Ambiguous genitalia in neonates

Parent information

Congratulations on the arrival of your baby!

You have been provided this factsheet because your baby has been born with genitals that look a bit different and it’s not possible to immediately tell the sex of your baby. This will be possible to determine, but your baby may need to have some further tests.

Your baby will be kept in hospital for a few days for blood tests and to ensure your baby is healthy. People who have these types of conditions often grow up to be happy, healthy, and live normal lives.

This can be a stressful time. You will receive support from a team of health professionals. Victorian parents should be referred to the Royal Children’s Hospital or the Monash Children’s Hospital in Melbourne.

Naming your baby

You may wish to wait until the sex of your baby is determined before choosing a name. You do not have to register your baby’s name until 60 days. In the meantime, you could give your baby a nickname (such as poppet or bubs). Many families take a bit of time to decide on a name for their baby anyway.

When announcing your baby to family and friends, you may not want to refer to the sex of the baby (him/her). Your baby is happy and healthy and there is no need to disclose the sex at this stage. If people ask and you don’t want to respond, you might like to say that you’re well and mother and baby are both resting. You may want to talk with family and friends about it – either option is right, do what best suits you.

Next steps

Your team of health professionals will now work with you to determine the sex of your baby. The process will include:

- looking at your baby’s external genitalia
- looking at internal organs (usually by ultrasound)
- reviewing hormones and your baby’s response to them (blood test)
- undertaking a blood test to look at their genetics.

There may be follow up tests to help keep your baby healthy.

Causes

Between 1 and 2 percent of babies are born with genitals that look different in some way. A small proportion of these differences result in genital appearances where the sex can’t be determined by appearance – this is sometimes referred to as genital ambiguity.

Differences in genital appearance may be due to a range of factors including hormones, chromosomes (genetic factors) or other physical characteristics. These conditions may be referred to as ‘differences of sex development’, or ‘intersex variation’ that refer to differences associated with reproductive development – just like the term ‘heart conditions’ is an expression that covers many different heart problems. In some cases, other hormones that are important for general health may also be affected – these can be replaced using medication.

Along with the support of your medical professional team, family and/or friends, you may wish to seek support from other parents who have similar experiences.

Support

DSD Families: http://www.dsdfamilies.org/
Royal Children’s Hospital Clinical Coordinator: (03) 9345 7033
Monash Hospital Department of Urology (03) 9594 4723

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