



Annual Report & Financial Statement

2023 - 2024



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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.

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.

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.

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.

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

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.

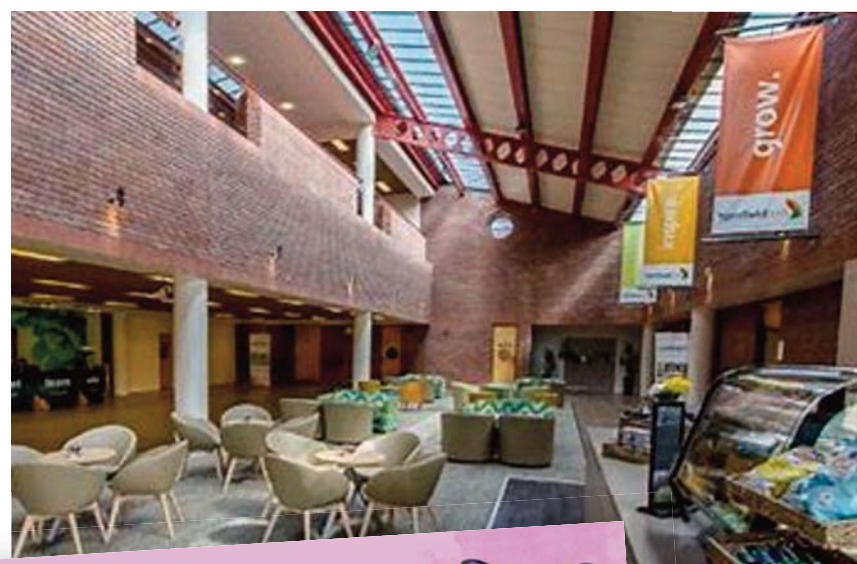
With a major interest in teaching, Professor Conway lectures in Reproductive Endocrinology, for the Society for Endocrinology, the Royal College of Obstetricians and Gynaecologists and internationally with the endocrine societies in the USA, Sri Lanka, India, New Zealand, Australia, Japan and throughout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

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

Susan Wall

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.





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