

TSSS Publications & Information

[Payment can be made by cheque, postal order or via www.justgiving.co.uk/turnersyndrome]

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| "Turner Syndrome – lifelong guidance & support" 2nd edition This book published by the TSSS and launched in 2002 covers everything you need to know about TS. It includes diagnosis, genetics, treatments, personal experiences, and other aspects of living with TS. It has been highly acclaimed by health professionals and those with TS and their families. A 'must have book'. Reprinted in August 2008 | A minimum donation of £5 to the TSSS please. Overseas GBP £10 |
| "Talking About Turner Syndrome" DVD & the Booklet This DVD is about members of the TSSS who have TS and their families talking about life with the condition and how their lives are affected and how they cope. It also includes doctors talking about TS and treatments and other aspects of the syndrome. It was made with international co-operation from members of TS Societies and doctors from the USA & Japan. The booklet has been produced to accompany the DVD | A minimum donation of £6 to the TSSS please. Overseas GBP £10 |
| "So you are considering a partnership – what does Turner Syndrome mean for us?" General information for Partners updated in 2005 | A minimum donation of £1 to the TSSS please |
| "How to help your child survive & succeed in school" An education information leaflet for teachers and parents | A minimum donation of £1 to the TSSS please |
| "Reach For The Stars" A children's book about their ambitions for the future. Supported by Novo Nordisk | A minimum donation of £5.99 to the TSSS please. |
| "Who is the woman I am less than anyway?" An information leaflet for women who have TS looking at self-esteem and how to improve it. Funded by a J4G grant | Donation to cover postage |
| "Employment & Turner Syndrome" An information booklet for employers & employees Funded by a J4G grant | Donation to cover postage |
| "Turner Syndrome: A Guide For Patients & Parents" Series 8 by Serono | Donation to cover postage |
| "The Turner Woman: A Patient Guide" Series 9 by Serono | Donation to cover postage |
| "A Parent's Guide to Turner Syndrome" by Novo Nordisk | Donation to cover postage |
| "A Teenagers Guide to Turner Syndrome" by Novo Nordisk | Donation to cover postage |
| "Turner Syndrome (TS)" Information for parents and carers. by Pfizer | Donation to cover postage |
| "Turner Syndrome – Information for you" by Ipsen | Donation to cover postage |
| Information Leaflets Payment can be made by cheque, postal order or via www.justgiving.co.uk/turnersyndrome | |
| TSSS Fact sheet Series - funded by An Endocrine Society Grant | |
| Fact sheet - 1 "Pubertal Induction" | Donation to cover postage |
| Fact sheet - 2 "Practical Tips for Pubertal Induction" | Donation to cover postage |
| Fact sheet - 3 "Footwear and Footcare Advice for Girls" | Donation to cover postage |
| Fact sheet - 4 "Footwear and Footcare Advice for Women" | Donation to cover postage |
| Fact sheet - 5 "Spatial Awareness" | Donation to cover postage |
| Fact sheet – 6 "Disclosure" | Donation to cover postage |
| Fact sheet – 7 "Top Tips on Coping with Tiredness" | Donation to cover postage |
| Fact sheet – 8 "Problems with Feeding" | Donation to cover postage |
| Fact sheet – 9 "Speech and Language Problems" | Donation to cover postage |
| Fact sheet – 10 "Genetic counselling" | Donation to cover postage |
| "Adult TS checks & Clinic information" | Donation to cover postage |
| "Paediatric and Adult Health Checklist for The Management of Turner Syndrome" by Ipsen | Donation to cover postage |
| "Massage techniques [For Lymphoedema]/Skin Care Advice" | Donation to cover postage |
| Information for in-utero diagnosis – produced by Guy's & St Thomas' Hospital | Donation to cover postage |
| "Every Picture Tells a Story" A children's book about GH treatment. Supported by Pfizer | Donation to cover postage |

Some of the publications listed above are available for you to download for free from our website www.tsss.org.uk

Please copy and keep for your information (July 2011)

Turner Syndrome Support Society [TSSS] [Reg Charity No. 1080507/SCO37932]

13 Simpson Court, 11 South Ave, Clydebank Business Park, Clydebank G81 2NR. Website www.tsss.org.uk

E-mail Turner.syndrome@tsss.org.uk Tel +44 [0]141-952-8006 Fax +44 [0]141-952-8025 Helpline 0300-111-7520

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Tel: 0141 952 8006 Fax: 0141 952 8025 Helpline: 0300 111 7520

Email: Turner.Syndrome@tsss.org.uk Website: www.tsss.org.uk

TSSS Charity Registration Number 1080507

Scottish Charity Number SCO 37932

The Turner Syndrome Support Society offers support and information to girls and women who have Turner Syndrome (TS), their families and friends.

Members of the Society receive regular newsletters and a range of TSSS information leaflets are available. Members can attend any of the Open Days and the Annual Conference (a charge will apply). Membership also offers access to a membership network for social contact with others who share the same interests and concerns. Friendship groups operate in several areas of the UK.

The Society enjoys a good relationship with relevant specialists to promote a good basis for education and understanding of the management of Turner Syndrome. The Society encourages research into all aspects of TS including medical, psychological and educational. Communication between other support groups, both national and international, offers the opportunity for an exchange of ideas to help develop awareness and greater understanding of TS both in the UK and elsewhere.

Health, Educational and Social Services professionals may also obtain information about TS from the Society and become members in order to keep up with research and treatment of TS.

Annual Membership Fee: UK: £30 by standing order, £35 by cheque or PO. OVERSEAS: GBP35 (membership is deemed to include the person with TS & her immediate family)

Membership Form

If you wish to become a member of the TSSS please complete the form below in BLOCK CAPITALS, remembering to sign and date it, and return to the TSSS.

It would be helpful if you could return the completed questionnaire with your membership form.

Name: _____

Address: _____

Postcode: _____ **Telephone:** _____ **Day:** _____ **Mobile:** _____

Email: _____

Parent of daughter with TS I have TS Other, please state: _____

Area of Work: _____ Ethnic Origin: _____

I enclose a cheque for £35 or postal orders to the value of £35
 (made payable to the Turner Syndrome Support Society)

I have completed the standing order mandate and sent it to my bank

£30 per year on the 1st June or £2.50 per month or amount of my choice

Overseas members please send a Sterling cheque for £35

I am also enclosing a donation to the value of £_____

I confirm I am a taxpayer and wish the TSSS to claim Gift Aid

I am already a member of the TSSS

Have you ever attended any of our Conferences or Open Days? Yes No

Signature: _____ Date: _____/_____/_____

All information is kept in the strictest confidence and in accordance with the Data Protection Act for your protection.

Questionnaire

You are under no obligation to complete this questionnaire but your answers will help the TSSS to compile a comprehensive database of information. This [in the future] may benefit others with TS with regard to treatment, education and attitudes towards those with TS. All information is kept in the strictest confidence and in accordance with the Data Protection Act for your protection.

Name of person with TS: _____ **Age/DOB:** _____

Name of person completing questionnaire on behalf of child under 16: _____

Relationship to child: _____

Participation (please delete as applicable)

I would like contact with other TSSS members YES/NO Other participation: _____
My child would like a penfriend YES/NO _____
I am willing to help with fundraising YES/NO _____
I would like to help in other areas YES/NO _____
I am willing to help with research YES/NO _____
I would like details on helping with the TS register YES/NO _____
I would like to be part of a web message board YES/NO _____
I am willing to be contacted by the media YES/NO _____

Education: does your child have issues with (please delete as applicable)

| | | | | | |
|------------------|--------|---------|--------|---------|--------|
| Learning support | YES/NO | Maths | YES/NO | Reading | YES/NO |
| Statemented | YES/NO | Writing | YES/NO | P.E | YES/NO |

Medical Issues (please delete as applicable)

Year of diagnosis: _____ Age: _____ Your Karyotype: _____

Name of Hospital(s): _____

Name of Specialist(s): _____

(please continue on a separate sheet of paper if required.)

| | | | | | | | |
|-------------|--------|---------------------------|--------|-----------|--------|---------------|--------|
| Eyes | YES/NO | Heart | YES/NO | Feeding | YES/NO | Weight | YES/NO |
| Dental | YES/NO | Behaviour | YES/NO | Speech | YES/NO | Psychological | YES/NO |
| Psychiatric | YES/NO | Urinary | YES/NO | Obs/Gynae | YES/NO | Feet Hands | YES/NO |
| Orthopaedic | YES/NO | Other, please state _____ | | | | | |

Treatments (please circle the appropriate treatments)

HRT THYROXINE INSULIN GROWTH HORMONE STEROIDS GROMMETS

Other, please state _____

To comply with the Data Protection Act the TSSS must inform you that this information will be stored on the TSSS Database. Please sign and date your agreement.

Signature: _____ Date: _____/_____/_____

The TSSS welcomes your involvement as a member. Please write any comments or suggestions below.

Gift Aid Declaration

Turner Syndrome Support Society Charity Registration No: 1080507

Scottish Charity No: SCO 37932

If you wish the TSSS to claim Gift Aid please complete the form below and return to the TSSS.

Title: _____ **Forename(s):** _____ **Surname:** _____

Address: _____

I want the charity to treat the statement below as Gift Aid:

The enclosed donation of £ _____, plus all donations I have made since 6th April 2000, and all donations I make from the date of this declaration, until I notify you otherwise, as gift aid donations.

Signature: _____ Date: _____/_____/_____

1. You must pay an amount of income tax and/or capital gains tax at least equal to the tax that the Charity reclaims on your donations in the tax year (currently 28p for each £1 you give).
2. You can cancel this declaration at any time by notifying the charity.
3. If in the future your circumstances change and you no longer pay tax on your income and capital gains equal to the tax the charity reclaims, you can cancel your declaration in writing. (see note 1)
4. If you pay tax at a higher rate you can claim further tax relief in your self-assessment tax return.
5. If you are unsure whether your donations qualify for Gift Aid relief, ask the Charity. Or ask your local tax office for leaflet IR65.

6. Please notify the Charity if you change your name and/or address.

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Membership Standing Order Instruction

You can pay monthly or annually, and may include your donation payment with your membership payment, thank you.

To the Manager of _____ (Branch title only)

Sort-code: Account Number:

Account Name: _____

Date: _____/_____/_____ Contact Telephone Number: _____

Standing Order Instruction:

Beneficiary Reference: TSSS MEMBERSHIP

Beneficiary Sort-Code: 40-47-07

Beneficiary Bank Address: HSBC BANK PLC, 24 MARKET SQUARE WITNEY OXFORDSHIRE OX7BG

Beneficiary Account Number: 71369458

Amount £ _____ per month/year Date of First Payment _____/_____/_____

Amount of subsequent payments £ _____

Date of Final Payment _____/_____/_____ or until further notice (UFN)

Signature: _____ Date: _____/_____/_____

PLEASE HAND THIS INTO YOUR BANK