Aims of the AIS Support Group

1. *To put parents and people with AIS and similar conditions in touch with each other in a safe and confidential environment and encourage them to seek support and information.*

2. *To reduce the secrecy, stigma and taboo surrounding AIS and similar conditions, by encouraging doctors, parents and society to be more open.*

3. *To encourage the provision of psychological support within the medical system, for people affected by AIS and similar conditions, including their parents.*

4. *To put people affected by AIS and similar conditions in touch with others and to encourage them to seek support and information.*

5. *To increase the availability of information on AIS and similar conditions both verbal (from health professionals) and written (from the support group and other sources).*

6. *To encourage improvements in the treatment for men and women with AIS and similar conditions in both surgical and non-surgical means.*

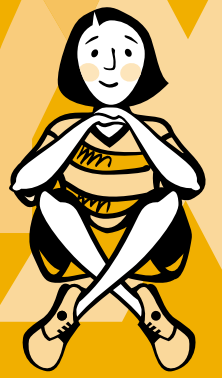
7. *To encourage research into Gender Identity and Sexual Identity issues.*

Membership, meetings, publications

The AISSGA has members in many countries including Australia, New Zealand, Canada, the United Kingdom and the USA. Our membership includes people with AIS, similar conditions, their families and supportive medical professionals. Publications include our newsletter "dAISy" (2 per year). We have members and representatives all over Australia and encourage our State Representatives to organise local functions. Membership includes a yearly subscription of dAISy and access to information and support.

AIS Support Group Australia Inc.
PO Box 1089, Altona Meadows
Victoria 3028 Australia
Telephone +61 3 9 315 8809
aissg@iprimus.com.au
http://www.vicnet.net.au/~aissg

Androgen Insensitivity Syndrome



Support and information
for those affected by
Androgen Insensitivity Syndrome (AIS)
and similar conditions

What is AIS?

Androgen Insensitivity Syndrome (old name is 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.

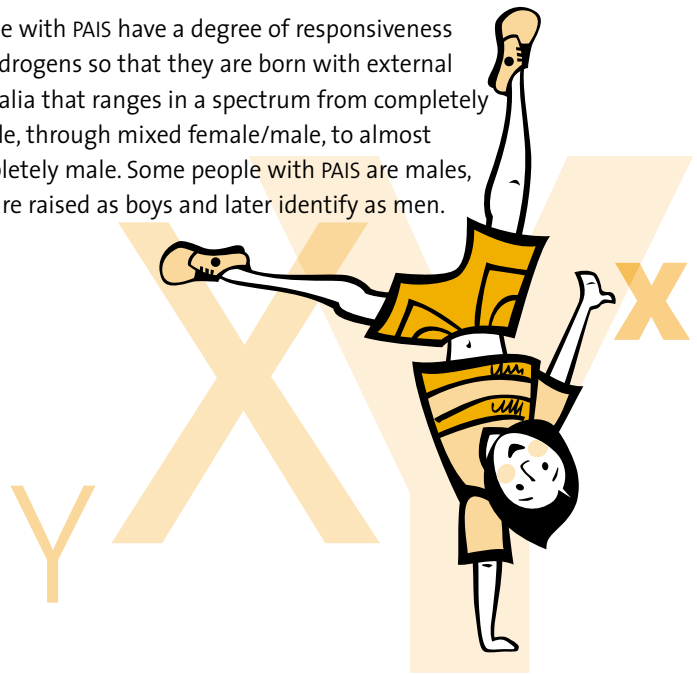
There are two basic types of AIS – Complete AIS (CAIS) and Partial AIS (PAIS).

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.



What other similar conditions do the AISSG support?

- 5 alpha-reductase deficiency
- 17-beta hydroxysteroid dehydrogenase deficiency or "17-beta HSD"
- XY gonadal dysgenesis (also known as Swyer Syndrome)
- Leydig cell hypoplasia,
- Mayer Rokitansky Kustner Hauser (MRKH) Syndrome (also known as vaginal agenesis)
- Mullerian Dysgenesis.

People with either one of the last two conditions are chromosomally 46XX.

What does 'intersex condition' mean?

Intersex conditions are one of the many long-established biological conditions where a child is born with reproductive organs, genitalia and/or sex chromosomes that are not exclusively male or female.

Incidence

Conservative estimates suggest at least one in 4000 people have intersex conditions, which equates to at least 5,000 Australians. AIS occurs in about one in 13,000 births.

Diagnosis and effects of AIS

People with AIS do not have ovaries or a uterus, and if they are born with a vagina it will be blind ending and possibly short. Undescended testes can result in an inguinal (groin) hernia in infancy, which may be the reason the condition is diagnosed in an otherwise typical girl. 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 conditions which may require different treatment.

Having a child with AIS or similar conditions

The birth of a child with AIS or a similar condition is not a medical emergency. 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 the emotional needs and anxieties of the parents are addressed first it will be easier for them to provide effective support to their child. Everyone will feel better if there are no taboos about the subject. Talking, like grieving is therapeutic, enabling feelings to be confronted and resolved. Pushing the matter under the carpet is just storing up psychological trouble for later. It is important that parents encourage discussion with their child and actively seek out information on their behalf. Unfortunately, keeping the condition a secret can become more important to some parents than acknowledging their child's need for emotional support and appropriate clinical intervention. It wastes mental/emotional energy that is better spent helping the child come to terms with the truth.

Living with AIS or similar conditions

Truth, counselling, peer support and appropriate medical support are vital to living successfully with AIS and similar conditions. Many have said meeting others is the single most useful therapeutic measure.

Medical issues vary for different intersex conditions, but we always recommend seeking opinions from others who have been through similar experiences. Never be afraid to ask questions.