

Please copy this sheet to hospitals (gynaecology - endocrinology - paediatrics - genetics - clinical psychology departments) and to family doctors

AIS Support Group (UK)

(see web site for overseas groups)

What we provide

- Information/support to individuals/families with AIS and similar conditions; XY gonadal dysgenesis (Swyer's syndrome), 5 alpha-reductase deficiency, leydig cell hypoplasia, MRKH syndrome etc.
- 22 issues of journal/newsletter (A^TS – *Looking At AIS*) for group members and medical/psychological care-givers.
- Informal UK group meetings with guest clinicians since Spring 1995.
- £15 p.a. UK subscription for patients/parents (free online newsgroup/meetings).
- Overseas groups (see web site).

What is AIS?

- **Androgen Insensitivity Syndrome** (old name, Testicular Feminization Syndrome) has been subject to secrecy, paternalism, and denial, leading to feelings of freakishness and isolation with a lack of psychological support. The support group is changing this.
- **'Complete' AIS (CAIS)** occurs when an XY foetus develops female external genitalia due to a rare (usually inherited) total insensitivity to male hormones (androgens).
- There are internal testes, and no ovaries, tubes or uterus; and the vagina is, at best, 2/3 of the normal length, and can be considerably shorter.
- Female body shape and breasts develop at puberty but there is no pubic/underarm hair.
- The internal testes are often removed at or before adulthood to remove a very slight risk of cancerous changes. This creates a need for long-term hormone replacement therapy.
- CAIS is diagnosed either in infancy following inguinal testicular herniation, or at puberty when there is failure to menstruate.
- AIS is an X-linked recessive condition. Sisters, maternal aunts and maternal girl cousins of the affected person have a 1 in 3 chance of being either a regular female, a carrier, or of having CAIS. But approx. 30% of cases arise from a spontaneous (de novo) mutation on the mother's X chromosome.
- **'Partial' AIS (PAIS)**, in which there is some sensitivity to androgens, results in varying degrees of masculinization at birth, and virilization at puberty with pubic/underarm hair. Men with PAIS may have problems with fertility.

How to get information

- See "Literature (ALIAS)/Subscriptions" page of web site.
- Multidisciplinary UK centres of expertise in treating AIS (and other rare reproductive conditions) are established at *University College Hospitals, London* (Dr. Gerard Conway – adult endocrinologist, Miss Sarah Creighton – gynaecologist) and at *Leeds General Infirmary* (Mr. Adam Balen –gynaecologist).

Literature & Joining forms →

www.medhelp.org/www/ais
AISSG Support Group (UK)
Literature Order Form

(£ = UK Pounds)

AISSG factsheet/brochure

UK £1.00; overseas £1.50 In English, French, Dutch, German or Italian? [_____]

GIG leaflet (“Does Your Child have a Genetic Disorder?”)

UK £1.00; overseas £1.50

ALIAS newsletter back issues

See www.medhelp.org/www/ais/newsletters/ALIAS_TOC.htm for contents of all the issues.

a) *ALIAS 1 to 19 on CD-ROM:*

The first 19 issues on a single CD-ROM with colour illustrations

CD-ROM £10.00 (plus postage): UK post-free, Eire/Europe £0.50, elsewhere £1.50

b) *ALIAS 20, 21 & 22 as hardcopy:*

ALIAS 20 £2.50 (plus postage): UK postage £0.34, Europe/Eire £0.79, elsewhere £1.20

ALIAS 21 £2.50 (plus postage): UK postage £0.34, Europe/Eire £0.79, elsewhere £1.20

ALIAS 22 £2.50 (plus postage): UK postage £0.34, Europe/Eire £0.79, elsewhere £1.20

Dr. Garry Warne’s CAIS book

£2.50 (postage UK £0.50, Eire/Europe £1.00, elsewhere £1.50)

Caroline Hawkrige’s HRT book

£7.50 (postage UK £1.00, Eire/Europe £2.00, elsewhere £3.00)

Name: _____ Patient/Parent/Doc: _____

Address: _____

_____ Email Address: _____

Please email AISSG UK (our email address is on the 'Contact Us' page of our site,
see www.medhelp.org/www/ais/11_group.htm#national)
for details of how to submit form and for payment methods.

AIS Support Group (UK) Joining Form

(£ = UK Pounds)

I am a Parent:

I am parent of **Complete** AIS (CAIS) youngster/s (tick) _____ Age of youngster/s _____

I am parent of **Partial** AIS (PAIS) youngster/s (tick) _____ Age of youngster/s _____

Youngster has other condition _____ (please specify)

I am an Affected Adult:

I have **Complete** AIS (CAIS) myself (tick) _____ My age is _____

I have **Partial** AIS (PAIS) myself (tick) _____ My age is _____

I have other condition _____ (please specify)

Other Enquirer: _____ (Doctor, Nurse, Counsellor, Psychologist etc.)

Name: _____ Tel: _____

Address: _____

Email address: _____ Date: _____

Joining fee £15 per year.

Please email AISSG UK (our email address is on the 'Contact Us' page of our site, see www.medhelp.org/www/ais/11_group.htm#national) for details of how to submit form and for payment methods.

Your annual joining fee entitles you to:

- Free sign-up to a private online newsgroup run by AISSG UK (with participants from UK and various European countries).
- Notification of UK group meetings, joining instructions, accommodation suggestions etc.
- Access to our newsletter/journal, A^TS (to download free sample issue, No. 6, see http://www.medhelp.org/www/ais/13_aliases.htm - to order back issues see literature order form).
- Free attendance at UK group meetings. Members with AIS, XY Gonadal Dysgenesis (Swyer's Syndrome), 5-alpha-reductase Deficiency, Leydig Cell Hyperplasia, Rokitansky (MRKH) Syndrome, Mullerian Dysgenesis etc. attend. Those without a clinical diagnosis are urged to get one before their second meeting. Our guest clinicians are at meetings to answer questions from people with a known diagnosis and *not* to help people diagnose themselves.