

TURNER SYNDROME SUPPORT SOCIETY

England & Wales · Charity number 1080507

Details

Other names	TUNER SYNDROME SUPPORT SOCIETY, UK TURNER SYNDROME SOCIETY, TSSS, TURNER SYNDROME SUPPORT SOCIETY
Status	Registered
Legal form	Other
Registered	2000-05-02
Register	View on the Charity Commission register

Contact

Address	12 Simpson Court 11 South Avenue Clydebank Business Park Clydebank Dunbartonshire G81 2NR
Phone	01419528006
Email	turner.syndrome@tss.org.uk
Website	www.tss.org.uk

Activities

Objects: SUPPORT AND RELIEVE ALL PERSONS (EITHER CHILDREN OR ADULTS) AFFECTED BY TURNER SYNDROME AND THEIR FAMILIES IN ANY MANNER WHICH IS CHARITABLE IN ACCORDANCE WITH THE LAW OF THE UNITED KINGDOM; PROMOTE AND FUND RESEARCH INTO THE CAUSES OF TURNER SYNDROME AND TREATMENT OF ITS EFFECTS IN CHILDREN AND ADULTS WITHIN THE AREA OF BENEFIT AND TO PUBLISH THE RESULTS OF SUCH RESEARCH; EDUCATE THE PUBLIC IN GENERAL AND WORKERS IN THE MEDICAL PROFESSION IN PARTICULAR IN THE PROBLEMS AND DIFFICULTIES ENCOUNTERED BY THOSE WITH TURNER SYNDROME

Activities: The TSSS is a national charity caring for the needs of those with Turner Syndrome [TS] throughout the UK. The Society offers support, advice, and information to both girls and adult women with TS, their families, and friends. The Society enjoys a good relationship with relevant specialists to promote a good basis for education and understanding of the management of Turner Syndrome.

Classification

- **How:** Provides Human Resources, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Other Defined Groups

Geography

- Northern Ireland
- Scotland

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£219,939	£200,689	-	-
2024-03-31	£400,813	£182,010	-	-
2023-03-31	£148,834	£114,135	-	-
2022-03-31	£326,138	£106,638	-	-
2021-03-31	£105,452	£101,319	-	-

Trustees

Name	Role	Appointed
SUSAN WALL	Chair	
Ella May Phillips -Ansell MAAT		2026-02-07
KERRY BRUERTON		
SIMON HOLDEN		
STEPHEN WALL		
Samantha Jane Cubitt		2014-01-10

TURNER SYNDROME SUPPORT SOCIETY

England & Wales - Charity number 1080507

Accounts



Annual Report & Financial Statement 2025 - 2025

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Legal and Administrative Information

For the year ended 31st March 2025

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
Mr P Hatcher

Sub Committee Chairs:

Mrs R J Raper
Miss M Cubitt
Miss E Phillips
Mrs A Smyth

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 2025

The Trustees present their report along with the financial statements of the charity for the period ended 31st March 2025. The accounts for the period 1st April 2024 to 31st March 2025 have been prepared in accordance with the revised Statement of Recommended Practice issued in 2019 Charities SORP (FRS 102) 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

Mr P Hatcher

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.

Conference 2024



TSSS Fundraising - Thank You

In these uncertain times, like many charities, we're facing challenges around future funding. But thanks to the incredible generosity and spirit of our members, we continue to move forward with hope and determination.

We're truly grateful to everyone who has supported us - whether it's children kindly donating their pocket money, or members taking on amazing fundraising challenges. Every single contribution, big or small, helps us make a real difference in the lives of those affected by Turner Syndrome. Your support keeps the Turner Syndrome Support Society going strong. Quite simply, we wouldn't be here without you - and we can't thank you enough.

Health and Economic Considerations

One of the Society's greatest strengths lies in the support we provide to one another - whether through Local Group meetings, Open Days, Conferences, or other activities. While we continue to face challenges, both economic and health-related, we remain committed to learning and adapting, just as organisations worldwide must do. Throughout the year, we have continually evolved our approach to overcome obstacles, always with the best interests of our members at heart.

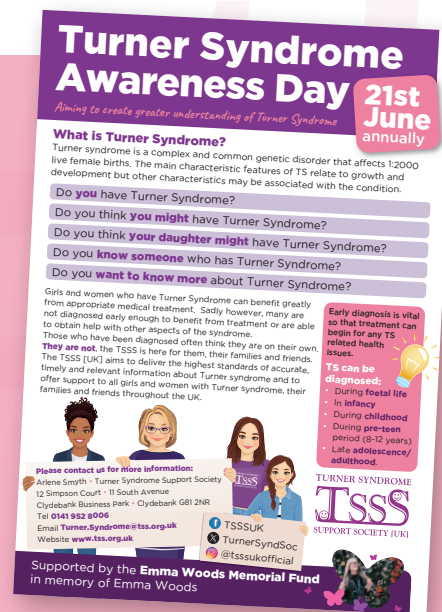
Strategic Development

We are proud to see the Society's ongoing growth and development. Our dedicated team of Trustees and Committee members convene formally - either in person or virtually - at least three times each year to plan, allocate responsibilities, and ensure we meet our aims and objectives. We strive to make the most of our volunteers' skills while being mindful not to overburden individuals, enabling the Society to operate effectively within the limits of our available resources.

Trusted Information, Shared Globally

We're really proud of the wide range of information the Society offers - and even prouder of how accurate, relevant, and helpful it continues to be. People from all over the world reach out to us for resources, and it's wonderful to know that what we share is making a difference far beyond the UK.

Our library of information is always growing. We regularly review and update everything to make sure it stays current and useful for anyone looking to learn more about Turner Syndrome.



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. Thank you to all who helped make this a success. An "I love TSSS because" poster was made available for posting online along with getting #proudtohaveTS #ThisismewithTS #mydaughterhasTS #mysisterhasTS #myfriendhasTS trending.

Patrons



Professor Melanie Davies is a consultant obstetrician and gynaecologist and accredited subspecialist in reproductive medicine, senior consultant at the Reproductive Medicine Unit, and chair of trustees of the EGA Hospital Charity.

Her special interests are in gynae endocrinology and fertility preservation. Specialities include, Reproductive endocrinology, Menopause and premature menopause (POI), Reproductive effects of cancer, Polycystic ovarian syndrome, Turner syndrome & Care of adolescents and young adults.

Melanie runs a large service for reproductive effects of cancer and chronic disease and leads dedicated clinics for women with premature ovarian insufficiency and adolescent care. She set up and leads an NHS

'emergency service' for women with a new cancer diagnosis to offer fertility preservation.

Melanie is the founding chair of Fertility Preservation UK and has been a member of the medical advisory committee of the British Menopause Society and the executive committee of the British Fertility Society. She was previously responsible for the HFEA-licensed fertility services provided at UCLH, a clinical advisor to the HFEA and a contributor to NICE guidance on fertility, menopause, endometriosis, and heavy menstrual bleeding.

NHS and Academic Posts - Consultant Obstetrician and Gynaecologist, University College London Hospitals. Professor of Reproductive Medicine, University College London.

Articles & Videos - Professor Davies is actively involved in research and training. She is the chief investigator for the POISE study, a multicentre NIHR-funded trial on treatment of premature menopause (POI), and the BLUSH study which looks at non-hormonal treatments for menopause symptoms. She lectures nationally and internationally and has publications in the New England Journal of Medicine, British Medical Journal, and Human Reproduction. She is an experienced RCOG training programme director for reproductive medicine and has chaired the national subspecialty training committee.



Professor Gerard Conway is a retired consultant endocrinologist at University College London Hospitals and Professor of Clinical Medicine in the Institute for Women's Health, University College London. His clinical practice covers general endocrinology including pituitary, adrenal, thyroid and reproductive endocrinology.

His clinical research interests are in the field of reproductive endocrinology particularly polycystic ovary syndrome, ovarian and testicular function, disorders of sexual development and Turner Syndrome. This research has formed the basis of over 160 academic publications. Professor Conway maintains a clinical research program with visiting international research fellows.

qualified from the Royal London Hospital in 1981 and trained in Diabetes, Endocrinology and General Medicine in several centres in central London. His research thesis was in the endocrinology of the polycystic ovary syndrome, and he then undertook as fellowship in genetic research in Prince Henry's Institute for Medical Research, Melbourne Australia. On return he became Senior Lecturer in Medicine at UCL in 1994 and subsequently Professor of Clinical Medicine in the Institute for Women's Health UCL in 2012.

With a major interest in teaching, Professor Conway lectures in Reproductive Endocrinology, for the Society for Endocrinology, the Royal College of Obstetricians and Gynaecologists and internationally with the endocrine societies in the USA, Sri Lanka, India, New Zealand, Australia, Japan and throughout Europe.

Patient care is at the heart of the clinical work of Professor Conway, and he works closely with many patient support groups.

Publications & Literature

All our factsheets 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 enormously 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.

Undiagnosed girls and women with TS

UK women and girls of all ages

UK Areas All ages	Female Population Census 2021	Estimated 1 in 2500 with Turner Syndrome (Live female births)	25% diagnosed estimated based on Data available	Estimated girls and women remaining undiagnosed
England	29,407,249	11,762	2,940	8,822
Wales	1,611,486	644	161	483
Scotland	2,821,149	1,128	282	846
Northern Ireland	974,897	389	97	292
Totals	34,814,781	13,923	3,480	10,443

Regions All ages	Female Population Census 2021	Estimated 1 in 2500 with Turner Syndrome (Live female births)	25% diagnosed estimated based on Data available	Estimated girls and women remaining undiagnosed
North East	1,368,350	547	137	411
North West	3,833,218	1,533	383	1,150
Yorkshire	2,826,043	1,130	282	847
East Midlands	2,516,819	1,007	252	755
West Midlands	3,071,043	1,228	307	921
East England	3,263,233	1,305	326	979
London	4,521,752	1,808	452	1,356
South East	4,783,715	1,913	478	1,435
South West	2,940,089	1,176	294	882

Please contact us for more information:
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 12 Simpson Court • 11 South Avenue
 Clydebank Business Park • Clydebank G81 2NR
 Tel **0141 952 8006**
 Email Turner.Syndrome@tss.org.uk
 Website www.tss.org.uk

TSSUK
 TurnerSyndSoc
 @tssukofficial

Our aim is to improve awareness, diagnosis and understanding of Turner Syndrome throughout the world. Below we have some interesting facts and figures showing how many girls and women remain undiagnosed and unable to access the best possible medical care. Please support us by talking about Turner Syndrome.



UK girls aged 0 to 14 years old

Aged 0 to 14 years Estimated Diagnosis rates	Female Population Census 2021	Estimated 1 in 2500 with Turner Syndrome (Live female births)	25% diagnosed estimated based on Data available	Estimated girls remaining undiagnosed
England				
0 to 4 years old	1,496,012	598	150	448
5 to 9 years old	1,635,842	645	163	491
10 to 14 years old	1,721,746	689	172	517
Total 0 to 14 years	4,853,600	1,941	485	1,456
Wales				
0 to 4 years old	72,911	29	7	22
5 to 9 years old	84,707	33	8	25
10 to 14 years old	91,176	36	9	27
Total 0 to 14 years	248,794	98	24	74
Scotland				
0 to 4 years old	120,263	48	12	36
5 to 9 years old	136,360	55	14	41
10 to 14 years old	148,974	60	15	45
Total 0 to 14 years	405,597	162	41	122
Northern Ireland				
0 to 4 years old	53,474	21	5	16
5 to 9 years old	59,989	24	6	18
10 to 14 years old	63,313	25	6	19
Total 0 to 14 years	176,776	71	18	53
Total UK estimated undiagnosed aged 0 to 14 years				1,705

Registered Charity Number: 1080507, Registered Scottish Charity Number: SC037932

Annual Conference

We were back at Yarnfield for the second time and we had learned a number of valuable lessons from our first conference there. Some of the ideas from our first conference worked and some didn't.

There were a number of tweaks and one of the main ones was the relocation of the registration desk. This in addition to the movement of the stalls and free information enabled a more centralised area which helped their visibility through the conference.

Due to some issues with the loop system and noise overflow from adjacent rooms in the first year we ensured this was not repeated in the schedule. The overall feedback was still positive on the venue, the facilities, food, accommodation and the conference, which was a great relief.

As well as the sessions on the Saturday and Sunday, the award presentations started on the Saturday morning and continued into the evening. Starting with the Emma Woods Memorial Butterfly in the morning, followed by Ambassadors & the Masters award in the evening. Well done to all the worthy winners.

The evening show then came front and centre, which from its humble beginnings 15 years ago, is now a full-on production taking months of planning for the theme, music choices and choreography.



As always, the show was a hit with the girls & ladies with parents, partners and some volunteers closing the show in the usual dramatic and "it will be alright on the night" attitude. We will continue to review feedback after each conference for ways to ensure the conference fits the needs of the members attending.

Aspects: Our Beloved Newsletter

Our newsletter remains one of the Society's most cherished ways of staying connected – and we couldn't be prouder of it. Thanks to the thoughtful leadership of our editor, Phil Hatcher, it continues to grow and evolve with each edition. Phil's dedication and eye for detail have kept the newsletter informative,



engaging, and beautifully put together. As the Society continues to flourish, we're excited to see how the newsletter will grow alongside it – bringing stories, updates, and inspiration to everyone involved.



Open Days & Events

Open Days are a way for members to connect and find information and the Society is as always extremely grateful to the health professionals who are willing to speak at these events. Thanks also go to all those committee members and volunteers who help out during the day ensuring the smooth running of these events. It is encouraging to welcome so many new families to TSSS gatherings. Very often close bonds are formed, and friendships develop that will last a lifetime. We also had the Turner Syndrome Awareness Football Festival in Glasgow on 20th July 24 which was made possible through the Emma Woods Memorial Fund. This raised media attention as well as being a fundraising success.

On Friday 7th March and Saturday 8th March we held a Meet the Expert Day followed by a Seminar day. This was where many talented expert speakers from Endocrinology, Cardiology, Fertility and Genetics attended. Members shared their experiences so both sides could see the journey.



Online Media

When people first want to learn about Turner Syndrome (TS), they often turn to online media – and we know how important it is to make that first impression count. That's why we put so much care into making sure the information on our website is clear, balanced, and trustworthy. But it's more than just facts – it's a welcoming space that shows there's a supportive community here in the UK for anyone affected by TS.

We're genuinely delighted that so many individuals and families have discovered the Society through our website. It's regularly updated to keep things fresh and accurate, and we're always exploring new ways to make our content even more helpful and accessible.

Spreading Awareness on Social Media

We're also active on platforms like Facebook and Instagram, using them to raise awareness, share updates, and offer support. Whether it's pointing people to reliable resources or simply being there to listen, we understand how powerful these spaces can be – especially in recent years, when staying connected online has become more important than ever.

Celebrating Community Voices

One of our wonderful committee members, Emily Seymour, has taken things a step further by launching her own podcast: **Turner Syndrome, Talk and Tea**. It's a heartfelt and insightful series where guests share their experiences with TS – not just those living with it, but also siblings, parents, and loved ones. It's a beautiful reflection of the richness and diversity of our community.



We're incredibly proud of Emily and truly admire the care, professionalism, and passion she brings to every episode. We're incredibly proud of Emily and deeply impressed by the care, professionalism, and passion she brings to every episode. There are now over 200 episodes which is an incredible achievement.

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 24 countries connected.



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. Whilst occasional meetings are online the majority are in person so this means that there is significant time on the road for Arlene as shown by the main conferences attended in person below.

European project on registries (EuRRECa)

Milan • 21st April 2024

Endo ERN General Assembly

Milan • 23 - 24th April 2024

ECE Stockholm • 11 - 14th May 2024

Endocrine Academy 3rd July 2024

BSPED Glasgow • 7th - 9th October 2024

ESPE Liverpool • 16th - 18th November 2024

Scottish Paediatrics Endocrine Group

Stirling • 28th Jan 2025

TS Meet the Expert Day for Health Care Professionals

Glasgow • 7th March 2025

TS Seminar Day Glasgow • 8th March 2025

BES Harrogate • 10th - 12th March 2025

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 • 20th September 2025

Trustees' Responsibilities

*For the year ended
31st March 2025*

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:

- Selecting suitable accounting policies and applying them consistently.
- Making judgements and estimates that are reasonable and prudent.
- Stating whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements.
- Preparing the financial statements on a going concern basis, unless it is inappropriate to presume that the Trust will continue in operation.

The Trustees are also responsible for maintaining proper accounting records that disclose, with reasonable accuracy at any time, the financial position of the Trust and enable them to ensure that the financial statements comply with the Charities Act 2006. Furthermore, the Trustees are responsible for safeguarding the assets of the Trust and for taking reasonable steps to prevent and detect fraud and other irregularities.

Approved by the Trustees on 20th Sept 2025 and signed on their behalf by:

Susan Wall

Susan Wall • Trustee



Treasurer's Report

For the year ended 31st March 2025

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, a single joining date of the 1st of June every year is used.

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 • 20th September 2025



Turner Syndrome Support Society (UK)

Receipts and Payments Accounts • 1st April 2024 - 31st March 2025

Receipts	2024/2025 01/04/24-31/03/25	2023/2024 01/04/23-31/03/24
Memberships	£17,005.00	£15,818.50
Donations & Fundraising	£85,952.21	£69,715.56
Gift Aid	£9,399.38	£6,189.17
Conference & Open Days	£53,305.16	£33,492.44
Benefactors/Restricted Funds	£39,115.31	£258,614.48
TS International Conference	£0.00	£0.00
Shop	£3,682.65	£3,498.65
Consult Fee/Expenses Received	£828.74	£4,579.59
Miscellaneous	£713.84	£0.00
Bank Interest Received	£9,937.12	£8,904.74
Sub Total	£219,939.41	£400,813.13

Opening Bank Balance	At 1st April 2023	£636,172.74	At 1st April 2023	£417,369.79
Total		£856,112.15		£818,182.92

Payments	2024/2025 01/04/24-31/03/25	2023/2024 01/04/23-31/03/24
Rent & Rates	£19,433.55	£12,908.56
Heat, Light, Insurance	£6,544.40	£3,874.08
Printing, Stationery, Postage	£14,136.34	£12,212.58
Conference & Open Days	£57,599.08	£50,032.67
Wages, Salaries & Employers NIC	£56,233.16	£52,790.20
Telephone	£1,509.07	£653.97
Computer/Database	£10,014.92	£12,208.58
Professional Fees	£2,880.00	£2,305.20
Processing Credit Fees	£5,474.18	£4,219.15
Bank Charges	£1,037.80	£1,012.89
Equipment Hire & Maintenance	£1,263.40	£885.39
Literature & Brochures	£1,203.71	£25.98
TSSS Merchandise	£4,360.23	£8,033.55
General Expenses	£1,084.32	£1,891.70
Travel & Governance Expenses	£5,803.52	£4,455.68
Training Courses	£2,425.00	£4,500.00
Projects	£1,267.98	£10,000.00
Advertising	£8,419.04	£0.00
Sub Total	£200,689.70	£182,010.18

Closing Bank Balance	At 31st March 2025	£200,689.70	At 31st March 2024	£636,172.74
Total		£856,112.15		£818,182.92

Surplus/Deficit for the year	£19,249.71	£218,802.95
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TURNER SYNDROME SUPPORT SOCIETY

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

PERIOD FROM 1 APRIL 2024 TO 31 MARCH 2025

I report on the accounts of the charity for the period from 1 April 2024 to 31 March 2025 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

21st September 2025

Fun Times!



TURNER SYNDROME



SUPPORT SOCIETY [UK]

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

TURNER SYNDROME SUPPORT SOCIETY

England & Wales - Charity number 1080507

Accounts



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Legal and Administrative Information

For the year ended 31st March 2024

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
Mr P Hatcher

Sub Committee Chairs:

Mrs R J Raper
Miss M Cubitt
Miss E Phillips
Mrs A Smyth

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 2024

The Trustees present their report along with the financial statements of the charity for the period ended 31st March 2024. The accounts for the period 1st April 2023 to 31st March 2024 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

Mr P Hatcher

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.



Conference
is back...



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..

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.

Open Days

Open days in their normal format have returned, although we understand some members were still careful in their contact during this period. Whilst the numbers attending the Open days were down, we hope over time they will return to the levels we saw pre-pandemic.

TSSS Awareness Week

The Annual Awareness Week is used to try and extend a greater awareness of Turner Syndrome and related issues.

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

All our factsheets 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 immensely 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.

Turner Syndrome Awareness Day 21st June annually
 Aiming to create greater understanding of Turner Syndrome

What is Turner Syndrome?
 Turner syndrome is a complex and common genetic disorder that affects 1:2000 live female births. The main characteristic features of TS relate to growth and development but other characteristics may be associated with the condition.

Do you have Turner Syndrome?
 Do you think you might have Turner Syndrome?
 Do you think your daughter might have Turner Syndrome?
 Do you know someone who has Turner Syndrome?
 Do you want to know more about Turner Syndrome?

Girls and women who have Turner Syndrome can benefit greatly from appropriate medical treatment. Sadly however, many are not diagnosed early enough to benefit from treatment or are able to obtain help with other aspects of the syndrome. Those who have been diagnosed often think they are on their own. They are not, the TSSS is here for them, their families and friends. The TSSS [UK] aims to deliver the highest standards of accurate, timely and relevant information about Turner syndrome and to offer support to all girls and women with Turner syndrome, their families and friends throughout the UK.

Early diagnosis is vital so that treatment can begin for any TS related health issues.

TS can be diagnosed:

- During foetal life
- In infancy
- During childhood
- During pre-teen period (8-12 years)
- Late adolescence/adulthood.

Please contact us for more information:
 Arlene Smyth • Turner Syndrome Support Society
 12 Simpson Court • 11 South Avenue
 Clydebank Business Park • Clydebank G81 2NR
 Tel 0141 952 8006
 Email Turner.Syndrome@tss.org.uk
 Website www.tss.org.uk

TSSSUK
 TurnerSyndSoc
 @tssukofficial

TURNER SYNDROME
TSSS
 SUPPORT SOCIETY [UK]

Supported by the **Emma Woods Memorial Fund**
 in memory of Emma Woods

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.

Thank you to all who helped make this a success. An “I love TSSS because” poster was made for posting online along with

getting **#proudtohaveTS #ThisismewithTS #mydaughterhasTS #mysisterhasTS #myfriendhasTS** trending.

Patron Announcement

It was with immense pleasure that we announce that both Prof Melanie Davies and Prof Gerry Conway from UCLH London, have kindly confirmed that they will be delighted to take on the role of Patron. As you know they have both shown their commitment to Turner Syndrome and the TSSS over many years. We felt that it was time that we acknowledge their support in a formal way. They will also co-chair our medical advisory board.



Professor Melanie Davies is a consultant obstetrician and gynaecologist and accredited subspecialist in reproductive medicine, senior consultant at the Reproductive Medicine Unit, and chair of trustees of the EGA Hospital Charity.

Her special interests are in gynaecology, endocrinology and fertility preservation. Specialities include, Reproductive endocrinology, menopause, and premature menopause (POI), Reproductive effects of cancer, Polycystic ovarian syndrome, Turner syndrome & Care of adolescents and young adults.

Melanie runs a large service for reproductive effects of cancer and chronic disease and leads dedicated clinics for women with premature ovarian insufficiency and adolescent care. She set up and leads an NHS 'emergency service' for women with a new cancer diagnosis to offer fertility preservation.

Melanie is the founding chair of Fertility Preservation UK and has been a member of the medical advisory committee of the British Menopause Society and the executive committee of the British Fertility Society. She was previously responsible for the HFEA-licensed fertility services provided at UCLH, a clinical advisor to the HFEA and a contributor to NICE guidance on fertility, menopause, endometriosis and heavy menstrual bleeding.

NHS and Academic Posts - Consultant Obstetrician and Gynaecologist, University College London Hospitals. Professor of Reproductive Medicine, University College London.

Articles & Videos - Professor Davies is actively involved in research and training. She is the chief investigator for the POISE study, a multicentre NIHR-funded trial on treatment of premature menopause (POI), and the BLUSH study which looks at non-hormonal treatments for menopause symptoms. She lectures nationally and internationally and has publications in the New England Journal of Medicine, British Medical Journal, and Human Reproduction. She is an experienced RCOG training programme director for reproductive medicine and has chaired the national subspecialty training committee.



Professor Gerard Conway is a retired consultant endocrinologist at University College London Hospitals and Professor of Clinical Medicine in the Institute for Women's Health, University College London. His clinical practice covers general endocrinology including pituitary, adrenal, thyroid, and reproductive endocrinology.

His clinical research interests are in the field of reproductive endocrinology particularly polycystic ovary syndrome, ovarian and testicular function, disorders of sexual development and Turner Syndrome. This research has formed the basis of over 160 academic publications. Professor Conway maintains a clinical research program with visiting international research fellows.

Professor Conway qualified from the Royal London Hospital in 1981 and trained in Diabetes, Endocrinology and General Medicine in several centres in central London. His research thesis was in the endocrinology of the polycystic ovary syndrome, and he then undertook as fellowship in genetic research in Prince Henry's Institute for Medical Research, Melbourne Australia. On return he became Senior Lecturer in Medicine at UCL in 1994 and subsequently Professor of Clinical Medicine in the Institute for Women's Health UCL in 2012.

With a major interest in teaching, Professor Conway lectures in Reproductive Endocrinology, for the Society for Endocrinology, the Royal College of Obstetricians and Gynaecologists and internationally with the endocrine societies in the USA, Sri Lanka, India, New Zealand, Australia, Japan and throughout Europe.

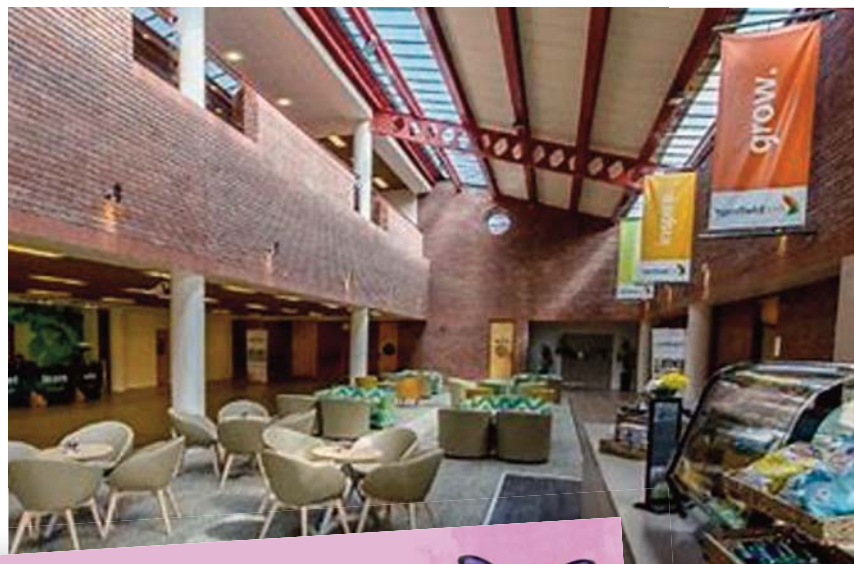
Patient care is at the heart of the clinical work of Professor Conway, and he works closely with many patient support groups.

Annual Conference

Planning for the annual conference takes a year and due to the disappointment of the 2022 Annual Conference being cancelled when Park Hall went into liquidation, we were determined to find a good replacement venue.

With more than a year before our next conference, this did allow us time to make sure that any new venue had the facilities and capacity that we require going forward, we were at Park Hall for 10 years! The required criteria for a venue 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 all at a reasonable cost. Whilst there are some genuinely nice hotels which met most of our criteria, reasonable costs didn't seem to be one of them.



After a lot of searching and numerous visits to several diverse types of venues we found our new home, Yarnfield Conference Centre, it has the facilities and capacity to look after us for many years. As with any new home it takes time to settle in and our first annual conference for 4 years went smoother than expected, we were a bit out of practice though!

Things were different which was to be expected, but we think better in that all the meetings rooms were on one floor and there was no need to brave the variable British

elements to go between sessions. There is a quiet area on the ground floor and the kids club has access to an outside area, weather permitting. Due to the size of our conference, we also have sole use of the venue which allows us some flexibility in certain areas. This is something we can only have dreamed of when we had to find our last change of venue.

The overall feedback was positive on the venue, the facilities, food, accommodation, and the conference which was a great relief. We also tried a number of new options, and some worked well and

some needed tweaks over the weekend as well as going forward. A couple of new things, like the EventWell room where you were able to chill out and relax away from all the hustle and bustle of the conference and the drinks reception before the Saturday evening event, seemed to go down well. Whilst not a hotel, the standard of food generated good feedback as well as keeping the costs down as much as possible.

As we have done in previous venues we will learn and tweak each year to help make this our TSSS family home from home, so any ideas to help in this quest, please tell us.

Welcome



Here's a little welcome back gift. We have missed you and we hope you have a great weekend.



International Turner Syndrome Committee

Arlene as President 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 twenty-three 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.



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 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 perspective, 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.

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.

Medical Conferences

The Society continues to develop and foster relations within the medical profession by attending conferences. Whilst the online conferences came with positives, the return of face-to-face meetings, has meant that there was significant time back on the road for Arlene as shown by the main conferences attended in person below.

European project on registries (EuRECa)

3rd & 4th April 2023

Endo ERN General Assembly

5th & 6th April 2023

Clinical Updates

24th-26th April 2023 in Birmingham

British Society Paediatric Endocrinology Diabetes (BSPED) Conference

8th-10th November in Manchester

British Society Endocrinology (BES) Conference 13-15th November 2023 in Glasgow

Scottish Paediatric Endocrine Group (SPEG) in Stirling on 25th-26th January 2024

Clinical Updates 25 - 27th March 2024 in Birmingham

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 (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 another challenging year for all, 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 • 29th September 2024

Trustees' Responsibilities

*For the year ended
31st March 2024*

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 29th Sept 2024 and signed on their behalf by:

Susan Wall • Co-Chair



Trustee



Treasurer's Report

For the year ended 31st March 2024

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, a single joining date of the 1st of June every year is used.

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 • 29th September 2024



Turner Syndrome Support Society (UK)

Receipts and Payments Accounts • 1st April 2023 - 31st March 2024

Receipts	2023/2024 01/04/23-31/03/24	2022/2023 01/04/22-31/03/23
Memberships	£15,818.50	£15,161.50
Donations & Fundraising	£69,715.56	£106,088.08
Gift Aid	£6,189.17	£5,072.92
Conference & Open Days	£33,492.44	£18,627.20
Benefactors/Restricted Funds	£258,614.48	£0.00
TS International Conference	£0.00	£0.00
Shop	£3,498.65	£1,179.90
Consult Fee/Expenses Received	£4,579.59	£978.12
Miscellaneous	£0.00	£0.00
Bank Interest Received	£8,904.74	£1,726.42
Sub Total	£400,813.13	£148,834.14

Opening Bank Balance	At 1st April 2023	£417,369.79	At 1st April 2022	£382,671.54
Total		£818,182.92		£531,505.68

Payments	2023/2024 01/04/23-31/03/24	2022/2023 01/04/22-31/03/23
Rent & Rates	£12,908.56	£12,266.30
Heat, Light, Insurance	£3,874.08	£4,668.97
Printing, Stationery, Postage	£12,212.58	£9,947.72
Conference & Open Days	£50,032.67	£1,130.16
Wages, Salaries & Employers NIC	£52,790.20	£48,110.68
Telephone	£653.97	£908.50
Computer/Database	£12,208.58	£10,366.34
Professional Fees	£2,305.20	£1,212.00
Processing Credit Fees	£4,219.15	£4,372.86
Bank Charges	£1,012.89	£849.49
Equipment Hire & Maintenance	£885.39	£1,136.24
Literature & Brochures	£25.98	£811.77
TSSS Merchandise	£8,033.55	£6,285.71
General Expenses	£1,891.70	£2,521.83
Travel & Governance Expenses	£4,455.68	£7,622.32
Training Courses	£4,500.00	£1,925.00
Projects	£10,000.00	£0.00
Bad Debts	£0.00	£0.00
Sub Total	£182,010.18	£114,135.89

Closing Bank Balance	At 31st March 2024	£636,172.74	At 31st March 2023	£417,369.79
Total		£818,182.92		£531,505.68

Surplus/Deficit for the year	£218,802.95	£34,698.25
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NOTES:

Projects £10,000.00 - Contribution to International Guidelines
£17,723.95 received for Conference in previous tax year.

TURNER SYNDROME SUPPORT SOCIETY

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

PERIOD FROM 1 APRIL 2023 TO 31 MARCH 2024

I report on the accounts of the charity for the period from 1 April 2023 to 31 March 2024 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

25th September 2024

We all need help, thank you.



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Accounts

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

TURNER SYNDROME

TSSS

SUPPORT SOCIETY [UK]

Annual Report & Financial Statement 2022 - 2023

TSSS Conferences through the years



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24 Market Sq.
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Registered Charity (*Scotland*):

1080507
SC037932

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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.

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Mrs S Cubitt (*Secretary*)

Ms K Bruerton

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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.



VOLUME 6: ISSUE 25: WINTER 2022

Aspects

Charity Reg No. 1080507 Scottish Charity No. SC037932

TSSS Conference 2023 Yarnfield Conference Centre 22nd to 24th September 2023



Publication of another new Factsheet!



See page 5

TURNER SYNDROME SUPPORT SOCIETY (UK)

TURNER SYNDROME SUPPORT SOCIETY NEWSLETTER

VOLUME 6: ISSUE 26: SPRING/SUMMER 2023

Aspects

Charity Reg No. 1080507 Scottish Charity No. SC037932

Say hello to your TSSS Committee members...



...and to Holly, the newest (and cutest) member of our Chairs' family!

TS Awareness Day
21st June - see page 7

TURNER SYNDROME SUPPORT SOCIETY (UK)

TURNER SYNDROME SUPPORT SOCIETY NEWSLETTER

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
Sub Total	£148,834.14	£326,138.22

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

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
Sub Total	£114,135.89	£106,638.03

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

Surplus/Deficit for the year	£34,698.25	£219,500.19
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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



TURNER SYNDROME



SUPPORT SOCIETY [UK]

Registered Office:

4 Overbury • Carterton • Oxon OX18 1HQ

TSS Office:

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

Registered Charity (*England & Wales*): 1080507

Registered Charity (*Scotland*): SC037932

TURNER SYNDROME SUPPORT SOCIETY

England & Wales - Charity number 1080507

Accounts



TURNER SYNDROME
TSSS
SUPPORT SOCIETY [UK]

Annual Report & Financial Statement 2021 - 2022

TSSS Conferences through the years



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Legal and Administrative Information

For the year ended 31st March 2022

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 30th March 2022

The Trustees present their report along with the financial statements of the charity for the period ended 30th March 2022. The accounts for the period 1st April 2021 to 30th March 2022 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 economic outlook and 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 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.

Ongoing Covid-19 Pandemic & Implications

As a society one of our strengths is the support we give one another. Whilst some of this was virtually, a significant part of it was in person, whether Local Group meet ups, Open Days, Conferences etc. Due to the ongoing nature of this pandemic, it meant that as a society we had to continue to evolve and change on how we did things. Whilst at the beginning of the pandemic everything had to go online, whether a committee meeting, meet ups or counselling sessions, as circumstances changed, we had to evaluate and understand the implications of any face-to-face meetings. It was not 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. Deciding to err on the side of caution we held off organising events until we could be reasonably sure that our members health concerns could be minimised.

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 and ongoing health implications 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.

Virtual Events

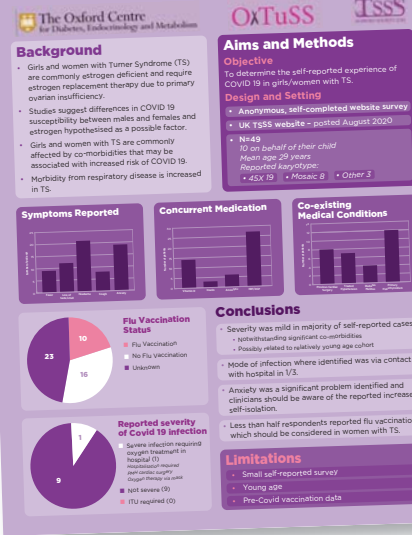
Once face to face meetings were not viable we looked at options to continue to support our members using social media or through virtual events. With this in mind, we applied for a grant from Pfizer of £6000 which has helped us provide these sessions, so our thanks to them.

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.

Novo Nordisk also added £3500 to their annual donation to help and support our friendship groups. This will be used to help deliver online services for them.

Covid 19 in Turner Syndrome: results of a self-completed website survey

Helen Turner Department of Endocrinology, OXDEM, Oxford University Hospitals NHS Trust
Ariene Smyth Turner Syndrome Support Society (UK)



Dr. Avril Mason in Glasgow's Children's Hospital. Along with all the other factsheets they are available for download direct from our website or a request can be made to the office. 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.

Publications & Literature

There were new publications and literature launched in this period.

In conjunction with The Oxford Centre for Diabetes, Endocrinology and Metabolism a survey was carried out on Covid 19 in Turner Syndrome. This was presented at the British Endocrine Society (BES) Conference in Nov 2021 and our thanks go to Dr. Helen Turner in Oxford for all her help in looking at the data.

We also launched more factsheets during this time, Turner Syndrome and Hypertension No. 12 and Turner Syndrome and your heart No. 13. For their help in preparing these our thanks to Dr. Helen Turner and her team in Oxford and Dr. Elizabeth Orchard, Emma Weingart and



Annual Conference

Planning for the annual conference takes nearly a year and was a major discussion at our January committee meeting in 2021. Whilst the effects of the pandemic were expected to ease, the fact that a number of our members had health issues and after time apart there would be significant face to face interactions, we decided not to plan an annual conference in 2021. We did not think it would be fair to raise hopes for them to potentially be dashed again as well as the potentially financial implications for all concerned.

At the 2022 January committee meeting 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 to all the staff there who had helped give us a very happy 10 years and 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. Due to pandemic, many events whether conferences or wedding etc. at venues of the capacity we required had been postponed, so everywhere had rebooked for 2022. This 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.

Note: After a significant amount of work trying to resolve this, we made the difficult decision that we would have to admit defeat and not do an annual conference in 2022. We have now found a suitable venue for 2023.

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 online and thank you to all who helped make this a success. An **"I love TSSS because"** poster was made available for posting online along with getting **#proudtohaveTS** **#ThisismewithTS** **#mydaughterhasTS** **#mysisterhasTS** **#myfriendhasTS** trending.

Open Days

As with all other face to face meetings, Open days in their normal format for this period had to be cancelled. While general society has started to meet up in groups, a number of our members are in the venerable groups so we decided that we could not take the risk of any organised meetups until we knew the risks had been minimised.

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.

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.

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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, 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 this time, 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. Due to all conferences going online during the pandemic there was an understandable reluctance with the every changing health landscape to commit too early to restarting "normal" conferences. Whilst the online conferences came with positives, a reduction in travel for Arlene there were also significant challenges, lack of face to face networking and significant learning curve for Arlene trying to create virtual stands for the conferences.

The following is a small selection of some of the conferences that Arlene attended on behalf of the Society.

The EuRReCa project (European Registries for Rare Endocrine Conditions) was a virtual conference between the 12-13th April 21 which was very exciting as they are working to create registries on Rare Conditions across Europe. Also, a virtual one, was the European Congress Endocrinology (ECE)/ Endocrine 22-25th May 21. Whilst these 2 may have been virtual, there is still a significant of prep work needed, especially as it requires the creation of a virtual stand which isn't the easiest, as everyone's systems are all new and are still works in progress so not the most user friendly.

With the new "normal", there was an in-person British Endocrine Society (BES) Conference in Edinburgh 8-10th November 2021 where the Covid 19 in Turner Syndrome poster was presented, as well as the British Society Paediatric Endocrinology (BSPED) 24-26th Nov 2021.

There is still a requirement for a mixture of event preparation as The Rare Disease Day on 1st March 2022 was a virtual reception Scottish Government.

As can be seen, 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 (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 • 29th October 2022

Trustees' Responsibilities

*For the year ended
30th March 2022*

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 29th October 2022 and signed on their behalf by:

Susan Wall • Co-Chair

Susan Wall

Trustee



Treasurer's Report

For the year ended 31st March 2022

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. 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 • 29th October 2022



Turner Syndrome Support Society (UK)

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

Receipts	2021/2022 01/04/21-31/03/22	2020/2021 01/04/20-31/03/21
Memberships	£13,828.50	£14,318.55
Donations & Fundraising	£77,427.04	£63,548.68
Conference & Open Days	£0.00	£0.00
Benefactors/Restricted Funds	£229,800.00	£16,500.00
TS International Conference	£0.00	£1,205.68
Shop	£856.45	£1,316.20
Consult Fee/Expenses Received	£500.00	£0.00
Miscellaneous	£3,691.09	£8,519.45 JRS
Bank Interest Received	£35.14	£43.55
Sub Total	£326,138.22	£105,452.11

Opening Bank Balance	At 1st April 2021	£163,171.35	At 1st April 2020	£159,038.35
Total		£489,309.57		£264,490.46

Payments	2021/2022 01/04/21-31/03/22	2020/2021 01/04/20-31/03/21
Rent & Rates	£13,290.30	£13,849.13
Heat, Light, Insurance	£3,529.20	£3,980.16
Printing, Stationery, Postage	£10,713.86	£8,079.09
Conference & Open Days	£125.00	£21,920.36
Wages, Salaries & Employers NIC	£43,643.68	£42,227.68
Telephone	£1,551.47	£1,576.33
Computer	£25,301.36	£743.00
Professional Fees	£1,194.00	£1,798.28
Processing Credit Fees	£754.80	£772.10
Bank Charges	£711.28	£648.28
Equipment Hire & Maintenance	£566.02	£75.00
Literature & Brochures	£0.00	£0.00
TSSS Merchandise	£851.86	£1,929.59
General Expenses	£1,774.79	£3,055.43
Travel & Governance Expenses	£1,350.41	£27.60
Training Courses	£0.00	£202.08
Projects	£1,280.00	£435.00
Bad Debts	£0.00	£0.00
Sub Total	£106,638.03	£101,319.11

Closing Bank Balance	At 31st March 2022	£382,671.54	At 31st March 2021	£163,171.35
Total		£489,309.57		£264,490.46

Surplus/Deficit for the year	£219,500.19	£4,133.00
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NOTES:

There would be a deficit of
without the donation of **£225,000.00**

£5,499.81

Eventbrite refunded
May 2020 **£21,680.68**
Adler invoice for pens in
May 2020 **£1,929.59**

TURNER SYNDROME SUPPORT SOCIETY

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

PERIOD FROM 1 APRIL 2021 TO 31 MARCH 2022

I report on the accounts of the charity for the period from 1 April 2021 to 31 March 2022 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

06 October 2022

TSSS Conferences through the years



TSSS Conferences through the years



TSSS Conferences through the years



TURNER SYNDROME



SUPPORT SOCIETY [UK]

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

TURNER SYNDROME SUPPORT SOCIETY

England & Wales - Charity number 1080507

Accounts

TSSS Conferences through the years



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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

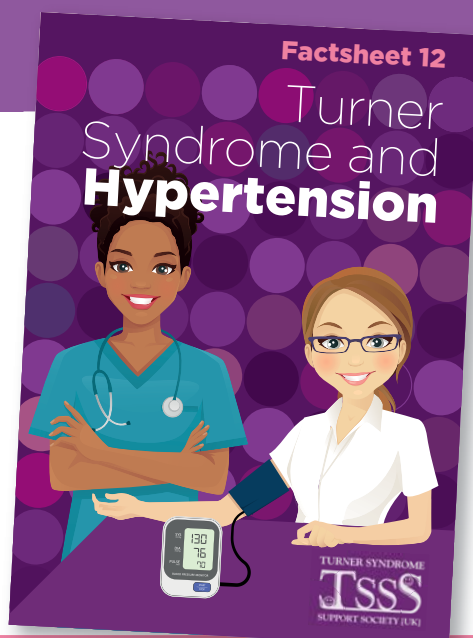
We are proud that the Society continues to expand and develop. The team of dedicated Trustees and Committee members meet formally at least 3 times each year to plan and allocate tasks, to meet its aims and objectives. Due to the pandemic this changed from face to face to conference calls like the rest 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.

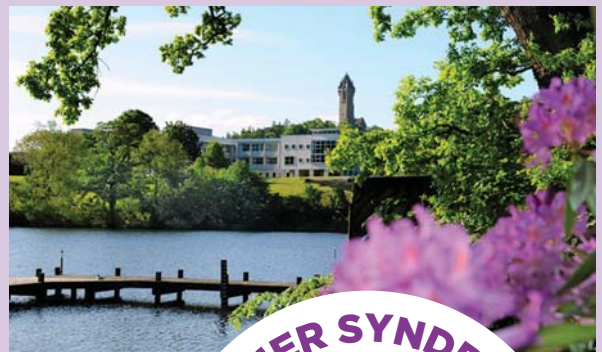
International Conference

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:

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- 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
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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



TURNER SYNDROME



SUPPORT SOCIETY [UK]

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