

AISIA's goals

- 1) Provide support for people affected by AIS (Androgen Insensitivity Syndrome), also known in Italy by the Italian names: "Sindrome da Insensibilità agli androgeni" o "Sindrome di Morris"; guarantee respect for people affected by AIS, safeguard the image and the integration in society,
- 2) Help people affected by AIS, and their families, meet and exchange information;
- 3) Increase the amount of information available about AIS and contribute to its distribution;
- 4) Encourage an open discussion about the problems related to Disorders of Sex Differentiation (DSD) between medical practitioners, parents and the society at-large;
- 5) Improve information, communication and treatment regarding medical and surgical care;
- 6) Support a global approach to DSD issues in the public health system;
- 7) Create a network of contacts between AIS groups in Italy and internationally;
- 8) Collaborate with associations that support people and families affected by DSD, in Italy and abroad.

AISIA non-profit Association

You can designate 5x1000 of your Italian taxes by indicating AISIA's fiscal code on your tax return
97434230583

Donate

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AIS

Androgen Insensitivity Syndrome

What is AIS?

AIS, Androgen Insensitivity Syndrome, provokes a variation in the genital apparatus in the fetal stage of development caused by complete or partial insensitivity to androgens ("male" hormones).

The girl will be born healthy, but will not have ovaries or a uterus, and will have XY chromosomes and “masculine” gonads.

AIS, known in Italy also as “Morris’s Syndrome”, manifests in two forms:

- CAIS, the more frequent form, in which the insensibility to androgens is complete. This form can be hereditary.
- PAIS, the less frequent form, in which there is a partial insensibility. PAIS is not usually hereditary.

CAIS

A girl with CAIS has female external genitals, and her body will develop in a feminine manner as she grows.

PAIS

In the case of PAIS the external genitals can be less defined in a masculine or feminine sense. The decision to raise the infant as a boy or a girl must be made on an individual level.

Consequences of AIS

A woman affected by AIS does not have a uterus or ovaries, and the vaginal canal can be short. Often during childhood a inguinal hernia appears, which leads to the discovery of CAIS.

If this does not occur, CAIS can be discovered when at puberty menstruation fails to appear.

The gonads, albeit “masculine”, produce female hormones and at puberty the body will develop in a feminine manner.

If the gonads are surgically removed, Hormone Therapy Replacement is necessary. The best age in which to eventually remove the gonads is still under discussion by specialists.

Sexuality

AIS is often indicated as a form of Intersexuality. This definition is acceptable if this simply means that the body of a person with AIS doesn’t contain exclusively male or female characteristics (**material?**).

The gender identity and the sexual orientation of people with CAIS, is clearly female, as is their physical appearance.

The occurrence of gender identity issues or homosexuality is similar to that found in the general population.

AIS does not prevent a person from having a satisfying sex life.

What to do

AIS is one of the numerous Disorders of Sex Differentiation, many of which present similar characteristics. The first thing to do is to get a precise diagnosis. Only then can one evaluate the best treatment option. In order to obtain a precise diagnosis you must go to a specialized medical center that has the necessary tools and experience. There are specialized centers in Italy and abroad. We also advise that you talk to other people in your situation. Support groups offer useful information and advice for both patients and families. The group can also provide precious psychological support in that they allows one to meet others with whom exchange information, experience and talk about your feelings and issues.

What not to do

AIS without a doubt poses a delicate issue, but it can be dealt with and accepted calmly. There is no need to be anxious or distressed, keep it a secret or be ashamed. Don't make hasty decisions, especially in regards to surgical interventions. It is a good idea to get more than one opinion, make sure you are dealing with competent doctors, talk to people in the support group, and remember that in a few years medical knowledge will be even better. For instance, up until recently, surgical intervention was used to lengthen the vaginal canal, while we now know this surgical operation is not necessary.