

# Turner Syndrome Support Society

Annual Report &  
Financial Statement  
2018 – 2019



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**LEGAL AND ADMINISTRATIVE INFORMATION  
FOR THE YEAR ENDED 31st March 2019**

|                                       |   |
|---------------------------------------|---|
| Trustees:                             | Mrs S Wall (Co-Chair)<br>Mr S Wall (Co-Chair)<br>Mr S Holden (Vice Chair)<br>Mrs J O'Keeffe (Treasurer)<br>Mrs S. Cubitt (Secretary)<br>Ms K Bruerton |
| Sub Committee Chairs:                 | Mrs R J Raper<br>Miss M Cubitt<br>Ms J Armytage<br>Miss E Phillips<br>Mrs A Smyth   |
| Staff Members                         | Arlene Smyth (Executive Officer)<br>Carlene Connor (Admin Assistant)  |
| TSSS Office:                          | 12 Simpson Court<br>11 South Bank<br>Clydebank Business Park<br>Clydebank<br>G81 2NR  |
| Registered Office:                    | 4 Overbury<br>Carterton<br>Oxon<br>OX18 1HQ   |
| Independent examiners:                | Nicola Jane Cadwallader FCCA<br>David Cadwallader & Co Limited<br>Suite 3 Bignell Park Barns<br>Chesterton<br>Bicester<br>OX26 1TD                    |
| Bankers:                              | HSBC<br>24 Market Sq<br>Witney<br>Oxon<br>OX28 6BG  |
| Registered Charity (England & Wales): | 1080507   |
| Registered Charity (Scotland):        | SC037932  |

## **REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31st MARCH 2019**

The Trustees present their report along with the financial statements of the charity for the period ended 31st March 2019. The accounts for the period 1<sup>st</sup> April 2018 to 31st March 2019 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. Particular 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.







# TSSS 2018-19 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 and every 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 wouldn't 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 in order 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

Having launched the Heart Awareness card the previous year, it was confirmed that it had already saved a life by Dr. Helen Turner.

The picture shows the ladies holding their cards aloft at the 2018 Annual Conference.



**Keith Masters** – It was with sadness that the first chair of the society, Keith Masters, passed away in September 2018. He had been instrumental in the early days of the Society, holding committee meetings at his house and we would not be where we are today without his guidance, support and kindness. The name lives on in the Masters award which is presented every year.

**Annual Conference** - Another excellent and emotional Conference was held at the Park Hall Hotel, Chorley in October 2018. The Annual Conference is always the highlight of the TSSS Calendar. Our gratitude is extended to all of 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 out wherever is needed. The highlight, as always was the Saturday evening where our talented members put on a fabulous show for all to enjoy.

In a very rare occurrence, there were 2 Masters Awards, which were awarded to Miss Emily Seymour and The Hatcher Family. Ambassadors Awards were given to the Ella Phillips and Dan Howard. 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 2018 we held an Open Day in July in Sheffield with a wide range of speakers which was a great success and we have been asked to do again.

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.

**Social Weekend** – In May 2018 we held a social weekend in Chester where members were able to get together, chat, shop, go on a river cruise and celebrate the bond that we have. The social aspect of the society is something we have always given high importance to, as well as the medical aspect.



**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 21<sup>st</sup> 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 Julie Champion has continued to produce to a high standard and will develop the newsletter as the Society continues to grow.

**TS International 2020** – Whilst the opening of the register of interest for the conference, followed by the opening of the accommodation booking facility were in the planning stages a humungous amount of effort has been ongoing in the background. As everyone knows it is the background effort that makes a conference and work was ongoing throughout the year working on the logistics of managing an event of this nature. Work on all aspects was on going with the planned launch of the website for registrations of interest so that we can judge how many delegates would be attending which will help with costings as well as planning.



**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 and the British Society for Paediatrics, Endocrinologist and Diabetics Conference. We also attended the Clinical Updates conference in Birmingham, European Congress of Endocrinology in Lyon and the ICOSEP meeting where Arlene is able to ensure that we have a voice. Having a presence at these conferences and meetings enables the Society to raise awareness and educate those within the medical profession and to gain valuable help and support in ensuring that all girls and women with TS are correctly looked after. Arlene also attends the Office for Rare Conditions in Glasgow and The Scottish paediatric Endocrine Group (SPEG) in Perth.

The Society had a presence at the ESPE (European Society for Paediatric Endocrinology) and this continues to be an area that the Society will develop and build over the coming years.

**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**

**30th Sept 2019**



# **REPORT OF THE TRUSTEES**

## **FOR THE YEAR ENDED 31st March 2019**

### **TRUSTEES' RESPONSIBILITIES**

Charity law requires the Trustees to prepare accounts for each financial year which give a true and fair view of the state of affairs 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 .....Susan Wall..... and signed on their behalf by:

*Susan Wall*

.....  
Trustee

## **TREASURER'S REPORT - THE YEAR ENDED 31<sup>ST</sup> MARCH 2019**

The Charity Commission requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs 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 1<sup>st</sup> June every year is used.

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

The 31st March 2019 closing balance of £108,257.89 is made up of £41,952.96 in the Reserves Account, £39,960.50 in the Restricted Grants Account, £1,976.84 in the Debit Card Account, £24,318.50 in the Current Account, £21.69 in the PayPal Account and £27.40 in the Cash Account.

During the accounting year the Society received £9,500 from benefactors, Novo Nordisk, Ferring Pharmaceuticals Ltd and Pfizer.

At the year end, 31st March 2019, a stock take took place and the value of the stock was £5,116.37.

The bank charges of £282.98 are for all the bank accounts the Society currently holds, Current Account, Restricted Funds Account, Reserves Account and Debit Card Account.

The Processing credit fees of £2,122.89, the Society has to pay, are made up of the charges we incur from Just Giving, Pay Pal, Charity Checkout and Virgin Money Giving.

Conference and Open Days are self-funding and no money is made on these events. If we have to put up the cost of members attending Conference, it is because costs to us for holding the event have risen.

Overall the Society's income has decreased compared to the previous year but 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 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**



.....  
**Treasurer**

**30<sup>th</sup> Sept 2019**



**Turner Syndrome Support Society (UK)**

**Receipts and Payments Accounts**

**1st April 2018 - 31st March 2019**

| <b><u>Receipts</u></b>                     | <b>2018/2019</b>  |  | <b>2017/2018</b>  |
|--|-------------------|--|-------------------|
|  | 01/04/18-31/03/19 |  | 01/04/17-31/03/18 |
| Memberships                                | £14,268.50        |  | £13,547.50        |
| Donations & Fundraising                    | £63,033.31        |  | £67,521.01        |
| Conference & Open Days                     | £29,273.53        |  | £25,160.64        |
| Benefactors/Restricted Funds               | £9,500.00         |  | £14,000.00        |
| TS International Conference                | £0.00             |  | £0.00             |
| Shop                                       | £3,071.04         |  | £2,439.88         |
| Consult Fee/Expenses Received              | £1,852.35         |  | £185.00           |
| Miscellaneous                              | £263.00           |  | £1,200.00         |
| Bank Interest Received                     | £123.94           |  | £39.74            |
| Sub Total                                  | £121,385.67       |  | £124,093.77       |
| Opening Bank Balance<br>at 1st April 2018  | £102,553.26       | Opening Bank Balance<br>at 1st April 2017  | £90,679.05        |
| Total                                      | £223,938.93       |  | £214,772.82       |
|  |                   |  |                   |
| <b><u>Payments</u></b>                     | <b>2018/2019</b>  |  | <b>2017/2018</b>  |
| Rent & Rates                               | £14,863.09        |  | £13,732.80        |
| Heat, Light, Insurance                     | £2,589.70         |  | £3,430.90         |
| Printing, Stationery, Postage              | £8,596.85         |  | £8,608.38         |
| Conference & Open Days                     | £28,010.90        |  | £27,346.42        |
| Wages, Salaries & Employers NIC            | £40,198.07        |  | £39,503.28        |
| Telephone                                  | £1,318.40         |  | £1,253.07         |
| Computer                                   | £4,404.92         |  | £3,915.82         |
| Professional Fees                          | £1,689.36         |  | £1,110.00         |
| Processing Credit Fees                     | £2,122.89         |  | £2,657.63         |
| Bank Charges                               | £282.98           |  | £268.58           |
| Equipment Hire & Maintenance               | £1,784.70         |  | £932.13           |
| Literature & Brochures                     | £91.97            |  | £0.00             |
| TSSS Merchandise                           | £3,436.15         |  | £1,732.50         |
| General Expenses                           | £1,189.83         |  | £2,542.30         |
| Travel & Governance Expenses               | £5,101.93         |  | £4,170.75         |
| Training Courses                           | £0.00             |  | £15.00            |
| Projects                                   | £0.00             |  | £1,000.00         |
| Bad Debts                                  | -£0.70            |  |                   |
|  | £115,681.04       |  | £112,219.56       |
| Closing Bank Balance<br>at 31st March 2019 | £108,257.89       | Closing Bank Balance<br>at 31st March 2018 | £102,553.26       |
|  | £223,938.93       |  | £214,772.82       |
|  |                   |  |                   |
| <b>Surplus/Deficit for the year</b>        | <b>£5,704.63</b>  |  | <b>£11,874.21</b> |

**TURNER SYNDROME SUPPORT SOCIETY**  
**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF**  
**TURNER SYNDROME SUPPORT SOCIETY**  
**PERIOD FROM 1 APRIL 2018 TO 31 MARCH 2019**

I report on the accounts of the charity for the period from 1 April 2018 to 31 March 2019 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

4 October 2019.

