

## Aims of the AIS Support Group

1 To put parents and intersex people in touch with others in a safe and confidential environment and encourage them to seek support and information.

2 To reduce the secrecy, stigma and taboo surrounding intersex through education and by encouraging parents, doctors and the community to be more open.

3 To encourage developments in medical pathways offered to intersex children, men and women which may include consensual surgery, HRT, counselling and referral to peer-based support groups.

4 To encourage the provision of appropriate psychological support within health care system, for all intersex people and their families.

5 To encourage further medical and psychosocial research into intersex and gender issues and to provide community consultation to service providers and government.

6 To advocate on behalf of intersex people to ensure their human rights of bodily autonomy, legislative inclusion, social wellbeing and physical health are both established and maintained.

7 To foster wellbeing and pride amongst the intersex community.

## Membership, meetings, publications

The AISSGA has members throughout Australia, Aotearoa/New Zealand, and from other countries. Our membership includes people with AIS, other intersex variations, their families and supportive allied professionals. We have members and representatives all over Australia and encourage our State Representatives to organise local events. The AISSGA host an annual conference every year where we gather together to share our experiences, knowledge, and friendship. Membership includes a biannual subscription to our newsletter dAISy, access to closed online chat groups, information and peer support.



### AIS Support Group Australia Inc.

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# Androgen Insensitivity Syndrome Support Group Australia



Peer-support, information and advocacy for people with Androgen Insensitivity Syndrome (AIS), other intersex variations and their families

The AIS Support Group Australia (est. 1985) is a peer support, information and advocacy group for all intersex people and their families.

### What is AIS?

Androgen Insensitivity Syndrome (previously called Testicular Feminisation Syndrome) causes a variation in the development of the reproductive system as a result of a complete or partial inability to respond to androgens ("male" hormones) during foetal development. People with AIS have 46XY sex chromosomes and are born with testes. Physical characteristics (phenotype) and gender identity can vary from male to female and anywhere in between.

There are two basic types of AIS – Complete AIS (CAIS) and Partial AIS (PAIS).

### CAIS

People with CAIS do not respond to androgens and have completely typical female external genitalia. The sex of rearing of people with CAIS is usually female.

### PAIS

People with PAIS have a degree of responsiveness to androgens so that they are born with external genitalia that ranges in a spectrum from completely female, through mixed female/male, to almost completely male. Some people with PAIS are males, and are raised as boys and later identify as men.

### The AISSGA Supports AIS and all other intersex variations including:

Partial and Complete / Gonadal Dysgenesis  
MRKH (also known as Vaginal Agenesis)  
5a-Reductase Deficiency  
3b-Hydroxysteroid Dehydrogenase Deficiency  
17-Ketosteroid Reductase Deficiency  
17b-Hydroxysteroid Deficiency

### What does 'intersex' mean?

Intersex is an umbrella term for a number of congenital, biological variations whereby an intersex child may be born with physical, hormonal or chromosomal features that are not exclusively female or male, a combination of male and female or neither of these. Intersex occurs naturally and is often hereditary. Just like everyone else, intersex people can identify their gender as male, female or neither and be of any sexual orientation. Intersex is sometime referred to as Disorder of Sex Development (DSD) in clinical settings.

### Incidence

Conservative estimates suggest between 0.05 and 2% of the population has an intersex variation. AIS is thought to occur in about one in every 40,000 births.

### Diagnosis

Diagnosis of an intersex variation may happen prenatally, during IVF, at birth, puberty or as an adult.

People with AIS do not have ovaries or a uterus, and a vagina that ends in a pouch. Undescended testes can result in an inguinal (groin) hernia in infancy, which may be the reason the variation is diagnosed in an otherwise healthy child. Alternatively, CAIS may not be discovered until puberty as a result of a girl not menstruating.

It is vitally important that any diagnosis is accurate and excludes other possible medical conditions which may require different treatment, if any.

### Having an intersex child

The birth of an intersex child is not a medical emergency. There are only a few intersex variations that do pose a medical risk at birth. Peer support and accurate information is vital at this time, and is only a phone call or email away. Please contact us to put you in touch with others who have been through what you are going through.

If your emotional needs and anxieties are addressed first it will be easier for you to provide the unconditional love and support necessary for your child to flourish. Everyone will feel better if there are no taboos about the subject. Talking is therapeutic, enabling feelings and fears to be confronted and resolved. Pushing the matter under the carpet just stores up psychological trouble for later and can damage family relations.

Keeping your child's variation secret may not acknowledge their need for emotional support and to be consenting to clinical interventions. Worry wastes mental/emotional energy that is better spent helping your child come to terms with the truth about their body. It is important as parents to encourage discussion with your child in age-appropriate ways and actively seek out information on their behalf.

### Living with AIS / intersex

Surgery, hormone replacement therapy (HRT), infertility, and issues with intimacy and social stigma are common for many intersex people. Truth, autonomy, counselling, appropriate health care, and peer support are vital to living well with any intersex variation. Many have said meeting others is the single most useful therapeutic measure.

Issues vary for different intersex variations, but we always recommend seeking opinions from others who have been through similar experiences. Never be afraid to ask questions, seek a second opinion or be self-directing in the medical treatment you receive.

