

|  |
| --- |
| Babies with atypical genitalia |
| Information for families |

# Congratulations on the arrival of your baby!

You have been given this factsheet because your baby has been born with genitals that look a bit different (atypical). These genital differences are sometimes referred to as ‘intersex variations’, ‘differences of sex development’ or ‘variations in sex characteristics’.

We understand this can be stressful for you, however it is not necessarily cause for serious concern. If the sex of your baby is not immediately clear, it will be possible to work this out with support from health professionals. Variations in sex characteristics are more common than people think – roughly equivalent to the number of people with red hair – and are part of our human diversity. People who have these types of variations can lead very happy and healthy lives.

Intersex variations are not always associated with medical problems, however there are certain health issues associated with particular intersex variations. This means your baby may be kept in hospital for a few days for review.

It is important to receive accurate information to fully understand the issues and risks associated with your child’s specific intersex variation in order to make informed decisions about their best care and treatment.

You will be referred to the Royal Children's Hospital or the Monash Children’s Hospital where you will receive support from a team of health professionals. Access to specialist peer support groups is also available. We encourage you to speak to these professional and peer supports who can answer your questions and provide you with more information.

# Announcing the arrival of your baby

When announcing your baby to family and friends, you may or may not want to refer to the sex of the baby (him/her). You are just getting to know your baby and there is no need to disclose the sex at this stage.

If you want to talk with family and friends, you could say there is some uncertainty and doctors will have more news in a few days. 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. Either option is right, do what best suits you and your family.

You may wish to wait until the sex of your baby is assigned before choosing a name. You have up to 60 days after birth to register your baby’s name. In the meantime, you could give your baby a nickname and it is quite common for families to take some time to decide their baby’s name.

# Next steps

The next step for you and your baby is to be referred to a specialist team of health practitioners who will do further examinations and tests, for example:

* looking at your baby’s genital area
* looking at internal organs (usually by ultrasound)
* blood and urine tests
* a blood test to look at their genetics.

This team will give you more information to help you understand what the test results mean. They will support you to care for your child throughout childhood and, if needed, they will help you decide whether to raise your baby as a girl or a boy. The specialist teams will help you to best support your child and to understand all of the options available to your child as they grow.

It is important to take your time when making treatment decisions on behalf of your baby. Many treatments can be deferred until your baby is old enough to make their own decisions. Seek advice and consider all options, including no treatment, wherever possible.

# Causes

Between one and two per cent of babies are born with some form of intersex variation or variation in sex characteristics. A number of these include minor variations of genital development that do not result in significant long-term interactions with health systems, or result in ongoing health needs. Only a small proportion of these differences result in genital appearances where the sex can’t be determined by appearance.

Differences in genital appearance (atypical genitalia) may be caused by a range of factors including hormones, chromosomes (genetic factors) or other physical characteristics. Intersex variations are different to gender identity (how people identify) and sexual orientation (who people are attracted to).

# Support

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

For more information, contact:

* Royal Children’s Hospital Clinical Coordinator: (03) 9345 7033 or (03) 9345 5522 (switchboard)
* Monash Hospital Department of Urology: (03) 9594 4723
* [AISSGA](http://www.aissga.org.au) (Androgen Insensitivity Syndrome Support Group Australia) <http://www.aissga.org.au>
* [Australian X and Y Spectrum Support](https://axys.org.au) (AXYS) <https://axys.org.au>
* [CAH Support Group Australia](http://www.cah.org.au) <http://www.cah.org.au>
* [Genetic Support Network Victoria](https://www.gsnv.org.au) <https://www.gsnv.org.au>
* [Intersex Human Rights Australia](https://ihra.org.au) <https://ihra.org.au>
* [Turner Syndrome Association of Australia](https://www.turnersyndrome.org.au) <https://www.turnersyndrome.org.au>.

|  |
| --- |
| To receive this publication in an accessible format, [email DHHS diversity](mailto:diversity@dhhs.vic.gov.au) <diversity@dhhs.vic.gov.au>  Authorised and published by the Victorian Government, 1 Treasury Place, Melbourne. © State of Victoria, Department of Health and Human Services, March 2019. ISBN 978-1-76069-686-3 (pdf/online/MS word) ISBN 978-1-76069-753-2 (Print) Available at [Health of people with intersex variations](https://www2.health.vic.gov.au/about/populations/lgbti-health/health-of-people-with-intersex-variations) <https://www2.health.vic.gov.au/about/populations/lgbti-health/health-of-people-with-intersex-variations> Printed by TDC3, Richmond (1810017 banner) |