What is Turner Syndrome?

Turner Syndrome (TS) is a relatively common chromosome abnormality affecting only females.

It is caused by the complete or partial deletion of the X chromosome in some or all of the cells of the body.
The incidence of TS is approximately 1 in 2000 live female births.

TURNER SYNDROME
TSSS
SUPPORT SOCIETY [UK]

There are a number of physical features and characteristics with TS whilst it is rare these will all appear in one child, short stature and infertility are nearly always present. Providing diagnosis is made early enough, there is the possibility of growth hormone treatment for short stature. In vitro fertilisation (IVF) treatment is also a possibility for infertility.

There is no increased risk of mental retardation in those with TS; intelligence spans the normal range, although there may be some problems with spatial awareness, concentration span and short-term memory. The majority of girls and women with TS are healthy, happy and lead normal lives.

What causes it?

The cause of the missing or abnormal X chromosome is not known. No risk factors e.g. maternal age, diet during pregnancy have been identified which increase the risk of having a baby with TS.

It is an accident that happens during cell division after conception. Parents with a diagnosis of TS during pregnancy or after birth are advised to have genetic counselling to ensure they receive clear, accurate and comprehensive information about TS.

TS is sometimes suspected during antenatal tests such as ultrasound, amniocentesis or chorionic villus sampling.

However, it is more usual for a diagnosis to be made later, after a baby is born. This may be due to the baby girl having certain features i.e. short wide neck, puffy hands or feet, widely spaced nipples and occasionally a heart problem.

Further more detailed information can be obtained by visiting the Turner Syndrome Support Society website: **www.tss.org.uk**

Support

The Turner Syndrome Support Society is a UK charity caring for the needs of those with TS throughout the United Kingdom. The Society offers support and information to both girls and adult women with TS, their families and friends.

Turner Syndrome Support Society (TSSS)

The Society enjoys good relationships with relevant specialists to promote a good basis for education and understanding of the management of TS.

Communication with other support groups, both domestic and international is important and offers the opportunity for an exchange of ideas to help develop awareness and greater understanding of Turner syndrome throughout the UK and worldwide.

Members of the Society receive regular copies of AspecTS, the TSSS newsletter. The title of the newsletter has been chosen to reflect its intention to cover all aspects of Turner syndrome from day to day living, medical issues, research, education, social issues and more.

Membership offers access to a membership network for social contact with others who share the similar interests and concerns. Local friendship groups operate in many areas of the UK.

Each year the Society holds an annual conference and a number of open days around the UK, sometimes with a theme i.e. Education & TS, HRT & TS, but always with a social element.

Experience has shown that one of the most important needs of those with TS and their families is to have contact with others who share their experiences.

Parents of young girls, adults and teenagers with TS benefit enormously from meeting each other at these events. Lasting friendships are formed, especially amongst teenagers with TS.

TS is a ‘cradle to grave’ condition and as such requires medical treatment throughout life. The Society actively promotes the setting up of ‘one stop’ adult clinics for those with TS and the smooth transition from paediatric to adult clinic for teenagers with TS. Enquiries about TS from health, education, social service and other relevant professionals are welcomed. Promoting greater awareness of all aspects of TS amongst the general population is one of the aims of the Society.

How does fundraising help the TSSS?

It is vital to the continued success and enhancement of the TSSS to maximise fundraising opportunities. It is only with a good source of donated income that through fundraising, leading to an increased profile that will allow the TSSS to grow and reach more people.

Currently, the TSSS membership is over 800 and it is estimated that there are as many as 10,000 people in the UK with TS, so there are many more people that the TSSS would like to reach, help and support. Unfortunately, because TS is not commonly known, we often lose out to better-known charities. The Society's national fundraising officer, a mother of a young daughter with TS, would greatly appreciate hearing from anyone (via the TSSS office) who can offer a donation or help with fundraising.

A number of information leaflets and guides are available from the TSSS. For more information & membership details please contact:

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