

We will work with you to get any support or help you need, including putting you in contact with other parents whose children have this condition. If your baby has CAH we will be able to discuss the medical issues which come with this condition. In most cases your baby will be able to remain in the postnatal ward with you while we wait for these results.



### **What should I tell other people?**

We understand that waiting for test results can be very hard and that you will have family, whanau members and friends waiting to hear news about your baby. You might feel confused and scared, or feel you don't want to tell anyone what is going on. Our experience with parents over the years however, says it is good for parents to have the support of family and friends at this time. A helpful thing to say to them might be:

*"Our baby was born with a kind of variation that happens more often than you hear about. Our doctors are doing some tests to figure out whether our baby is probably going to feel more like a boy or a girl. We expect to have more information soon, and then we'll send out a birth announcement with the gender and the name we've chosen. We appreciate your love and support and we're looking forward to introducing you to our little one in person soon."*

Other things you can do are share a picture of your baby with people or have people come and meet your baby. Parents sometimes wonder about naming their baby, this is a personal decision, some parents choose to wait until a decision is made about gender while others choose a name which would suit a girl or a boy.

### **Where else can I find information?**

There is a lot of information about these conditions on the internet but other parents have expressed that they have often found it very overwhelming or sometimes frightening and confusing. As soon as we have a name for your baby's condition, we can give you a lot of specific information about the condition both in our talks with you and as written material. We will also give you information about support groups and the addresses of good websites. We also have some good resources which answer a lot of the questions which parents have such as how to talk to their child, what will it be like to grow up, how do I talk to other people about my baby's condition and how can I meet other parents of children with the same condition?



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## *A Girl or a Boy?*

**Information for parents  
when a baby's gender  
is uncertain at birth**



**Newborn  
Services**

## Introduction

Congratulations on becoming new parents and welcome to your new baby. We know the first question many new parents ask is “Is my baby a girl or a boy?” Someone from the paediatric service has come to see you and look at your baby because this is a question we haven’t been able to answer just by looking at your baby’s genitals (sex organs). Parents are often very shocked when told this kind of news, but we’d like to reassure you we see a number of babies each year whose genitals are different from what you might expect to see in a female or male baby. Although your baby has a condition you have probably never heard of, these conditions are not that uncommon. We will do a number of tests over the next few days to find out more about your baby’s condition so we can help answer your question “Is my baby a girl or a boy?”

## What condition might my baby have?

When developing in the uterus, all babies start out with the same sexual organs. Boys usually develop a penis, scrotum and testes, whereas girls usually develop a uterus, ovaries, vagina and clitoris. There can however, be a number of things that happen in the early weeks of development which cause variation in a baby’s reproductive organs, either inside or outside. These are a biological variation and very seldom indicate anything life threatening.

There are medical terms which cover a large group of these conditions and two you might hear

(Disorders of Sexual Development). Some people don’t like these terms, “intersex” because it has become a political term, and “DSD” because of the word ‘disorder’, but at present these are the terms used. Individual conditions have their own names and the tests we do over the next few days will help to give a specific name to your baby’s condition.

## What tests will my baby have?

The condition that most commonly causes genitals to look different is Congenital Adrenal Hyperplasia or CAH. We will do a blood test to check for this, as this condition does have a medical complication, as babies with CAH lose too much salt from their bodies, and medication will be needed for this. We will also do blood tests to look at your baby’s chromosomes and the level of certain hormones in the blood. We may need to give some medication to your baby, and then do blood tests to look at the response to these medications. Your baby will have an ultrasound to check the internal organs. We will also need to examine your baby. You can be present for all these tests and hold your baby throughout them when possible, or immediately afterwards. You can ask as many questions as you like and we will explain what we are doing at the time. Some tests give a result immediately while others may take hours or a few days.

There are a number of health professionals we may need to speak to or ask to come and see you and your baby. We will try our best to have as

few people as possible examine your baby. Some of these other people may be endocrinologists (looking at your baby’s hormones), genetics (to do with your baby’s chromosomes) and urology (looking at your baby’s ability to produce urine). We will inform you when we get results, and as soon as we have them all we will sit down with you and discuss the findings. We realise waiting is hard and as soon as we have these test results we will be able to talk about your baby’s condition.



## The test results

The results of the tests will help us find out which condition your baby has and then there will be some decisions to make. The biggest of these will be which gender to assign to your baby. Sometimes this is easy to decide and sometimes a little harder. We will discuss everything with you and the final decision will be yours. We suggest you choose the gender your baby is most likely to identify with as they grow up but it’s important to keep in mind that all people – whether or not they have a genital variation make this decision as they mature, and may choose not to identify with the gender they’ve been given as a baby. This does not have to be an instant decision. We will give you as much help, information and support as you need. You can talk to your midwife or nurse, the paediatric staff from the neonatal unit or the paediatric service, a social worker or a patient advocate.