

TSSS Conferences through the years



Contents

Legal and Administrative Information	3
Trustees' Report	4
Annual Report	5
Trustees' Responsibilities	9
Treasurers' Report	10
Balance Sheet	11
Independent Examiners' Report	12



Legal and Administrative Information

For the year ended 31st March 2021

Trustees:

Mrs S Wall (Co-Chair)
Mr S Wall (Co-Chair)
Mr S Holden (Vice Chair)
Mrs J O'Keeffe (Treasurer)
Mrs S. Cubitt (Secretary)
Ms K Bruerton

Sub Committee Chairs:

Mrs R J Raper
Miss M Cubitt
Miss E Phillips
Mrs A Smyth
Mr P Hatcher

Staff Members:

Arlene Smyth (Executive Officer)
Carlene Connor (Admin Assistant)

TSSS Office:

12 Simpson Court
11 South Bank
Clydebank Business Park
Clydebank G81 2NR

Registered Office:

4 Overbury
Carterton
Oxon OX18 1HQ

Independent Examiners:

Nicola Jane Cadwallader FCCA
David Cadwallader & Co Limited
Suite 3 Bignell Park Barns
Chesterton
Bicester OX26 1TD

Bankers:

HSBC
24 Market Sq.
Witney
Oxon OX28 6BG

Registered Charity (England & Wales):
Registered Charity (Scotland):

1080507
SC037932

Report of the Trustees

For the year ended 31st March 2021

The Trustees present their report along with the financial statements of the charity for the period ended 30th March 2021. The accounts for the period 1st April 2020 to 30th March 2021 and have been prepared in accordance with the revised Statement of Recommended Practice issued in 2005 (SORP 2005) and comply with the charity's governing document.

STRUCTURE, GOVERNANCE AND MANAGEMENT

The Charity's governing document is its constitution which was adopted on 19 October 1999 and subsequently revised on 25 March 2000. The Charity was registered as a charity in England and Wales (registered number 1080507) on 2 May 2000 and registered as a charity in Scotland (registered number SC037932) on 9 March 2007.

New Trustees are proposed for election by existing Trustees, checked in accordance with Charity Commission's guidelines, and appointed by Deed. New Trustees are appointed either to fill a casual vacancy or by way of addition to the Board. Emphasis is placed upon the appointment of Trustees with knowledge and experience relevant to the charity's activities. When new Trustees are appointed, they are introduced to the work of the charity and provided with the information they need to fulfil their roles, which includes information about the role of the Trustees and their responsibilities under the Charities Act.

Day-to-day administration of the Society is delegated to an administrator under the supervision of the Trustees. Decision-making powers are retained by the Trustees and exercised at regular Trustees' meetings. The Trustees meet at least four times a year. The Trustees do not receive remuneration except reasonable expenses.

The Trustees have identified the major risks which may affect the charity and have taken reasonable steps to mitigate those risks.

The trustees set out below held office during the whole of the year except where otherwise stated.

Mrs S Wall (*Co-Chair*)

Mr S Wall (*Co-Chair*)

Mr S Holden (*Vice-Chair*)

Mrs J O'Keeffe (*Treasurer*)

Mrs. S. Cubitt (*Secretary*)

Ms K Bruerton

The Trustees would also like to express their thanks to all those who supported the charity during this exceptional year, whether financially, by volunteering their time or in other ways.

The Trustees have identified and considered the major risks to which the charity is

exposed and have established systems and procedures to manage those risks. The principal risk associated with the charity's operation remains the availability of operational grants.

OBJECTIVES AND ACTIVITIES

The objects of the charity are to care for the needs of those with Turner Syndrome throughout the United Kingdom and to provide information, advice and assistance on all matters relating to caring for those with Turner Syndrome. The Society offers support and information for girls and women with Turner syndrome, as well as to their family and friends. The Society enjoys an excellent relationship with relevant specialists to promote a good basis for the education and management of Turner syndrome.

The Trustees have had regard to the requirement to demonstrate Public Benefit. They are satisfied that the charity's activities are demonstrably for the benefit of those members of the public who seek to avail themselves of its services.

TSSS Fundraising

Like many other charities we have concerns about our future income in this fragile economic and unprecedented circumstance. Our members continue to help us by raising as much funds as they can. We would like to thank each one of them very much. From the children who have given up their pocket money to the incredible challenges that many members have taken part in. Every penny is making a real difference to those who have TS and the TSSS. Without the fundraising of the members, we would not be here.

Covid 19 Pandemic & Implications

As a society one of our strengths is the support we give one another. Whilst some of this is virtually, a significant part of it was in person, whether Local Group meet ups, Open Days, Conferences etc. Due to the nature of this pandemic, it meant that as a society we had to change rapidly on how we did things. Everything had to go online, whether a committee meeting, meet ups or even an International Conference meet up. It wasn't without its challenges and the same as the rest of the world we learnt as we went, but as always we adapted and overcame the challenges whatever they were.

Strategic Development

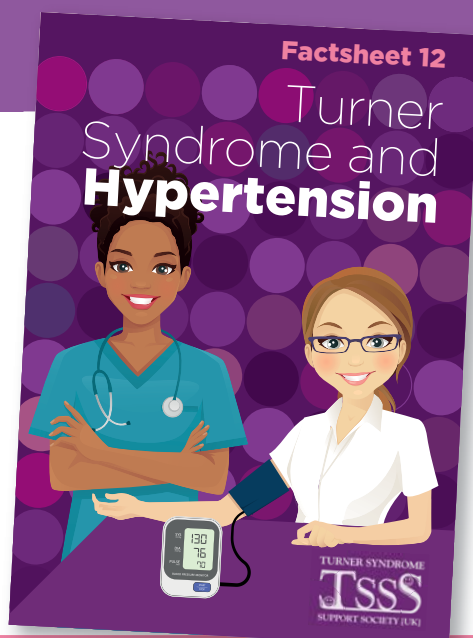
We are proud that the Society continues to expand and develop. The team of dedicated Trustees and Committee members meet formally at least 3 times each year to plan and allocate tasks, to meet its aims and objectives. Due to the pandemic this changed from face to face to conference calls like the rest of the world. We aim to fully utilise volunteer's skills without overwhelming the individuals allowing the Society to be effective with the limited resources at our disposal.

Information

The Society's list of information is extensive and we are proud of the accuracy and relevance of the literature that we produce and promote. There are requests for information from all over the world. The information that the Society has continues to be added to and reviewed.

Publications & Literature

There were several new publications and literature launched in this period including the Blood Pressure Factsheet and the Heart in TS. Both especially important aspects of managing health based on accurate information.



Virtual Events

Once face to face meetings were not viable we looked at options to continue to support our members using social media or through virtual events. With this in mind, we applied for a grant from Pfizer of £6000 which has helped us prove these sessions, so our thanks to them.

This grant enabled us to host multiple virtual events. These events covered a wide range which were of help and support to our members. Some were medical orientated events such as "Blood Pressure and Heart in TS" which helped launch our new factsheets. There were also online Christmas and Easter parties, which were free to our members and which included craft packs being posted out. There are ongoing, regular sessions which are targeted at the Teens to help them through this time in a way that sessions at the annual conferences did. Additionally utilising some of the money from the grant, we have booked several sessions with Moya Fletcher, who was a major attraction at our conference for mindfulness sessions. These have been oversubscribed and have proved to be extremely successful.

Open Days

As with all other face to face meetings, Open days in their normal format for this period had to be cancelled. When things initially started to open up in the summer of 2020 and as a number of our members were in the vulnerable group, we decided that we could not take the risk of any organised meetups until we knew the risks were minimal.

TSSS Awareness Week

The Annual Awareness Week is used to try and extend a greater awareness of Turner syndrome and related issues. The annual awareness week, based around the 21st of June, is when we try to raise awareness through co-ordinated events, where members and friends of the Society take part in events in their local areas. As with everything else during this period it moved totally online and thank you to all who helped make this a success. A "I love TSSS because" poster was made available for posting online along with getting **#proudtohaveTS #ThisismewithTS #mydaughterhasTS #mysisterhasTS #myfriendhasTS** trending.

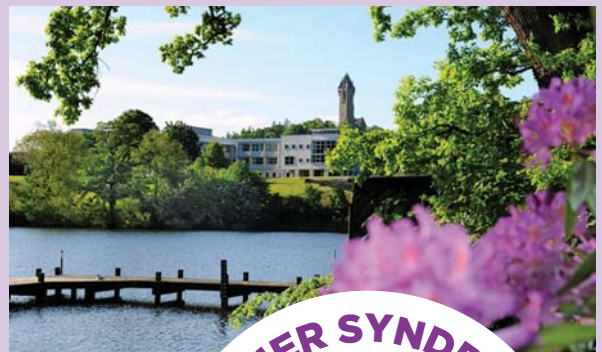
International Conference

Planning for the International conference had been ongoing even as the pandemic and its potential implications, along with the first UK lock down happened. Whilst we were getting numerous calls about cancelling, the financial implications for the individuals as well as the society were significant if we cancelled. Individuals would have likely lost any payments made to the University, as well as potentially a significant penalty payment being held against the society.

Whilst hoping with our heart rather than our head on the possibility of the conference happening, once it became totally unrealistic for the event to happen, the fact that the University cancelled the booking meant that all monies were repaid to the individuals and the society was not responsible for any penalty payments. We thank everyone for their patience at that time, as we were just as nervous as everyone else about the potential loss of money.

Years of hard work had been put into making the conference viable and to have it snatched away at the 11th hour caused a lot of heartache and many tears. As Carlene had been put on furlough, a lot of the stress and admin of sorting out the cancellation fell on Arlene's shoulders who was then working at home.

As we were unable to meet face to face, a virtual International Celebration happened on the night we should have been having the Gala dinner. It was attended by people from across the globe, in their PJs from Australia/New Zealand, to drinking in the afternoon in the US and multiple countries in between. Nearly 200 people logged in and although manic at times with everyone still learning how to interact in these meeting, it showed that even a pandemic will not be stopping us getting together to enjoy ourselves.



Annual Conference

As the International Conference had been planned for the July there wasn't a plan for a national conference in October as normal, although a 21st birthday party for the society was being planned. Along with all other face to face events this was curtailed by the pandemic.

As we were unable to have our 21st celebration face to face we held an online virtual 21st birthday on 10th Oct 2020 with music and enjoyment, without the usual need to get up early the following morning after only a few hours' sleep.

2.6 Challenge

When it became obvious that fundraising was going to be severely curtailed the TSSS family stepped up to the 2.6 Challenge. Whether 26 high kicks, 26 sit-ups, running 2.6KM or 2.6 miles, even rowing 26 minutes a day for 26 days across the land people fundraised. In all over £4000 was raised by this challenge, so a very big thank you to all for making this so successful.

International Turner Syndrome Committee

When it became obvious that fundraising was going to be severely curtailed the TSSS family stepped up to the 2.6 Challenge.

Whether 26 high kicks, 26 sit-ups, running 2.6KM or 2.6 miles, even rowing 26 minutes a day for 26 days across the land people fundraised. In all over £4000 was raised by this challenge, so a very big thank you to all for making this so successful.



Online Media

Online media is very often the first port of call for individuals wishing to learn more about TS and related issues. It is therefore of paramount importance that the information that appears on the Society's website is clear, impartial, and unbiased. The website also provides a valuable means of spreading the word that there is a support organisation in the UK for those with TS. Many families and individuals have joined the Society as a direct result of visiting the website. The website is continually updated on an on-going basis so that all information is current and up to date.

As a society we are active in numerous online media sites, Facebook, Instagram etc. They are utilised to help raise the profile of the Society as well as trying to help individuals when able including sign posting to reliable information.

Due to the nature of this past year, online media has become even more critical in communications and are very aware of our duty to ensure factually correct information is available in the relevant spaces.

AspectS

This is still one of the most important communication sources that the Society has and we are justifiably immensely proud of this newsletter. Under the guidance and leadership of the Society's editor it continues to develop, and our editor Phil Hatcher has continued to produce to a high standard and will develop the newsletter as the Society continues to grow.



Friendship Groups

It is important that area-based groups continue to thrive as they play an important part supporting girls and women with TS and their families within different regions. The Society's role is to encourage and facilitate additional groups once an interest in setting one up has been expressed. We currently have Friendship groups in Scotland, Central England, Wales, Northern Ireland, Northeast England, London, Southwest England, and they continue to go from strength to strength. Ex Chair Hayley Cleaver has taken over the co-ordination of these groups and they have made great advances under her guidance. It is hoped that more and more friendship groups will start in all regions of the country. Friendship packs have been created to assist in the setting up and running of Friendship groups.

Medical Conferences

The Society continues to develop and foster relations within the medical profession by attending conferences but during this period they all moved online which came with positive, reduction in travel for Arlene but also significant challenges, lack of face to face networking and significant learning curve for Arlene trying to create virtual stands for the conferences.

Several planned conferences were cancelled/postponed due to the ongoing pandemic but some continued online. The British Endocrine Society Conference (BES), the British Society for Paediatrics, Endocrinologist and Diabetics Conference (BSPED), Clinical Updates.

Having a presence at these conferences and meetings whether in person or virtual enables the Society to raise awareness and help educate those within the medical profession. It also enables us to gain valuable help and support in ensuring that all girls and women with TS are correctly looked after.

Arlene also represents the TSSS by being on the board of the Office for Rare Conditions in Glasgow and The Scottish Paediatric Endocrine Group (SPEG). European Registries for Rare Endocrine Conditions (EuRECa) and Endocrine European Reference Network (ERN). All these projects bring together expertise to improve treatment and build rare condition registries.

All the above allows the society to work collaboratively to improve awareness, diagnosis, treatment, and overall care of those who have TS. We are proud to play our part in the worldwide TS community.



Conclusion

The Society continues to grow and develop, and its positive approach is fuelled by the wonderful girls and women with TS that we strive to serve. In what was a challenging year for all, we adjusted to a new normal where we weren't allowed to hug, but could still be there for each other, in the good and the not so good times.

Special thanks are extended firstly to all our members as without whose support we would be unable to continue and to the Trustees, Committee Members, Executive Officer, Admin Assistant and all the volunteers for their support, loyalty and sheer hard work in shaping the future of the Society.

By order of the Trustees

Mrs S Wall & Mr S Wall • Co-Chairs
10th November 2021

Trustees' Responsibilities

*For the year ended
31st March 2021*

Charity law requires the Trustees to prepare accounts for each financial year which give a true and fair view of the situation of the Trust and of the surplus or deficit of the Trust for that period. In preparing those accounts, the Trustees are required to:

- select suitable accounting policies and apply them consistently.
- make judgements and estimates that are reasonable and prudent.
- state whether applicable accounting standards and statements of recommended practice have been followed, subject to any departures disclosed and explained in the financial statements; and
- prepare the accounts on the going-concern basis unless it is inappropriate to presume that the Trust will continue in operational existence.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the Trust and to enable them to ensure that the Accounts comply with the Charities Act 2006. They are also responsible for safeguarding the assets of the Trust and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the Trustees on 10th November 2021 and signed on their behalf by:

Susan Wall • Co-Chair

Susan Wall.

Trustee



Treasurer's Report

For the year ended 31st March 2021

The Charity Commission requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the situation of the Turner Syndrome Support Society for that period. In preparing those financial statements, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently.
- Make judgements and estimates that are reasonable and prudent.
- Prepare the financial statements on the going concern basis.

To simplify membership administration there is a single joining date of the 1st June used every year. Overall, the Treasurer and Trustees realise that there is no guarantee of future income and therefore need to be mindful of this when planning for the future. Additionally, whilst grants have never been a significant income stream for the society, due to the heavy administrative burden in producing them, we realise that this is an income stream that we cannot ignore and will therefore put more emphasis on in the future. The on-going aim is to continue to ensure that value for money is achieved within all areas of expenditure and that the Society continues to seek to attract additional corporate benefactors, as well as increased membership and fundraising income.

Mrs J O'Keeffe



Treasurer • 10th Oct 2020



Turner Syndrome Support Society (UK)

Receipts and Payments Accounts • 1st April 2020 - 31st March 2021

Receipts	2020/2021 01/04/20-31/03/21	2019/2020 01/04/19-31/03/20
Memberships	£14,318.55	£14,435.00
Donations & Fundraising	£63,548.68	£78,602.17 (J Donaldson £10,000)
Conference & Open Days	£0.00	£29,201.65
Benefactors/Restricted Funds	£16,500.00	£17,744.00
TS International Conference	£1,205.68	£31,680.68 (Novo £10,000)
Shop	£1,316.20	£2,405.79
Consult Fee/Expenses Received	£0.00	£628.22
Miscellaneous	£8,519.45 JRS	£1,500.00
Bank Interest Received	£43.55	£188.55
Sub Total	£105,452.11	£176,386.06

Opening Bank Balance	At 1st April 2020	£159,038.35	At 1st April 2019	£108,257.89
Total		£264,490.46		£284,643.95

Payments	2020/2021 01/04/20-31/03/21	2019/2020 01/04/19-31/03/20
Rent & Rates	£13,849.13	£13,873.96
Heat, Light, Insurance	£3,980.16	£3,934.94
Printing, Stationery, Postage	£8,079.09	£13,834.05
Conference & Open Days	£21,920.36	£29,482.48
Wages, Salaries & Employers NIC	£42,227.68	£41,424.06
Telephone	£1,576.33	£1,405.38
Computer	£743.00	£4,298.46
Professional Fees	£1,798.28	£1,170.00
Processing Credit Fees	£772.10	£3,346.00
Bank Charges	£648.28	£323.89
Equipment Hire & Maintenance	£75.00	£2,479.71
Literature & Brochures	£0.00	£324.00
TSSS Merchandise	£1,929.59	£2,299.61
General Expenses	£3,055.43	£1,542.49
Travel & Governance Expenses	£27.60	£4,166.57
Training Courses	£202.08	£0.00
Projects	£435.00	£1,700.00
Bad Debts	£0.00	£0.00
Sub Total	£101,319.11	£125,605.60

Closing Bank Balance	At 31st March 2021	£163,171.35	At 31st March 2020	£159,038.35
Total		£264,490.46		£284,643.95

Surplus/Deficit for the year	£4,133.00	£50,780.46
NOTES: Eventbrite refunded May 2020 Adler invoice for pens in May		£21,680.68 £1,929.59

TURNER SYNDROME SUPPORT SOCIETY

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF TURNER SYNDROME SUPPORT SOCIETY

PERIOD FROM 1 APRIL 2020 TO 31 MARCH 2021

I report on the accounts of the charity for the period from 1 April 2020 to 31 March 2021 which is set out on the accompanying pages.

RESPECTIVE RESPONSIBILITIES OF TRUSTEES AND EXAMINER

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this period under section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10(1)(a) to (c) of the Charities Accounts (Scotland) Regulations 2006 (the 2006 Regulations) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act 2011 and under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act);
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

BASIS OF INDEPENDENT EXAMINER'S REPORT

My examination was carried out in accordance with the general Directions given by the Charity Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

INDEPENDENT EXAMINER'S STATEMENT

In the course of my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 130 of the 2011 Act and section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act and section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations.

have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Nicola Jane Cadwallader FCCA



For and on Behalf of

David Cadwallader & Co Limited • Independent Examiner • Chartered Certified Accountants
Suite 3 Bignell Park Barns • Chesterton • Bicester • Oxon OX26 1TD

27 September 2021

TSSS Conferences through the years



TSSS Conferences through the years



TSSS Conferences through the years





Registered Office:

4 Overbury • Carterton • Oxon OX18 1HQ

TSSS Office:

12 Simpson Court • 11 South Avenue
Clydebank Business Park • Clydebank G81 2NR

Registered Charity (*England & Wales*): 1080507

Registered Charity (*Scotland*): SC037932