



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

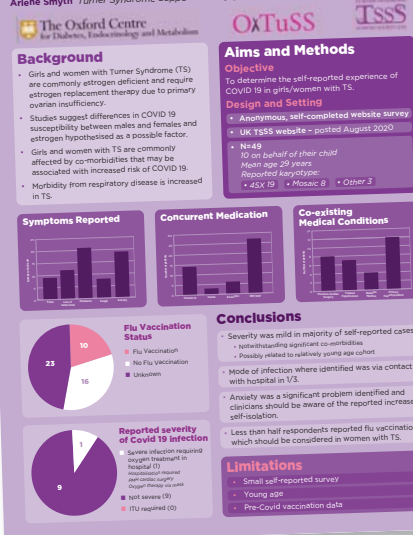
Once face to face meetings were not viable we looked at options to continue to support our members using social media or through virtual events. With this in mind, we applied for a grant from Pfizer of £6000 which has helped us provide these sessions, so our thanks to them.

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, OCEM, Oxford University Hospitals NHS Trust
Ariane Smyth Turner Syndrome Support Society (UK)



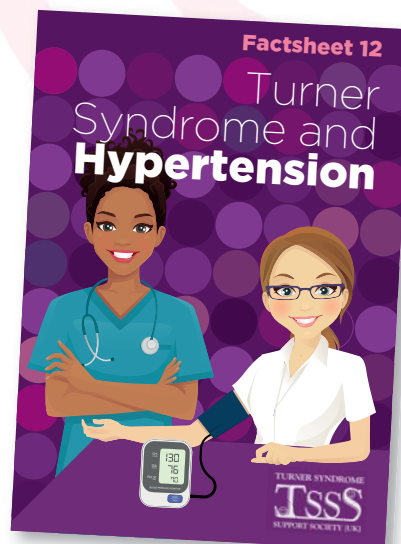
Dr. Avril Mason in Glasgow's Children's Hospital. Along with all the other factsheets they are available for download direct from our website or a request can be made to the office. We are very proud of all our literature, especially the important aspects of managing health based on accurate information. 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.

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 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.

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.



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.

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
NOTES: There would be a deficit of £5,499.81 without the donation of £225,000.00		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





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