

IF YOU DON'T  
BELIEVE IN  
MIRACLES  
PERHAPS YOU'VE  
FORGOTTEN  
YOU ARE  
ONE.

TURNER SYNDROME



SUPPORT SOCIETY [UK]

# **Annual Report & Financial Statement**

## 2022 - 2023



# TSSS Conferences through the years



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# Legal and Administrative Information

*For the year ended 31st March 2023*

## 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 Avenue  
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 2023*

The Trustees present their report along with the financial statements of the charity for the period ended 31st March 2023. The accounts for the period 1st April 2022 to 31st March 2023 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 economic outlook and availability of operational grants.

## OBJECTIVES AND ACTIVITIES

The objectives 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.



# Some previous TSSS award winners



## TSSS Fundraising

Like many other charities we have concerns about our future income in this fragile economic climate where plans constantly change. 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.

## Health & Economic Considerations

As a society one of our strengths is the support we give one another. Whilst some of this was virtually during the pandemic and some still is, a significant part is now in person, whether Local Group meet ups, Open Days, Conferences etc. It is not without its challenges, now economic as well as health and the same as the rest of the world we learn as we go, but as always, we continually adapt and aim to overcome the challenges for the benefit of our members, whatever they are.

## Strategic Development

We are proud that the Society continues to expand and develop. The team of dedicated Trustees and Committee members meet formally (in person or virtual) at least 3 times each year to plan and allocate tasks, to meet its aims and objectives. 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

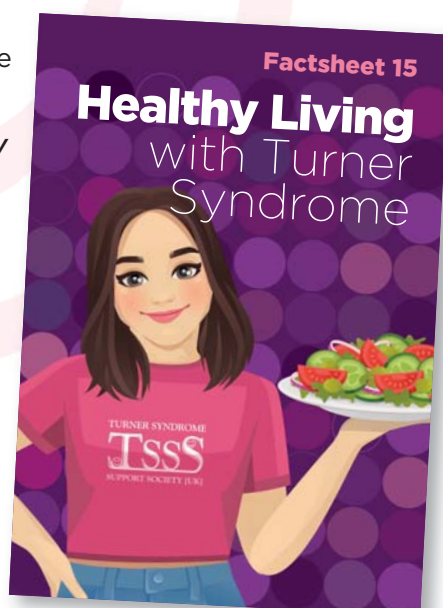
The Society's list of information is extensive and we are proud of the accuracy and relevance of the literature that we produce and promote. There are requests for information from all over the world. The information that the Society has continues to be added to and reviewed.

## Publications & Literature

There were new publications and literature launched in this period.

We launched the *"Healthy Living with Turner Syndrome Factsheet 15"*.

We also have a new updated version of *"Health tips for the over 40's and beyond"*. With all the other factsheets, they are available to download direct from our website or a request can be made to the office (with a donation to cover P&P) for a hard copy.



We are very proud of all our literature, especially the important aspects of managing health based on accurate information. As a testament to this we frequently receive requests from other TS societies around the world for permission to translate our literature.

A Turner Syndrome Covid-19 Survey was also launched that will help us understand the impact that this had.



## Annual Conference

Planning for the annual conference takes over a year and was a major discussion at our January committee meeting in 2022. We were excited to be planning and looking forward to welcoming everyone back to an annual conference once again. Frustratingly other circumstances, Park Hall going into liquidation, threw a major spanner in the works. Our thanks go to all the staff there who had helped give us a very happy 10 years and we hope they have all managed to find new employment. Once we knew Park Hall was not a viable option, a major search began for other venues. The required criteria for a venue severely limited our options and crystallised that we are not a small conference anymore, with our requirement for a meeting room for 350+, multiple additional meeting rooms as well as onsite accommodation and dining facilities for all delegates.

Due to the timing, we knew we had only a small window to be able to find a new conference venue. Whilst the whole committee looked for

venues, most of the work fell on Arlene and Carlene's shoulders in the office. From these a potential shortlist was created, with in-person visits carried out by Arlene and Carlene. Due to the pandemic, many events whether conferences or weddings etc. at venues of the capacity we required had been postponed, so everywhere had been rebooked for 2022. Whilst there were some options, we felt that with the significant compromises required, location, accommodation, short notice or a vastly increased cost meant that we had to make the very difficult decision not to hold a conference in 2022.

What this did do was allow us time to make sure that any new venue had the facilities and capacity that we require going forward. Whilst you never know until actually having an event, our new venue, Yarnfield Conference Centre has the facilities and capacity to look after us for a number of years. The proof will be in the pudding, as they say, and we await feedback from the members attending the 2023 Conference to see whether we have found our long-term conference home.

## 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 these past years, online media has become even more critical in communications and we are very aware of our duty to ensure factually correct information is available in the relevant spaces.

One of our members and now committee member, Emily Seymour launched her own podcast, *"Turner Syndrome, Talk and Tea"*. On the podcast Emily has guests talking about their experience of Turner Syndrome. It is not just for girls with Turners, it is also from the sibling perspective and parents perceptive, as well as the ladies and girls with Turners. The society is so proud of Emily, and we were so impressed with all her hard work and professionalism.



## International Turner Syndrome Committee

Arlene, as Chair of the committee, has worked tirelessly to ensure that this moves forward. This is updated on a continual basis and Societies around the world are being added on an on-going basis and now has 23 countries connected.



## 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 continue to 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, Northwest 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 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. Whilst unable to do face to face meets during the pandemic, several groups had virtual meet ups.



## Medical Conferences

The Society continues to develop and foster relations within the medical profession by attending conferences but this was a period of transition and change. Whilst the online conferences came with positives, such as a reduction in travel for Arlene there were also significant challenges, lack of face-to-face networking and a significant learning curve for Arlene trying to create virtual stands for the conferences. With the return of face-to-face meetings, this meant that there was significant time back on the road for Arlene as shown by the main conferences attended in person below.

**European Society Endocrinology (ESE) Conference** in Milan  
21st-24th May 2022

**European Paediatric Society Endocrinology (ESPE) Conference**  
in Rome 15th-17th September 2022

**British Society Paediatric Endocrinology Diabetes (BSPED) Conference** in Belfast  
2nd-4th November 2022

**British Society Endocrinology (BES) Conference** in Harrogate  
14th-16th November 2022

**Scottish Paediatric Endocrine Group (SPEG) 26th-27th January 2023**

**ICOSEP meeting**  
24th-26th February 2023

**European project on registries (EuRRECa) 3rd & 4th April 2023**

**Endo ERN General Assembly 5th & 6th April 2023**

**Clinical Updates April 2023**

As can be seen, having a presence at these conferences and meetings 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 (EuRRECa) 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 another challenging year for all, we adjusted to the new normal and whilst there was still an issue with some face-to-face meetings, we 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 • 9th September 2023**



# *TSSS Conferences through the years*





# Trustees' Responsibilities

*For the year ended  
31st March 2023*

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 11th September 2023 and signed on their behalf by:

**Susan Wall • Co-Chair**

*Susan Wall.*

**Trustee**



# Treasurer's Report

*For the year ended 31st March 2023*

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.

Overall, the Treasurer and Trustees realise that there is no guarantee of future income and therefore need to be mindful of this when planning. 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 • 9th September 2023**





# Turner Syndrome Support Society (UK)

## Receipts and Payments Accounts • 1st April 2022 - 31st March 2023

Receipts	2022/2023 01/04/22-31/03/23	2021/2022 01/04/22-31/03/22
Memberships	£15,161.50	£13,828.50
Donations & Fundraising	£106,088.08	£77,427.04
Gift Aid	£5,072.92	£0.00
Conference & Open Days	£18,627.20	£0.00
Benefactors/Restricted Funds	£0.00	£229,800.00
TS International Conference	£0.00	£0.00
Shop	£1179.90	£856.45
Consult Fee/Expenses Received	£978.12	£500.00
Miscellaneous	£0.00	£3,691.09
Bank Interest Received	£1,726.42	£35.14
<b>Sub Total</b>	<b>£148,834.14</b>	<b>£326,138.22</b>

<b>Opening Bank Balance</b>	At 1st April 2022	<b>£382,671.54</b>	At 1st April 2021	<b>£163,171.35</b>
<b>Total</b>		<b>£531,505.68</b>		<b>£489,309.57</b>

Payments	2022/2023 01/04/22-31/03/23	2021/2022 01/04/22-31/03/22
Rent & Rates	£12,266.30	£13,290.30
Heat, Light, Insurance	£4,668.97	£3,529.20
Printing, Stationery, Postage	£9,947.72	£10,713.86
Conference & Open Days	£1,130.16	£125.00
Wages, Salaries & Employers NIC	£48,110.68	£43,643.68
Telephone	£908.50	£1,551.47
Computer	£10,366.34	£25,301.36
Professional Fees	£1,212.00	£1,194.00
Processing Credit Fees	£4,372.86	£754.80
Bank Charges	£849.49	£711.28
Equipment Hire & Maintenance	£1,136.24	£566.02
Literature & Brochures	£811.77	£0.00
TSSS Merchandise	£6,285.71	£851.86
General Expenses	£2,521.83	£1,774.79
Travel & Governance Expenses	£7,622.32	£1,350.41
Training Courses	£1,925.00	£0.00
Projects	£0.00	£1,280.00
Bad Debts	£0.00	£0.00
<b>Sub Total</b>	<b>£114,135.89</b>	<b>£106,638.03</b>

<b>Closing Bank Balance</b>	At 31st March 2023	<b>£417,369.79</b>	At 31st March 2022	<b>£382,671.54</b>
<b>Total</b>		<b>£531,505.68</b>		<b>£489,309.57</b>

<b>Surplus/Deficit for the year</b>	<b>£34,698.25</b>	<b>£219,500.19</b>
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### NOTES:

In 2021/22 there would have been a deficit of £5,499.81 without the donation of £225,000.00

# TURNER SYNDROME SUPPORT SOCIETY

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

### PERIOD FROM 1 APRIL 2022 TO 31 MARCH 2023

I report on the accounts of the charity for the period from 1 April 2022 to 31 March 2023 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

7th September 2023



# *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