



TURNER SYNDROME



SUPPORT SOCIETY [UK]

Annual Report & Financial Statement 2019 - 2020



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Legal and Administrative Information

For the year ended 31st March 2020

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 2020

The Trustees present their report along with the financial statements of the charity for the period ended 31st March 2020. The accounts for the period 1st April 2019 to 31st March 2020 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 given an introduction 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 the 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.

2020 Update...

Trustee Statement

As Trustees we know that this will be a very difficult 12-18-month period. It will impact the Society in several ways, both functionally and financially. As a support society we have always prided ourselves on supporting and helping each other, whether on the end of a phone or in person. This will continue, possibly using different formats e.g. Zoom, email, webinars etc., but we will still be there as a Society. Our ethos will not change and whether laughing or crying, we will survive this together.

2020 Covid-19 Update

Whilst this Annual Report covers the period Apr 2019 to 31st Mar 2020, the effects that Covid-19 would have on the Society were beginning to be felt. With that in mind I thought we should explain a couple of the decisions that have been made post the official period of this report.

TSI 2020

Whilst we had to continue to work towards holding the International Conference, if there was any chance of it happening, the likelihood of cancellation became ever more certain. Whilst we wanted to do this as early as possible, we had to wait for the venue to cancel, as otherwise there was the potential of a cancellation fee, which the Society would have been liable for of over £50k+, as well as no refunds. As the venue cancelled, we were able to get all accommodation fees refunded to delegates which would not have happened if we had cancelled. This has massively skewed the accounts, as since the enclosed accounts were finalised, over £21,000 has been returned to delegates. Additionally, there is £10,000 in the accounts which was a grant towards the conference, so this needs to be held in Restricted Funds, until a decision is made on the way ahead in conjunction with the company who gave us the grant.



Furloughing Carlene

With the expected significant decrease in income, we made the difficult decision to furlough Carlene in April. This left Arlene having to run the office on her own during this difficult time, which included handling the cancellation of the International Conference and the refund of the delegate fees. With the introduction of flexible furlough, Carlene is working 1 day a week to help lighten the load. This is until the end of October when Carlene will return to her normal hours, but as I am sure you can appreciate, this has put a greater burden on Arlene during this time. Carlene, thank you for being so understanding of the decision and a massive thank you to Arlene for shouldering the burden during this difficult time.



2019-20 Annual Report

TSSS Fundraising

Like many other charities we have concerns about our future income in this fragile economic climate. 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 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 a number of new publications and literature launched in this period including the New Turner Syndrome Guideline (clinical_practice_guidelines.pdf) as well as the health check lists.

Annual Conference

Another excellent and emotional Conference was held at the Park Hall Hotel, Chorley in October 2019. The Annual Conference is always the highlight of the TSSS Calendar. Our gratitude is extended to all the speakers at Conference, all of whom are at the forefront of their field, for their commitment and friendship to the Society. We would also like to extend our thanks to all the numerous volunteers for all their hard work during the weekend and in making the annual conference such a success by helping wherever is needed. The highlight, as always was the Saturday evening where our talented members put on a fabulous show for all to enjoy.





The Masters Award was given to Miss Rachel Coysh, who has been part of the TSSS community for several years and has been very active in fundraising through car boot sales and sponsored walks. She is a ray of sunshine and has shown true TS spirit over several years. This year she has been on a major journey and in true TS style she was soon talking, singing, progressing with rehab, and looking forward to the next ladies get together.

The Ambassadors were unusual in that they were not just for an individual. We therefore had great pleasure giving an Ambassadors Award to Miss Kacey Reid, as well as an Ambassadors Award to Team Penny, Penny Jones-Parry, Mum Frances, brother Dominic and friend Charlie. Unusually, we also awarded an Ambassadors Award to an organisation, Best Childcare and this was accepted on their behalf by Emily Raper.

Thank you to all for their efforts in helping the Society and promotion of awareness for TS you are all worthy winners



Open Days

During 2019 we held an Open Day in June in Sheffield with a wide range of speakers which was a great success and we have been asked to do again. Due to the ongoing background efforts for the Meet the Experts Day, International Conference, and the Seminar Day we hope the members understand why there were not more during this period.

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 during these TSSS gatherings. Very often close bonds are formed, and friendships develop that will last a lifetime.

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 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.

Website

The website 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 site 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.



AspectS

This is still one of the most important communication sources that the Society has and we are justifiably

very 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.



Seminar Day

On November 2nd, a Seminar Day with the Programme of "Life-long management of Turner Syndrome" was held in the OCDEM unit at the Churchill Hospital in Oxford. There were a number of topics discussed including the New Turner Syndrome Guideline, http://tss.org.uk/downloads/clinical_practice_guidelines.pdf as well as newly launched health check lists.



It was very well attended and oversubscribed. This was the 2nd such seminar day to be held in Oxford and our thanks must go to Arlene Smyth, TSSS Executive Officer, Dr Helen Turner, Consultant Endocrinologist, Dr Kate Wilson, Consultant in Genetics, Dr Elizabeth Orchard, Cardiology Consultant, Emma Weingart, Cardiac Nurse Specialist, Kathy Baker, Fertility Nurse Specialist and Dr Taffy Makaya, Paediatric Endocrinologist to name just a few in the medical profession that helped make this day a resounding success.

TS International 2020

The period covered by this report was a critical and very busy period for the planning and implementation of all the components required to host a conference of this nature.

The Accommodation booking site went live first, which was hosted and managed directly by Stirling University and due to some technical issues with the go live date, meant that we extended the early booking discounts dates to help delegates.

The Delegate booking facility then went live which managed by the Society and once again we were able to add in some facility for extended discount dates to help with flexibility. To help with the administrative burden of managing a conference of this size, after a trial with our own conference, we used Eventbrite to help manage the booking process. There was a cost to this, but the cost of not using such a facility, in tracking and managing such a large amount of bookings would have been immense and could not have been taken on by the limited resources of the societies office.

Another reason for splitting the accommodation and delegate fees, was that the finances of the Society would look significantly out of proportion to a normal year due to the intake of tens of thousands of pound for accommodation costs in one financial year, which wouldn't have been fully resolved until the following financial

year. This is apparent in this reports Financial Accounts as the delegate fees were paid to us, over £21,000. This artificially inflates the accounts for the year although there is a note against it explaining the extra income. If the accommodation costs had gone through us as well, this would have been more than twice that as well as the significant extra administrative burden this would have placed on the office.

With both live, the interest and bookings from all over the world started, and with it the expected questions and requests for guidance on what would be the best options for individuals and group bookings.

Due to the uncertainty that was apparent at the beginning of 2020 and whilst planning for the conference happening, we were working on the implications of the conference not being able to go ahead. This had the potential for major financial implications for the Society which necessitated waiting for the venue to cancel, rather than the Society. This would absolve the Society of cancellation fees from the venue and allow for negotiation on potential refunds.

The International Conference was being preceded by the ***“Meet the Experts Day”***, with a theme of ***“Improving Diagnosis”***. This was intended to get medical professionals from around the UK and the world to meet and exchange ideas on the management and treatment of Turner Syndrome. It also has had the potential for visiting professionals to stay for the conference, as well as be in an environment where they could get first-hand accounts of how diagnosis and care varied around the world.





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, North East England, London, South West 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 the British Endocrine Society Conference (BES) in Brighton, the British Society for Paediatrics, Endocrinologist and Diabetics Conference (BSPED) in Cardiff, Clinical Updates conference in Birmingham and the European Society for Paediatric and Endocrinology (ESPE) in Vienna. We were also invited to join the Turner Syndrome ESPE Working Group. Unfortunately, we were not able to attend the European Congress of Endocrinology (ECE) in Lyon and the ICOSEP in Vienna in person but shared information and views.

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.

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 October 2020

Trustees' Responsibilities

*For the year ended
31st March 2020*

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

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

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

Approved by the Trustees on 10th October 2020 and signed on their behalf by:

Susan Wall • Co-Chair

Susan Wall.

Trustee



Treasurer's Report

For the year ended 31st March 2020

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. The figures in this year's accounts are for 12 months.

As at the 31st March 2020 the closing balance of **£159,038.35** was made up of **£51,495.10** in the Reserves Account, **£54,097.30** in the Restricted Grants Account, **£3,163.43** in the Debit Card Account, **£50,253.17** in the Current Account, and **£29.35** in the Cash Account.

During the accounting year the Society received **£17,744.00** from benefactors, Novo Nordisk, Pfizer, Ferring Pharmaceuticals Ltd and Ipsen.

At the year end, 31st March 2020, a stock take was completed, and the value of the stock was **£5,334.58**.

The bank charges of **£323.89** cover all the bank accounts the Society currently holds, Current Account, Restricted Funds Account, Reserves Account and Debit Card Account.

The Processing credit fees of **£3,346.00**, were made up of the charges incurred from Just Giving, Pay Pal, Charity Checkout and Virgin Money Giving and have been paid by the Society.

Conference and Open Days are self-funding, and no money is made on these events. If the cost for a delegate to attend Conference increases, it is only due to the increase of costs incurred to the Society.

This year the Society's income is showing a large increase. Firstly, there was a single anonymous donation of **£10,000.00** and then **£31,680.68** was income received from delegates to attend the International Conference and sponsorship money. However, due to COVID-19 and the sad and devastating decision to cancel the International Conference the sum of **£21,680.68** has had to be refunded to all individuals, but this did not happen until after the financial year end in April 2020. Therefore, the true surplus for the year ending March 2020 is **£19,099.78**.

There is no guarantee of future income and the effects of COVID-19 is going to be huge, therefore we need to be mindful of this when planning for the future of the Society. 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 be 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 2019 - 31st March 2020

Receipts	2019/2020 01/04/19-31/03/20	2018/2019 01/04/18-31/03/19
Memberships	£14,435.00	£14,268.50
Donations & Fundraising	£78,602.17	£63,033.31
Conference & Open Days	£29,201.65	£29,273.53
Benefactors/Restricted Funds	£17,744.00	£9,500.00
TS International Conference	£31,680.68	£0.00
Shop	£2,405.79	£3,071.04
Consult Fee/Expenses Received	£628.22	£1,852.35
Miscellaneous	£1,500.00	£263.00
Bank Interest Received	£188.55	£123.94
Sub Total	£176,386.06	£121,385.67

Opening Bank Balance	At 1st April 2019	£108,257.89	At 1st April 2018	£102,553.26
Total		£284,643.95		£223,938.93

Payments	2019/2020 01/04/19-31/03/20	2018/2019 01/04/18-31/03/19
Rent & Rates	£13,873.96	£14,863.09
Heat, Light, Insurance	£3,934.94	£2,589.70
Printing, Stationery, Postage	£13,834.05	£8,596.85
Conference & Open Days	£29,482.48	£28,010.90
Wages, Salaries & Employers NIC	£41,424.06	£40,198.07
Telephone	£1,405.38	£1,318.40
Computer	£4,298.46	£4,404.92
Professional Fees	£1,170.00	£1,689.36
Processing Credit Fees	£3,346.00	£2,122.89
Bank Charges	£323.89	£282.98
Equipment Hire & Maintenance	£2,479.71	£1,784.70
Literature & Brochures	£324.00	£91.97
TSSS Merchandise	£2,299.61	£3,436.15
General Expenses	£1,542.49	£1,189.93
Travel & Governance Expenses	£4,166.57	£5,101.93
Training Courses	£0.00	£0.00
Projects	£1,700.00	£0.00
Bad Debts	£0.00	-£0.70
Sub Total	£125,605.60	£115,681.04

Closing Bank Balance	At 31st March 2020	£159,038.35	At 31st March 2019	£108,257.89
Total		£284,643.95		£223,938.93

Surplus/Deficit for the year	£50,780.46	£5,704.63
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 2019 TO 31 MARCH 2020

I report on the accounts of the charity for the period from 1 April 2019 to 31 March 2020 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

21 September 2020





Registered Office:

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TSSS Office:

12 Simpson Court • 11 South Avenue
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Registered Charity (*England & Wales*): 1080507

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