

# **‘When our baby was born their sex was not what our prenatal testing indicated’**

Differences in sex development

DEPARTMENTS of Endocrinology, Urology & Gynaecology

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## *'When our baby was born their sex was not what our prenatal testing indicated'*

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Maybe you had a prenatal test that suggested your baby was a boy, but when your baby was born they did not match the sex you were expecting, or maybe your baby has genitals that look different.

These differences may mean that it will take a little longer than usual to decide the sex of your baby. Doctors and other health professionals will work with you to make the best decision for your baby; as the parents, you play an important role in this process.

You may never have heard of people who have differences in their sex development and may feel like you are the only people who are experiencing this; however our team meets lots of families every year where this is the case. Differences in sex development can happen for a number of reasons that may be due to with variations in the development of your baby's gonads (ovaries or testes), or hormonal signals that are responsible for sex development during pregnancy. There are many terms used to describe these variations or differences. Some health professionals refer to this as a 'DSD'.

At the Royal Children's Hospital, we have a team of doctors, nurses and allied health professionals who work together with you and your baby. Sometimes things can be sorted out in a few days, but sometimes it may take more time to find the cause for your child's differences.

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## *Who is on the team?*

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A team of specialised doctors from different departments will be involved in helping you and your baby. Not all departments will need to see your baby. The group of doctors is referred to as the multidisciplinary team who are:

Endocrinologists, Urologists, Gynaecologists, Social Workers, Genetics and the Clinical Coordinator – the clinical coordinator is your point of contact at the hospital, you may call them to discuss appointments, accessing resources, for support or to connect with other families.

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## *What happens in the first few weeks?*

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The team of doctors will work together to identify how to best care for your baby. There are a few factors such as hormones, physical features and genetics that help doctors understand the sex of your child. There are a few tests that might be done to help with the diagnosis.

**Genetic tests** – Karyotype or microarray (looking at genes and chromosomes)

Chromosomes are made up of many genes. Chromosomes and genes play a role in sex development, variations in some specific genes can sometimes cause a DSD.

**Hormone tests** – These tests look at how your baby responds to hormones and whether your baby will need immediate medicine and care.

**Ultrasound** – ultrasounds help doctors look at your baby’s internal organs.  
**MRI** (magnetic resonance imaging) – help doctors look inside the body at your baby’s organs.

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*How to talk with friends and family.*

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“*Is it a boy or a girl*” is one of the first questions that friends and families might ask when you have had your baby. You may not know what to say or may not want to speak with people about what is happening. Some parents like to share what is happening with friends and family.

Sometimes families are unsure about what to tell others about their baby’s health when they have to spend time in a hospital. Some simple things to say might be:

*“Our baby was born (last night), baby and mum are recovering well.”*

*“We have had to go to the hospital just to make sure baby and mum are well.”*

*“We may not be able to respond to all your lovely messages, as we are taking our time to get to know our new arrival”*

Some people might find it easier not to respond to well-wishers during this time. Family and friends understand that you have just welcomed a new member to your family and may be too tired to respond.

Some new parents like to share some more information with their friends and family if you would like some help planning these discussions you can contact the RCH clinical coordinator (see contact details at the end).

There is no right or wrong way when speaking with your friends or family.

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*Looking ahead*

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When you take your baby home the multidisciplinary team will keep in touch with you and be available to answer questions, provide support and follow-up care. It can be complicated understanding medical information, some people find it helpful to write their questions down before speaking with doctors and you may ask for a summary letter for you to have at home.

Babies born with differences in their sex development grow up to be healthy successful and happy people who have a career, friends, relationships, and families. We can link you and your family into peer support groups where you can meet with other families and individuals who have been through similar experiences.

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*Further information:*

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Please contact the Clinical Coordinator if you would like to talk further:  
For more information contact the DSD Clinical Coordinator  
Royal Children's Hospital Ph: 03 93457033