed. It can be caused by a variety of genetic, hormonal, and environmental factors.

Atypical genitalia falls into a group of conditions known as differences of sexual development (DSDs), which affect approximately 1 in every 4,500 newborns. While the diagnosis or even suspicion of atypical genitalia can be concerning for parents, these babies are usually born healthy. The team at the SSM Health Cardinal Glennon St. Louis Fetal Care Institute has experience in counseling families in preparation for their baby's birth, including an explanation of the evaluations that the baby may undergo after delivery to assist in assigning the baby's sex.

If I've been told my unborn baby may have atypical genitalia, what can I expect during my visits to the Cardinal Glennon St. Louis Fetal Care Institute?

Our team will set up prenatal evaluations as well as multidisciplinary consultations. These evaluations will include advanced ultrasound imaging as well as a possible fetal MRI. Additionally, genetic counseling will be offered to discuss available pre- and post-birth genetic testing options. Finally, our team will provide counseling for you and your family to help you prepare for the birth of your baby and to help you understand how sex assignment (also sometimes referred to as gender assignment) is undertaken after birth.

The team at the Cardinal Glennon St. Louis Fetal Care Institute will also work with your family and the team of pediatric specialists who will care for your baby to prepare for delivery.

After delivery, specialists from Urology, Endocrinology and Genetics typically assess babies with atypical genitalia in order to assist with assigning the baby's sex as well as to look for any associated conditions that might affect the baby's overall well-being. Various tests may be used to help obtain a diagnosis and identify any medical problems that would require immediate or later treatment. These tests can include physical examinations by specialists, an ultrasound to visualize internal organs, and blood tests to analyze genes and/or hormone levels.

A Cardinal Glennon St. Louis Fetal Care Institute nurse is available 24 hours a day, seven days a week to discuss referrals with physicians and potential families by calling 314-268-4037, option 2.

Phone 314-268-4037, option 2
Toll-free 1-877-SSM-FETL (776-3385)
Web stlouisfetalcare.com
Email fetalcare@ssmhealth.com
Facebook facebook.com/fetaldocs

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How does atypical genitalia affect my baby?

Depending on the cause of the DSD and the presence of any additional disorders, atypical genitalia may have little to no long-term effect on the baby. DSDs are rarely associated with syndromes that would require emergency medical care. Most individuals born with atypical genitalia live healthy lives and have a normal life expectancy.

Our team of specialists at the Cardinal Glennon St. Louis Fetal Care Institute will provide more information about potential recommendations for care for your baby after birth. Some individuals with atypical genitalia will need treatments such as hormone therapy or surgery. Many others may not need any treatment. In some cases, while treatment may be available, families are involved in the discussions to decide what, if any, treatment is right for their child.

How does atypical genitalia affect delivery?

Babies with atypical genitalia are typically stable at birth and able to be delivered normally. The team at the Cardinal Glennon St. Louis Fetal Care Institute will help you make a delivery and post-birth care plan that prioritizes your time to bond with your new baby while ensuring your baby receives the best and most timely medical care and evaluations that are indicated.

What can I expect after delivery?

The team at the Cardinal Glennon St. Louis Fetal Care Institute will perform thorough evaluations and, using that information, work with your family to assign the baby's sex. This consultation may take several days, during which a team of medical providers and other support staff will be available to your family. After sex has been assigned, a baby with a DSD may require surgeries, medications, and/or additional follow-up with pediatric specialists.

We understand that atypical genitalia can be a scary diagnosis.

That's why we're available to help 24 hours a day, 7 days a week. For more information or to schedule an appointment, call us at 314-268-4037 or toll free at 877-SSM-FETL (877-776-3385).

While we can't change the diagnosis, we can provide you with expert care and support, helping your baby get the most out of treatment and life.
