

Possible signs and symptoms associated with Klinefelter's Syndrome in children

- Speech and language development disorders
- Short attention span/easily distracted
- Lack of agility & dislike of physical games
- Passive, shy
- Trouble with self-expression
- Moderate learning difficulties
- Long limbs
- Testes fail to develop

Possible signs and symptoms associated with Klinefelter's Syndrome in adults

- Small testicles
- Body & facial hair is sparse
- Tired or lethargic for no apparent reason
- Infertility
- Depression
- Low sex drive
- Poor muscle bulk
- Mood swings
- Evidence of osteoporosis
- Breast development
- Low self-esteem
- Difficulty remembering recent conversation
- Poor communication skills

Membership Form

Please send your completed form to:

The KSA Membership Secretary,
30 Alandale Close, Reading, Berkshire, RG2 8JP

Name:

Address:

Postcode: Telephone:

Email address:
(By supplying your email address you agree to be contacted by email)

Details of person diagnosed as KS: Karyotype:

Name: Date of Birth

Relationship to member:
(E.g. self, son, friend, etc).....

Type of Membership (delete as necessary): Individual/Family

Subscription rates:

UK Only: **ONE year at £22.50**
TWO years at £40.00 (£20.00 per year)
THREE years at £52.50 (£17.50 per year)

OAPs, Students, Unwaged **£12.00** per year
(Please enclose copies of proof of entitlement)

Europe: **£27.00 per year**
Rest of the World: **£30.00 per year**

GP/Medical Professional Membership:
(Contact Membership Secretary for forms & terms)

Payment Methods:

If paying by cheque please make payable to KSA (UK Only)

To pay by Credit Card or PayPal visit www.ksa-uk.net

Standing Order Payment is ONLY available for renewals. Please pay first year by cheque, credit card or PayPal.

£15.00 per year - (Contact Membership Secretary for form)

All the information on this form will be treated in the strictest confidence by the Klinefelter's Syndrome Association. Details will normally be given only to the Committee Members. Occasionally, however, the Committee will supply a member of the KSA with name and address details only, for a specific task, such as, mailing out fundraising catalogues.

Signed: Date

**75% of Males
with Klinefelter's
Syndrome
don't know they
have it!**

eXtra
Klinefelter's
Syndrome
Association

A Registered Charity, number 1058319

This leaflet provides
a brief overview of
the symptoms and
answers some of the
most frequently
asked questions

ADVICELINE: 0845 230 0047

WEBSITE: www.ksa-uk.co.uk

FAQs

What is Klinefelter's Syndrome (KS)?

KS is a congenital condition (i.e. something a male is born with and present from the moment of conception) caused by the presence of one or more extra X sex chromosomes. KS is a lifelong condition treatable by Testosterone Replacement Therapy (TRT)

How common is KS?

Studies have shown that the extra X sex chromosome may occur in as often as 1 in 650 live male births and is probably the most common single chromosome variation in the general male population.

How is KS diagnosed & confirmed?

KS is diagnosed by a physical examination (for example, small testicles are a common indicator of KS) and by taking a blood sample to look at the level of Testosterone, Sex Hormone Binding Globulin (SHBG), Follicle Stimulating Hormone (FSH) & Luteinising Hormone (LH).

To confirm KS another blood sample is required which is analysed to reveal that the Karyotype or chromosome pattern is 47XXY or a variant.

How is Testosterone made available?

Testosterone is a controlled drug and is only available on prescription from a doctor. Methods for delivery include: Fortnightly or quarterly Injections, Gel, Implants, Tablets, and Patches. Individual choice, as well as, effectiveness, age and ease of use will also influence which method is most suitable.

Isn't Testosterone linked to aggression?

Testosterone has a variety of effects on behaviour including increased energy levels, confidence, and assertiveness. In some cases testosterone can increase aggression but it may also have the opposite effect.

It is often sensible to start with small doses and to build up the dose gradually to help acclimatise patients and or their relatives to an increase in independence and assertiveness.

What are the psychological aspects of KS?

The teenage years can be difficult for any boy, but can be particularly stressful for those with KS who have to come to terms with hormone treatment, possible breast development and infertility. Boys will need the support and understanding of their families (counselling may be required). At this time of their life some young men may want to talk to others with KS. The Klinefelter's Syndrome Association holds Local Male Meetings, Activity Weekends and an Annual Conference where those with KS can meet. A contact list is also available and a helpline.

What about Career Prospects?

Some boys with KS appear to have few or no problems at school and have gone on to university, gaining degrees and having successful careers. Given appropriate intervention boys with learning difficulties in early childhood may have overcome any problems by adolescence. Others make progress but continue to have learning difficulties into adulthood.

What about infertility & sex drive?

The vast majority of men with KS are unable to become fathers by natural means. The only way to be sure about their fertility is to have a sperm count. If there is evidence of sperm there are techniques of sperm implantation into the ovum, which can be carried out as part of IVF. If there are no viable sperm then artificial insemination by donor (AID) or adoption are possibilities.

Sex drive is not usually affected as long as testosterone levels are in the normal range or supplemented where necessary.

What is the long term picture?

In terms of the hormone treatment, there is continuing improvement in the methods of delivery of testosterone, and the male with KS should be assured that with TRT he will develop like a non-KS male in terms of his bone, muscle, hair growth and behaviour. However, the earlier the diagnosis the better

Note:

The information contained in this leaflet has been approved by our Medical Advisers but should not be treated as specific advice to individuals. All such information should be checked with your Health Provider. Drug usage in particular is a matter for your Medical Practitioner.

Klinefelter's Syndrome Association

Charity no. 1058319

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