How are funds given to the Turner Syndrome Support Society (TSSS) spent?

TSSS is a UK based organisation dedicated to supporting those who have Turner Syndrome (TS) their family and friends. We aim to offer accurate and up to date information on all aspects of living with TS to make a difference each and every day.

TURNER SYNDROME
TSSS
SUPPORT SOCIETY [UK]

Thank you so much for taking the time to read this leaflet and learn a little more about our work and how you can help us make a real difference.

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. However, few people have heard of TS. There are a number of physical features and characteristics associated with TS.

Short stature and infertility are nearly always present. Heart and Kidney require careful monitoring as does Hearing, Thyroid, and Blood Pressure. Providing a diagnosis is made early enough, there is the possibility of growth hormone treatment for short stature, appropriate heart, kidney scans or surgery.

In vitro fertilisation (IVF) treatment is also a possibility for infertility. Intelligence spans the normal range, although there may be some problems with spatial awareness, poor concentration and short-term memory.

We would like to share with you how your efforts make a difference and enrich the lives of girls and women with TS and how your money helps to support our families and raise awareness and diagnosis of TS.

Emotional and informational advice & support

The period following diagnosis is a time when parents need the greatest support as they often feel isolated and are frightened of what the future looks like for their daughter. Many will never have heard of TS before. Mums may particularly struggle to come to terms with the fertility aspect of TS. The support received from the Society is invaluable, with parents talking through their fears and actively seeking reassurance. This may be in the form of one call or several calls over a period of weeks or months. Listening and offering information is the key service the Society provides and why funding is so important to be able to maintain it.

Spreading the word

In addition to supporting girls, women and their families, a vital area for the society is working with the wider influencing circle including medical professionals, teachers, and employers.

Leaflets and Publications

Our leaflets and publications are second to none and in demand from all over the world. We work closely with experts to ensure the information contained remains accurate and up to date.

Exhibitions & Conferences

Attendance as an exhibitor at key professional conferences has great value to us not only to educate, but to raise awareness, improve diagnosis, build relationships and the profile of the Society. We work hard to seek sponsorship to pay for the stands, which can cost up to £2,000. We continually evaluate the return on the investment, and only attend those where the value is great.

Making a difference – some examples of how your money is spent

- **TSSS Newsletter** – This contains updates on items such as medical research, information, success stories, motivational articles, reports on local friendship group meet ups. These help to reduce feelings of isolation. Each newsletter costs in excess of £3,000 and is circulated quarterly when funds allow.
- **Support and Information Helpline** and contact via e-mail, social media, friendship groups.
- **Open Days** – We hold up to two each year at various locations across the UK. These are smaller meetings often used as a 1st step before a family with a new diagnosis attends our annual conference. They help to reduce the feelings of isolation felt by many members. The cost of these varies however they can cost up to £500 each.
- **Seminar Days** – These are one day conferences with a number of medical specialists sharing their knowledge with our members.
- **Publications** – These are very highly regarded and are in demand from all over the world, not only by our members. Where possible we source grants and sponsorship to cover the production costs of leaflets and publications. Some are funded through direct fundraising efforts e.g. Our Cardiac Alert Cards.
- **Annual Conference** – Although the conference is largely self funding with attendees paying to attend, we aim to keep the costs of conference at an affordable level with the additional costs borne by the Society. It is a large event and needs a team to run successfully.
- **Core costs** of the office such as phones, postage, stationery, salary, rent, heating, lighting, etc.
- **Education support**, e.g. expenses incurred when a face to face meeting is required at a school.
- **Employment support**, e.g. expenses incurred when a face to face meeting is required at a workplace.
- **Research** – Where possible we help and support small research projects that will have a direct benefit for those with TS.
- The majority of our work is undertaken by a **wonderful team of volunteers**. We only have a very small paid staff. Together we work to improve the quality of life for those affected by TS. We support over 800 members.
- **TSSS stands at medical and educational conferences.** We work hard to get these at a reduced rate; however we attend key conferences to enable us to raise awareness and improve diagnosis. These are expensive but we continually assess the impact to ensure we get a good return on our investment.

Thank you so much for your kind generosity and for supporting us through fundraising. This allows us to continue providing support to girls, women and their families now and in the future. Each and every penny is spent to help and support our members and raise awareness and understanding of TS as widely as possible.

For further information please contact Arlene Smyth – Executive Officer at the TSSS.

The TSSS website has a wealth of information available www.tss.org.uk

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