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| Sex characteristic variations in babies and children |
| Information for families |

You have been given this factsheet because your baby or child has been diagnosed as having a variation in sex characteristics. This means your child was born with naturally occurring characteristics that do not fit the typical definitions for male or female bodies.

These differences are also sometimes referred to as ‘intersex variations’, ‘differences of sex development’ or ‘conditions associated with reproductive development’. Different people prefer different terms. For this factsheet, we will use ‘intersex variations’.

There are more than 30 intersex variations that can affect people in different ways. Intersex variations can result from chromosomal, hormonal and/or anatomical differences. They can include different combinations of the X and Y sex chromosomes, varying levels or sensitivities to hormones typically associated with one or other sex, and genitals that look a bit different to the norm.

Some variations in sex characteristics are possible to find before birth, at birth or during infancy. Some become apparent around puberty, particularly those that involve differences in reproductive functions. Other variations may go undetected during a person’s lifetime.

Some people with intersex variations do not develop sex characteristics typical of one sex or the other and some combine features of both sexes. Nonetheless, your child will be (or has been) raised as a boy or a girl.

For most people with intersex variations, their variation is not visible or noticeable to others in everyday, social interactions.

Your child’s intersex variation is different to their gender identity (their inner sense of feeling male or female) and their sexual orientation (who they will be attracted to). Most people with intersex variations identify as male or female and as heterosexual. These traits are not predictable in advance for anyone in society, including people with intersex variations, and only your child will be able to know their preferences and identity.

# How common are intersex variations?

Reliable information about the number of people with intersex variations is difficult to obtain for many reasons, including that many variations go undetected throughout a person’s lifetime.

Intersex variations are more common than many people might think, being roughly equivalent to the number of people with red hair. Conservatively it is estimated that between one and two per cent of babies are born with some form of variation in sex characteristics. Some of these include minor variations of genital development that do not result in ongoing health needs or long-term interactions with health systems.

Mixed sex chromosome variations, such as Klinefelter syndrome, Triple X syndrome and Turner syndrome, are the most commonly diagnosed. Intersex variations associated with genitals that look different (atypical) are less frequent.

# Do intersex variations require treatment?

Most people with intersex variations are physically healthy and lead happy, successful lives. There are certain physical health and cognitive and developmental issues associated with particular intersex variations. It is important to receive accurate information to fully understand the issues and risks associated with your child’s specific intersex variation to make informed decisions about their best care and treatment.

If you are receiving a diagnosis of an intersex variation for your newborn baby, the decision to raise your baby as a girl or boy is an important decision. Your health professional team can support you in the decision making. But it is also only a decision for now. Only your child will know if they identify as male or female.

If you are receiving a diagnosis of an older child having an intersex variation, then your child will already have been raised as a boy or a girl. In some circumstances their variation may impact on their pubertal development or their gender identity. We strongly encourage you to discuss these issues openly with your child. Supporting and affirming their choices is very important for their wellbeing.

It is important to take your time when making treatment decisions on behalf of your child. Some treatments are irreversible and many can be deferred until your baby or child is old enough to make their own decisions.

Take your time, seek advice, and avoid feeling pressured to make decisions before you or your child is ready. It may be preferable to defer treatments until your child is old enough to be involved in the decision themselves.

Figure 1. Step-by-step guide for parents

**Note**: Adapted from *A guide for parents of children with atypical genitalia, 2016,* Androgen Insensitivity Syndrome Support Group Australia Inc., [Peer Support, Information and Advocacy for Intersex People and their Families](http://aissga.org.au/fact_sheets.htm) <http://aissga.org.au/fact\_sheets.htm>.

# What should I tell people?

Receiving a diagnosis of an intersex variation may be a stressful time for you and your child. Receiving accurate information and quality support from trusted sources will be important at this time.

You may have mixed feelings about talking with family and friends about your child’s intersex variation or be uncertain about how to answer any questions they may have. It may take time to balance your desire to protect your child and their privacy with an openness about their experience that avoids secrecy or shame. It is important to do what best suits you, your child and your family.

As your child gets older, it will be important to offer age-appropriate explanations about their variation, the medical treatments they may be experiencing, and the range of options and choices available to them.

# Where can I get more information?

You will be supported by a referral to the Royal Children's Hospital or the Monash Children’s Hospital where you will receive support from a team of health professionals. Along with the support of your family and friends, you may also wish to seek support from specialist peer support groups made up of 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>.

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