



Tuberosclerosis Association Annual Report



**“Providing help for today
and a cure for tomorrow”**

Annual report and financial statements for the year ended 31 December 2024
Registered charity 1039549 (England & Wales). Registered charity SC042780 (Scotland)
Company registration number 02900107

Trustees' and Directors' report

The TSA Board of Trustees, who are also directors of the charity, present their annual report and financial statements for the charity for the year ending 31 December 2024.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the Charity's governing document, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)".

The Tuberous Sclerosis Association (TSA) was founded by four TSC families in 1977. It was registered as a charity in England (02900107) in 1994 and Scotland (SC042780) in 2011. It was also incorporated as a company limited by guarantee in England and Wales in 1994. Its registered address is: TSA, Courtenay House, Pynes Hill, Exeter, EX2 5AZ.

None of the trustees have any beneficial interest in the company. All of the trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

The company's current policy concerning the payment of trade creditors is to follow the CBI's Prompt Payers Code (copies are available from the CBI, Centre Point, 103 New Oxford Street, London WC1A 1DU).

The company's current policy concerning the payment of trade creditors is to:

- Settle the terms of payment with suppliers when agreeing the terms of each transaction
- Ensure that suppliers are made aware of the terms of payment by inclusion of the relevant terms in contracts
- Pay in accordance with the company's contractual and other legal obligations

Trade creditors of the company at the year end were equivalent to five days' purchases, based on the average daily amount invoiced by suppliers during the year.

Information on TSA Trustees who served during the year and up to the date of signature of the latest financial statements can be found on [pages 8-9](#).

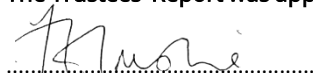
In accordance with the company's articles, a resolution proposing who be reappointed as auditor of the company will be put at a General Meeting.

Auditor: Griffin Accountancy (Courtenay House, Pynes Hill, Exeter, EX2 5AZ)

Public benefit

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

The Trustees' Report was approved by the Board of Trustees.



Dr Frances Elmslie (Chair of the Board of Trustees)
22 August 2025

Statement of Trustees' responsibilities

The Trustees are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales 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 Charity and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the Trustees are required to:

In preparing these financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles of the Charities SORP (FRS 102)
- Make judgements and accounting estimates that are reasonable and prudent
- State whether applicable UK Accounting Standards (FRS 102) have been followed, subject to any material departures disclosed and explained in the financial statements
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the Charity's transactions and disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the Trust deed. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Disclosure of information to auditors

Each of the persons who are Trustees at the time when this Trustees' report is approved has confirmed that:


- So far as that Trustee is aware, there is no relevant audit information of which the charity's auditors are unaware, and
- That Trustee has taken all the steps that ought to have been taken as a Trustee in order to be aware of any relevant audit information and to establish that the charity's auditors are aware of that information

Auditors

The auditors, Griffin, have indicated their willingness to continue in office. The designated Trustees will propose a motion reappointing the auditors at a meeting of the Trustees.



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Legal and admin information

Trustees

- Frances Elmslie
- Simon James
- Annemarie Cotton
- Sanjay Sethi
- Chris Kingswood
- Jane Rogers
- Martin Short
- Stacey Bissell (appointed November 2024)
- Maxine Smeaton (appointed November 2024)

Secretaries: Luke Langlands,
Dr Pooja Takhar

Charity numbers: 1039549 (England and Wales), SCO42780 (Scotland).
Company number: 02900107

Registered office: The TSA, Courtenay House, Pynes Hill, Exeter, EX2 5AZ

Auditor: Griffin, Courtenay House, Pynes Hill, Exeter, EX2 5AZ

HALLIE'S STORY

When Louise and Darian's little girl Hallie was diagnosed with TSC, they entered an unfamiliar world. By connecting with others in the TSC community, the family found their feet once more.

"Our daughter Hallie was diagnosed with TSC when she was two months old. Before the diagnosis, we had no indications that there was anything of concern.

It all started when we noticed that Hallie's arm was twitching. It slowly progressed to the point that her whole body was twitching. We went to the hospital and what followed was two weeks of no sleep, trying to control seizures happening to Hallie at least twice every 30 minutes. Hallie had lots of tests and we were then told that she has TSC.

We were then moved to Cardiff Children's Hospital and met Hallie's new specialist clinicians. Hallie was on many different medicines throughout the day and night, as well as baby formula every three hours. The biggest gap we had in the day was when the doctors would come in to talk to us! We wrote Hallie's timetable on a hospital coffee cup because there was no way we could remember it all.

After another month in hospital, we were discharged. We were told to look out for infantile spasms (seizures) and that they'd show within six months. We thought we'd got away with no spasms, but at five months and three weeks they started. We've been very lucky that Hallie responded well to the seizure medicines she's been on, we've been seizure free for over a year.

After this, we attended TSA Big Day. It was really nice to see and talk to others who know what we're going through. The biggest struggle is not knowing how TSC will affect Hallie in the long run. Talking to others going through what you are really helps.

Hallie's still on medication, but we're down to twice a day which is a world away from where we started! She has infusions twice a week at home and monthly blood tests. She's recently had her yearly scans and although the TSC tumours are growing the doctors are still happy with how she's doing. Hallie started walking and is a very confident little girl who has a brilliant personality and sense of humour."



ABOUT THE TSA

Our goals, values and public benefit

The Tuberous Sclerosis Association (TSA) is the only UK-wide charity dedicated to improving the lives of people with the rare genetic condition Tuberous Sclerosis Complex (TSC).

Around 1 million people worldwide live with TSC and there is currently no cure. TSC causes tumours to grow in different areas of the body. Common ways that TSC impacts people include epilepsy, autism, learning difficulties and skin, kidney, heart and lung problems. TSC can be devastating on all aspects of life, for people with TSC but also their families and carers.

We have three main charitable objectives:

- Support individuals affected by TSC, together with their families or carers
- Encourage and support research into the causes and management of TSC
- Provide education, publicity and information to promote awareness of the condition

We do this through:

- **Support and advocacy.** Including a dedicated support line, up-to date information and annual events
- **Research.** Funding world-class research all aspects of the causes, management and treatment of TSC
- **Campaigns and advocacy.** Influencing public policy and awareness to ensure that people with TSC get the support they deserve
- **Professional development.** Expanding knowledge and expertise of TSC in health, social care and education

Some of our most recent achievements in these areas, and some of our plans for the future, are listed later in this report.

Our **vision** is a world where TSC and its effects are conquered. Our **mission** is to provide help for today and a cure for tomorrow.

We are a small but extremely ambitious charity, demonstrated even by this annual report which surpasses the reporting requirements as set out by charity regulators.



A MESSAGE FROM OUR CHAIR AND CHIEF EXECUTIVES

Dear reader,

This annual report captures the recent journey and impact we have all made together, in improving the lives of people affected by Tuberous Sclerosis Complex (TSC). It is an opportunity to reflect on our work throughout 2024, as well as what we're doing in 2025 and beyond as we work to do even more.

Highlights of what we've recently accomplished include:

- Offering more opportunities than ever before for the TSC community to come together, both virtually and in-person
- Being a key voice in ensuring equal and fair access to new TSC medicines across the UK
- A new and exciting way to fund TSC research, opening more doors for new researchers to start their journey in unlocking new TSC discoveries

You can read more about some of the things we achieved in 2024 on pages **13 - 25**.

As we enter a new strategic period for 2025 - 2027, we have lots of reasons for optimism. Our new strategy is extremely ambitious for a charity of our size, but we truly believe that everything in there is achievable and reflects what the TSC community should expect and certainly deserves. You can read more about our new strategy on page **12**.

A key area of our work for the last few years has been on strengthening financial resilience. Looking ahead, this continues to be a key pillar for us, such as diversifying our funding streams and ensuring that we remain adaptable in the face of any challenges. You can read more about our finances on pages **26 - 31**.

We are proud that the TSA is a charity that remains transparent, approachable and impactful. This report underlines all of this, with our team making a conscious effort to really show our work, its impact, and the foundations that underpin everything.

Everything we achieve is possible only thanks to the passion and commitment of the TSC community, the TSA team, and our incredible volunteers. Our deepest gratitude goes to all individuals and groups we worked with over the last 18 months. Whether you provided us with insight and feedback, fundraised for us, or partnered with the TSA on any of our projects: Thank you, from us to you.

Dr Frances Elmslie
Chair, TSA Board of Trustees

Dr Pooja Takhar and Luke Langlands
TSA Joint Chief Executives

MEET YOUR TSA TEAM

Current TSA Board of Trustees

Dr Frances Elmslie (Chair)

Frances is the Clinical Lead for South West Thames Centre for Genomics, based at London St George Hospital, as well as Clinical Director of the South East Genomic Medicine Service Alliance. Frances leads the team that delivers St George's TSC service which cares for over 700 people with TSC. Dr Elmslie is also the Clinical Lead for the NHS England TSC Rare Disease Collaborative Network. Frances became Chair of the TSA in December 2023. She is also a Co-Investigator for the Rare Disease Node in mTOR pathway disorders.



Dr Frances Elmslie

Annemarie Cotton (Vice Chair, appointed November 2024)

Annemarie is a parent to a young adult daughter with TSC and has been involved with the TSA for the past 20 years. She has previously worked clinically in the NHS and currently works for a local authority supporting families of children and young people with Special Educational Needs to navigate the education system. Annemarie is passionate about equality of care and about working to ensure all members of the TSC community can access high quality relevant information to meet their needs.



Annemarie Cotton

Simon James (Treasurer)

Simon is a Fellow of the Institute and Faculty of Actuaries. He has worked in actuarial roles in life insurance, pensions and banking. Until his recent retirement, Simon was Director of Actuarial Apprenticeships at BPP Actuarial Education. In addition to leading a large team, he taught and developed materials for various actuarial subjects including risk management, business finance, investments and communications. He is keen to use this knowledge to help the TSA. Simon is also Treasurer and Trustee for his local village hall and also Trustee for a multi-academy trust in Swindon.



Simon James

Our other highly valued Trustees are:

- Sanjay Sethi (Vice-Chair until November 2024. Investment manager)
- Dr Chris Kingswood (Consultant nephrologist)
- Jane Rogers (Nurse)
- Rev. Martin Short (Retired)
- Dr Stacey Bissell (appointed November 2024. TSC researcher)
- Maxine Smeaton (appointed November 2024. Charity consultant)

Company secretaries: Luke Langlands and Dr Pooja Takhar.

Seven out of nine Trustees either have a lived experience or professional focus on TSC. This alongside our other engagement work ensures that the TSA is steered by the views of individuals, families and professionals in the TSC community.

We were delighted to welcome Dr Stacey Bissell and Maxine Smeaton to the board in 2024, with both candidates bringing valuable experience in TSC research. Dr Bissell is a passionate and active member of the TSC research community, while Maxine was previously Chief Executive of the TSA and the Epilepsy Research Institute UK.

The TSA Board of Trustees formally meets four times a year but communicate much more regularly with the senior TSA team in order to achieve the activities in our strategic plan. The Joint Chief Executives hold separate monthly meetings with the Chair and Treasurer to allow for ongoing updates, strategic planning, and addressing any issues that may arise.

Board members have a wide range of backgrounds, skills and lived experiences related to TSC, and are encouraged to take up training and development opportunities to increase their knowledge and expertise. A skills audit is performed every 12 months by the Trustees, to gain a better understanding of the Board's overall makeup and to identify knowledge or background gaps.

When recruiting for a new Trustee, the role is advertised on popular third-sector websites and also across TSA platforms. We encourage and welcome applications from the TSC community. Candidates are considered only if they can demonstrate that they may fill skills gaps identified within skills audits.

The roles of Chair and Vice Chair of the TSA Board of Trustees is regularly rotated, with the candidate selected based on their overall experience and expertise. New members of the Board of Trustees are voted in as part of the TSA's Annual General Meeting (AGM).



“
The TSA has been very supportive and I'm truly thankful”
- Person with TSC

“
You're very supportive, and really the only people who have ever really listened”
- Parent of child with TSC

TSA leadership

The TSA staff is small but mighty, with 10 individuals (seven people full-time equivalent) achieving everything that we do for the TSC community. The team is led by two Joint Chief Executives, Dr Pooja Takhar and Luke Langlands.

Pooja and Luke bring stability and passion to the TSA, holding the Joint Chief Executive role for several years. With a combined 15 years of experience at the TSA, the pair have helped to ensure that the charity is built on strong foundations that enable the greatest impact possible for people with TSC. However, **this is not possible without the wider TSA team.** Pooja and Luke are very grateful for their amazing work.



Dr Pooja Takhar

The wider and vital TSA team

The TSA is proud of the small but incredibly impactful TSA team. Our team is extremely valued, with a working environment based on kindness, respect and understanding. We're committed to providing salaries that are competitive with similar sized organisations, and we ensure that the effort of our team is acknowledged and celebrated.

New members of the TSA team are provided with a clear and in-depth induction, including an employee handbook. The induction largely focuses on the TSC community and what life is like for people affected by TSC, as this is the best way for team members to have the biggest impact as quickly as possible.



Luke Langlands



Some of the TSA team during lunch at Big Day 2024

The TSA team is proud to improve the lives of people with TSC. However, being part of TeamTSA can sometimes mean dealing with challenging circumstances. This is why we've introduced an Employment Assistance Programme, providing mental health support and financial advice so that the team can provide the best work possible for the TSC community. It's also important that our team develops professionally, which is why we actively seek opportunities for the team to grow through online and in-person training.

Volunteers and ambassadors

Our work is possible only thanks to the generosity, passion and commitment of those formally and informally volunteering their time and expertise to improve lives in the TSC community.

Those who choose to volunteer for the TSA, or agree to become TSA Ambassadors, play a vital role in everything that we do and achieve for the TSC community. In order to provide clear guidelines and expectations, and as safe an environment as possible, we kindly ask that people who take on formal volunteer roles sign our Volunteer and Ambassador Agreement.

Our Volunteer and Ambassador agreement sets out what volunteers and ambassadors can expect from the TSA in their voluntary roles, what activities they might be asked to do, and what actions we hope from volunteers and ambassadors in return.

TSA ANNUAL GENERAL MEETING 2025

The TSA's AGM for 2025 will take place virtually on **Thursday 27 November 18:00 - 19:30**.

Including TSC and genetics Q&A, with specialist TSC consultant geneticist

Agenda items are:

- Discuss the Accounts of the Association for the year ended 31 December 2024 and the accompanying Reports of the Trustees and Auditors
- Elect and re-elect members of the TSA Board of Trustees
- Appoint an Independent Examiner until the conclusion of the next AGM in 2026
- Authorise the Trustees to determine the remuneration of the Independent Examiners

This notice is given by order of the TSA Board of Trustees. Courtesy of the TSA's Company Secretaries (Luke Langlands and Dr Pooja Takhar).

Register for the AGM at: tuberous-sclerosis.org/agm2025

If you've been in touch with the TSA, you're considered a member. This means that you can attend and vote at the AGM. You're entitled to appoint one or more proxies to attend and, on a poll, vote instead of you. A proxy need not be a member of the TSA. There is no contract of service between any Trustee and the TSA. Any member interested in joining the Board of Trustees, or would like to discuss anything with the TSA's Chair, should email admin@tuberous-sclerosis.org or telephone 0300 222 5737.

A NEW STRATEGIC PERIOD FOR 2025 - 2027

The TSA's strategy for 2025–2027 builds on our past successes and our deep commitment to the TSC community, all underpinned by clear priorities. The next three years are focused on sustainable growth while making ambitious and meaningful progress in all areas of our work.

Our strategy's ultimate goal is to ensure that everyone affected by TSC gets the support, care, and research advancements they need and deserve, both now and in the future. Our guiding mission remains the same: "To provide help for today and a cure for tomorrow."



Our 2025 – 2027 strategy has four key priorities:

- **Advocacy and awareness.** Campaign for TSC to be a higher priority in the health, social care and education sectors. Improve specialist care access, treatments, and therapies - especially for TSC-Associated Neuropsychiatric Disorders (TAND) and through championing TSC clinics
- **Research.** Make more world-class TSC research possible. Invest in studies that strengthen evidence-based tools for daily management of TSC. Make collaboration a key focus, with the TSC community influencing our research priorities
- **Support and information.** Ensure that everyone affected by TSC can receive support, and creating information on all aspects of TSC, in a range of formats and platforms. Provide ways for the TSC community to learn, connect, and share together, both virtually and in-person
- **Sustainability.** Strong financial foundations are central to everything. Make the TSA resilient and adaptable, so we can be here in the future. Refine our fundraising approach, to secure reliable income across a wider range of sources

We'll accomplish our strategic priorities by continuing to foster strong relationships with the TSC community, who remain firmly at the heart of everything we do.

WHAT WE ACHIEVED IN 2024

The end of our previous strategy: A major success

2024 was the final year of our previous strategic period for 2019 – 2024. We had three strategic aims for this period, all of which we were successful in achieving:

1. Reach more people

There are around 10,000 people with TSC in the UK. **By the end of 2024, our reach increased by 86%, to 6,482 people**, compared to the start of 2023 when we reached just 3,489 people.

2. Drive more research

Since our launch, we've been at the heart of research in the areas most important to people affected by TSC. We had to temporarily reduce expenditure to balance the books which meant we were unable to run funding rounds annually. We then acknowledged that TSC is too big to tackle alone. Therefore, we began greater collaboration with other funders to create real impact and progress. These partnerships, such as with Epilepsy Research Institute UK, unlocked £1.5m in TSC research. **For every £1 invested by the TSA, we unlocked a further £5 into TSC research** from external partners that might not have otherwise happened.

3. Continue to balance the TSA's finances

After several unsustainable high deficit years, the TSA team has steered the charity back to stronger financial foundations. It remains an incredibly challenging time for all small charities, including at the TSA, but we now have greater financial resilience to be able to achieve our ambitious aims. Without this, the long-term future of the charity would be in doubt.



Support and information

TSA Support Line

In 2024, the TSA Support Line continued to be central to our support and information projects. The support line received similar enquiry levels to 2023, with **292 enquiries** across telephone (100), email (144), webchat (32), social media and web form (17), and post (1).



You couldn't have possibly helped any more than what you did

- TSA Support Line user



The service that you provide is amazing

- TSA Support Line user

The most common reasons people contacted the TSA Support Line in 2024 were:

1. Emotional support
2. The physical impact of TSC
3. The TSA Support Fund
4. Accessing specialist TSC clinics
5. Information for professionals, such as doctors, teachers and social workers

Compared to previous years, we received lots of questions about access to **cannabidiol (Epidyolex)** for TSC-related epilepsy. This is likely because the medicine received approval for use on the NHS by UK decision-makers during this time. We made sure our support team was well prepared for this, with briefing documents and training on cannabidiol beforehand.



TSA Welcome Packs

TSA Welcome Packs continue to be a vital reminder to the TSC community that you're never alone with the condition. These packs, available as physical or digital format, are particularly important to individuals and families recently diagnosed with TSC.

In 2024, **23 TSA Welcome Packs** were sent to households new to TSC. This meant that an individual or family were given a vital foothold into a new and likely confusing world, so they could start to navigate it more effectively and confidently, starting with the strongest foundations possible.

TSA Support Fund

TSC can have a devastating impact on all aspects of the lives of individuals and families, including finances. To help with this, the TSA Support Fund offers small but important financial grants to people in the TSC community who are in financial hardship.

In 2024, 18 TSA Support Fund grants were awarded to the TSC community. Reasons that people requested the fund include:

1. Items to help with physical disabilities, such as wheelchairs
2. Medical items, such as seizure monitors
3. Part-funding of respite breaks or days out
4. Emergency funding for new household items
5. Repairs and purchases of whitegoods, such as washing machines



“The TSA Support Fund is a lifeline for people who really need help. The TSA, for us, means a lifeline.”
- TSA Support Fund user



Keeping you updated

In 2024, **35,000** users accessed our website, underlining how important our website is in sharing TSC information. In comparison, this figure was 22,000 in 2023.

The TSA's social media channels continue to be an important source of information for the TSC community. Our social reach **increased by 31%** in 2024, making more people aware of TSC as a condition and also the impact that the TSA has on improving people's lives.

In 2024, we launched a new monthly round-up newsletter, responding to the feedback that people in the TSC community are incredibly busy and short of time. This gives readers a bitesized view of all-things TSA and TSC. Around **4,000** people receive this newsletter monthly.

TSA community events

TSA face-to-face and virtual events offer a much-needed chance for connection, support, and shared learning in the TSC community.

Outlook is for adults with TSC. It's a way to make lifelong friends in-person and virtually. The event is the highlight of the year for many attendees. **We welcomed 40 people to Outlook 2024**, which was held in Cardiff.

Big Day is our largest event, with everyone in the TSC community invited. Families, individuals, professionals and researchers all come along to discuss life with TSC, learn about TSC research and make new connections. **We were delighted to have 120 people attendees at Big Day 2024**, which took place in Reading.

Across 2024, we offered virtual opportunities for people to meet, learn and connect. This included a special monthly TSC Art Club. Professional artist Sarah Goy, who has TSC, provided an empathetic environment for people in the TSC community to express their feelings and thoughts creatively.

We had **19 virtual and in-person events in 2024**.

9 in 10 people say our events are very important to them

“TSA events are well organised and give the opportunity to meet other people with TSC and be part of a community that support each other”
- TSA event attendee



“It was very informative and engaging, it was good to talk about TSC with others”
- TSA event attendee

In 2025, some of the things we plan to do are:

- Achieve re-accreditation of the TSA Support Line with the Helplines Partnership, a membership body that evaluates support services for their level of quality
- Expand the TSA Support Fund so that it's easier to apply for and is more impactful. This is in direct response to the TSC community facing greater ongoing financial challenges
- Begin to update our TSA Welcome Packs to include more materials, plus additional materials on how to explain TSC to children
- Start work on relaunching our website so it's easier to use and more fitting of the TSA and TSC community needs
- Expand and improve our range of face-to-face events, including more opportunities for people affected by TSC to come together locally
- Launch a pilot programme of more local TSC events, starting with a range of regional get-togethers and family days across Wales

Working with TSC professionals

A key part of our work for the TSC community is working with professionals across the sectors who support people with TSC. This includes doctors, nurses, social workers and education professionals.

TSC Rare Disease Collaborative Network

The TSA is proud to be secretariat to the TSC Rare Disease Collaborative Network (RDCN), which is made up of 23 clinics across the UK focused on TSC. Through the network, TSC specialist healthcare professionals can connect and learn from one-another on best practice in TSC care.

The TSC RDCN entered its second year in 2024, with the network achieving major milestones:

- **44 people** attended our annual face-to-face TSC RDCN meeting
- National virtual multidisciplinary team (MDT) meetings were launched for the first time allowing the clinicians to discuss complex cases with other experts
- Our annual TSC education session, as part of the TSC RDCN, was successful in allowing healthcare professionals to learn more about TSC

Thanks to the TSC RDCN, there is greater equality across the UK in diagnosing, treating and managing TSC. This means improved care for everyone in the TSC community, no matter where you live in the UK.



Valued experts

We do our utmost to support the TSC clinical community. However, this also works the other way around, with the TSA being incredibly grateful for the support that we receive from TSC clinics.

We ask individual clinicians to review TSC information that we share that's focused on the medical side of the condition, such as information on our website, the TSA Support Line, or physical leaflets. This helps to ensure that all the medical information that we share with the TSC community is up-to-date, relevant and meaningful.

Accredited TSC courses for professionals

One of the major ways that we support professionals who aren't familiar with TSC is in helping them to better understand the condition and what it means to live with TSC.

We regularly hear from people through lots of different channels, such as the TSA Support Line or at our events, about the challenges in ensuring people with TSC get the support they need away from TSC specialists. Lots of professionals also get in contact with us directly, asking for more information about TSC. This is especially common in schools - such as with teachers or teaching assistants - and in social care, such as staff at residential homes. We heard this challenge so often, from so many people, that we knew that we had to act to make sure that things could change.

The result of this was the TSA launching the world's first and only Continual Professional Development (CPD) courses about TSC for education professionals and social care professionals. In 2024, these courses were further boosted with additional updates, ensuring that they remain relevant. Future updates are also planned.

Our TSC CPD courses help give professionals who are working with people with TSC the confidence to support people with the condition more effectively.

100%

professionals agree that TSA training courses met their learning objectives

“

Thank you for this great course and your efforts, much appreciated!”

- Teacher who completed TSA training course



In 2025, some of the things we plan to do are:

- Host a face-to-face TSC nurse specialists meeting
- Once again be a key partner in updating the UK clinical guidelines for TSC, ensuring greater equality in TSC care
- Create a more holistic support package for people with TSC, by encouraging TSC clinics to signpost to the TSC Support Line
- Launch a CPD course for medical professionals unfamiliar with TSC, so that they can better care for people with the condition

Research and advocacy

Funding TSC research

The TSA is the only UK-wide charity that focuses its research funding on TSC. **Our research grant commitment in 2024 was £65,666.** The TSA Board of Trustees remained committed to honouring all research commitments in 2024, utilising the Designated Endowment Fund to cover the costs of our ongoing research grants programme.

The TSA's research portfolio of previously committed grants in 2024 consisted of **6 live grants**, which were all jointly funded. Our portfolio of ongoing projects is worth **£188,474.**

Our live grants for 2024

Lead researcher	Institution	Research project
Dr Sam Amin Dr Ingram Wright	University of Bristol	Better understanding the accessibility of mental health services for children and young people with TSC This project is developing more appropriate and effective ways for children and young people with TSC to access mental health services and psychological support in the UK. This research hopes to demonstrate a clear benefit of providing therapies to children and young people with TSC who are experiencing psychological or emotional distress. Co-funded by an anonymous major donor.
Prof. Petrus de Vries Prof. Anna Jansen	University of Cape Town UZ Brussels	The TANDem Project The TANDem Project brings together a worldwide team of families affected by TSC, researchers and clinicians to provide scientific evidence for greater intervention and treatment of TSC-Associated Neuropsychiatric Disorders (TAND, which includes anxiety, depression and challenging behaviour). The two-part project will first focus on the development of a self-report TAND checklist and identification app, to measure how people are affected by TAND. The second part of the study will investigate the best ways to treat TAND. Co-funded by the King Baudouin Foundation.

Lead researcher	Institution	Research project
Ms Shoba Srivastava	University of Cape Town	<p>TAND in India</p> <p>This PhD project will ask families affected by TSC and their clinicians what they know about TAND, what their TAND needs are and what their priorities would be for TSC-related action in India. It'll examine how useful certain TAND identification and management strategies currently are for families in India, with the potential for findings to have worldwide importance.</p> <p>Rigorous work by the TSA as part of the funding application confirmed that the research will not result in committed funds filtering beyond the remit and focus of the research itself.</p> <p>Co-funded by the TANDem Consortium.</p>
Dr Liezl Schlebusch	University of Cape Town	<p>Well-Beans for Caregivers Programme</p> <p>This study is investigating the feasibility, acceptability, and potential impact of a World Health Organization-developed Caregiver Skills Training programme when used in the TSC community.</p> <p>Co-funded by TANDem Consortium.</p>
Dr Stacey Bissell	University of Birmingham	<p>Exploring Sleep experiences in people with TSC (e-Slept)</p> <p>Getting to sleep and waking up during the night are major challenges in the TSC community. The e-Slept project aims to document sleep challenges in people with TSC, by asking their caregiver to document the experiences. It's hoped that this will ultimately help to better manage sleep problems in TSC.</p> <p>Co-funded by TANDem Consortium.</p>

Lead researcher	Institution	Research project
Dr Amanda Almacellas Barbanoj	University College London	<p>Investigating new targets for TSC treatments</p> <p>This project will explore the other ways in which a mutation in the TSC1/2 genes affects how neurons form and connect with each other. It's hoped that this will help scientists gain a better understanding of how seizures and difficulties associated with development, mental health and learning abilities arise in TSC and other neurodevelopmental disorders. More importantly, this in-depth study will uncover potential targets of new therapies that could significantly improve the quality of life of the one million people living with TSC worldwide and their carers.</p> <p>Co-funded by the Epilepsy Research Institute UK.</p>

TSC Research Volunteer Network

Involving the TSC community in TSC research, called Patient and Public Involvement (PPI), is vital in improving our understanding of TSC. After all, the TSC community are the experts.

By working with the TSC community on our research priorities, we ensure that the priorities focus on what matters the most and has the biggest impact. **There are 39 members of the TSC Research Volunteer Network**, including people affected by TSC, parents, carers and siblings of people with TSC. In 2024 they helped shape the TSC research landscape by:

- Reviewing researcher project proposals to receive major funding to ensure that the work was impactful and meaningful to people affected by TSC
- Providing feedback on clinical trial protocols and documentation
- Sharing their lived experience of TSC with UK regulatory bodies during campaigns for new TSC-related medicines

The network plays an invaluable role in shaping TSC research. For example, exclusion criteria (reasons people might not be allowed to take part) for a recent clinical trial of a potential TSC medicine was updated after the network said that it was too restrictive and would significantly reduce the number of people who could participate. This led to more involvement in the clinical trial by people in the TSC community.

“The comments from the TSA Research Volunteer Network mean we’ll definitely make some changes to the research, to highlight these points. Great suggestions!”
- TSC researcher

Researchers supported by the network highlight how working with people in the TSC Research Volunteer Network has enhanced their project, making it more impactful and relevant.

Campaigning and advocacy

Throughout 2024, the TSA continued to ensure that the voices, needs and expectations of the TSC community were heard clearly, and acted upon, across different situations and opportunities:

Access to new and vital treatments

The TSA actively represented the TSC community in four NHS funding reviews for:

- Fenfluramine (Fintepla), to treat seizures in Lennox-Gastaut syndrome, a condition that some people with TSC also have
- Topical sirolimus cream (Hyftor), for TSC-related facial angiofibromas (bumps and marks on the face caused by TSC)

These reviews were with the National Institute of Health and Care Excellence (NICE), which decides what is funded by NHS England, and the Scottish Medicines Consortium (SMC), which decides what is funded by NHS Scotland. We ensured that the perspectives and experiences of people living with TSC were genuinely considered in these meetings, leading to those in the TSC community being central to decisions that will dictate their health and wellbeing.

Influencing national rare disease policy

The TSA is a passionate and active influencer in national policy forums. This ensures that the TSC community is front-of-mind when progressing rare disease care. Places we did this in 2024 include:

- The UK Rare Disease Forum, supported by the Department of Health and Social Care. This provides meaningful discussions and collaboration across everyone in the rare disease community, such as the TSA and other rare condition charities
- The Specialised Healthcare Alliance (SHCA), chaired by Lord Sharkey. In the Alliance, we added to Government and NHS consultations on specialised care for rare conditions. This helps the TSA to share public policy in the interests of those with TSC
- Attending Rare Disease Day 2024 events. One was hosted in Westminster by Liz Twist MP, Chair of the APPG on Rare, Genetic and Undiagnosed Conditions. The Scotland Rare Disease Day 2024 reception took place at the Institute of Genetics and Cancer, Edinburgh
- Attending a Patient Advisory Group meeting by Public Policy Projects, as part of their Rare Disease programme. The meeting focused on the effective delivery of treatment for those living with, and those caring for, rare and ultra-rare conditions



Dr Amanda Almacellas Barbanoj
(TSC researcher)



Dr Elaine Dunlop (TSC researcher)

Ensuring a TSC-focus at professional gatherings

When wider health, research and social care professionals come together, we make sure that the TSC agenda is heard, understood and acted upon. In 2024, this included:

- Advocating at the British Association of Dermatology (BAD), and the Dermatology Council, for a better understanding and management of TSC-associated facial angiofibromas and other skin conditions related to TSC
- At the Neurology Transformation event, we were invited to speak to a group of commissioners, clinicians and Highly Specialised services at NHS England about the NHS TSC RDCN, as we are viewed as having an exemplary model
- When medical research agency Adelphi held their annual all-team meeting to better understand the challenges faced by small charities, the TSA was one of the main guests



In 2025, some of the things we plan to do are:

- Have a central role in the development of new clinical guidelines for TSC, ensuring that diagnosis, care and management of TSC is better and more equal across the UK
- Connect with likeminded organisations on key issues that affect the TSC community, such as disability and social rights charities
- Continue to fund a wide range of TSC-related research, including special funding for early career researchers so they can kickstart a lifelong love of making the next big TSC discovery that will change lives forever

Fundraising and income generation

We simply wouldn't be here without the incredible passion and determination of the TSC community. Your fundraising and support means everything to us and we are very thankful.

London Marathon 2024

We had a record-breaking year for us at the London Marathon. We had 8 runners and their efforts were well worth it, with an incredible **£27,550** (including Gift Aid) raised for our work – the most ever raised by the TSA at the London Marathon!

Big Give 2024

Big Give is a popular way for people to give back to the TSC community, where for one week only the value of donations is doubled. In 2024, we asked people to donate to help fund the TSA's support services. We raised a fantastic **£10,424!**

In memory giving

In memory and legacy giving is an incredibly powerful way to give back to the TSA and TSC community. We're very thankful for all donations we give but treat those given in memory or as part of a gift in Will with the greatest of respect.

In 2024, we received **£21,466** through in memory giving, such as from families asking loved ones to donate to the TSA to mark the life of someone now departed. We also received a major legacy gift from an incredibly kind individual who considered us in their Will. This legacy gift has helped to shape future years at the TSA.

Corporate giving

Corporate giving is increasingly important at the TSA, with opportunities to connect with businesses and places of work with an interest in TSC being something we want to do more. Our work to expand corporate giving in 2024 started with the new TSA Corporate Community, highlighting the fantastic efforts of our corporate partners in a quarterly newsletter, inspiring our connections to find ways to support the TSA that align with their values and goals.

Coveris made the TSA their Charity of the Year in 2024 and raised a fantastic **£3,777**. Also in 2024, mobile phone network operator Giffgaff awarded the TSA a wonderful **£5,648** after a TSC community member nominated us for their charity payback scheme. Giffgaff members voted for the TSA after reading some touching stories shared by our community.

We were delighted to receive an amazing **£50,000** from a one-off donation by Foresters Financial. We received this after Becca Rasho and her family shared a video with Foresters on what life is like with TSC.

In 2025, some of the things we plan to do are:

- Further increase our areas in corporate giving, such as being selected as Charity of the Year more often
- Widen opportunities for the TSC community to be involved in challenge and DIY fundraising
- Have a greater focus on trusts and foundations, made possible with much clearer targets and projects across all areas of the charity



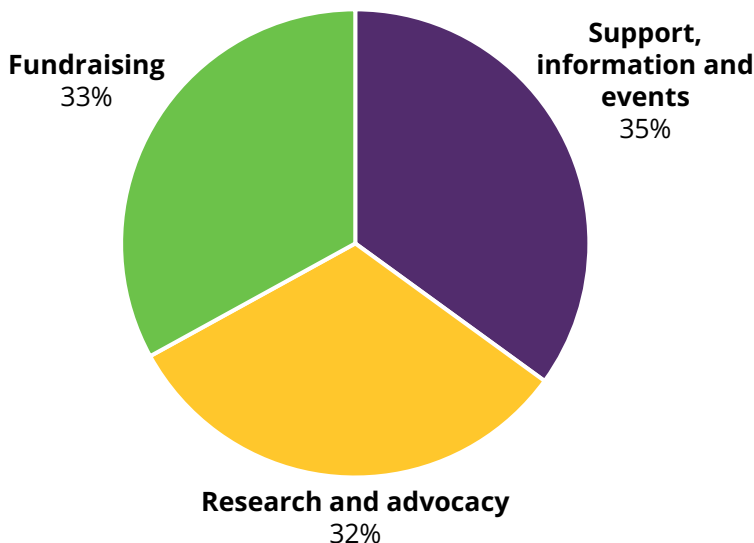
MONEY MATTERS

Where we spent funds in 2024

We're committed to doing as much good as possible for the TSC community, across all aspects of life with TSC. This means making sure that as much of our outgoings as possible is used where it's going to have the biggest difference. We try to keep overheads to a minimum, while giving our small and passionate team the things they need to do their very best across support and information, research, advocacy and fundraising.

As shown in the chart below, in 2024 we had a roughly even split across spend in our different teams and projects. 33% of outgoings in fundraising might seem high, but income generation is the only way we can continue to survive and be here for the TSC community.

On average, UK charities get £3 - £4 for every £1 that they invest in fundraising. **We exceeded this in 2024, bringing in £5 for every £1 spent in fundraising.** This shows that we are very effective in getting the maximum return possible in what is given to us, meaning that donations are as impactful as possible.



Financial overview at the end of 2024

At the end of 2024, the TSA had total funds of **£1,299,561**. This consisted of:

- **£567,820** in designated funds, which are expected to be largely spent down in the immediate future years
- **£12,960** in restricted funds
- **£718,781** in non-designated funds, with a clear plan now in place to designate and maximise these funds for our charitable activities from 2025 onwards (see [page 31](#))

More information on each fund is provided in our financial statements, starting on [page 37](#).

The total income for the year was **£656,551** (2023: **£511,349**). Our total investment gains were **£50,981** (2023: £22,290). The overall surplus for the year was **£239,063** (2023: £230,787).

The surplus is largely driven by two substantial gifts from two individuals in the TSC community who kindly included the TSA in their Wills. The designated funds have been broadly treated as an endowment, invested with professional advisers to provide a resource which supports the TSA in delivering its charitable objectives. This enables the TSA to:

- Fund or co-fund out of capital, even at short notice, major medical research projects determined by Trustees and the TSC Research Volunteer Network as crucial to improving TSC care
- Fund charitable activities out of investment income, helping to secure the future of the charity and to provide continuing support to the TSC community

We anticipate that **our strategic period for 2025 – 2027 will include managed, considered deficit years with the goal of returning to a small surplus by 2028**. This is in contrast to previous deficit periods, where covering the costs was in danger of becoming unmanageable. This is why sustainability is a significant focus of our charity's strategy for 2025 – 2027, which includes ambitious projects and vital ongoing activities to improve the lives of the TSC community now and in the future.

The TSA Board of Trustees has a clear and transparent plan to maximise the potential of our surplus, stewarding funds in a way that's sustainable and sensible.

The plan encourages financial resilience, helping us to achieve what we want to do in our strategic plan for 2025 – 2027. The alternative option, to increase expenditure to levels unsustainable beyond several years, would risk the long-term financial viability of the charity and everything that we achieve for the TSC community.

Read about this plan on [page 30](#).



Non-designated reserves and reserves policy

The TSA Board of Trustees has agreed to hold up to the equivalent of six months of running costs as free reserves. This is around **£222,000** and allows the charity to cover operating deficits and unexpected drops in income, while ensuring liquidity for ongoing costs. We also hold designated funds in order to deliver vital projects aligned with our ambitious strategic plan. This overall approach strengthens the TSA's resilience and grows our services to meet the unmet needs of our community, while ensuring funds remain readily available to support key activities that help us achieve our vision and mission.

This reserve level has been determined based upon analysis of cash flow requirements from previous financial years and estimated cash flow requirements for forecasted years of the charity's current strategic plan. All of this is based on pre-planned activities. Reserves are spread across cash, savings and investment products. Where and how capital is held is determined by how these funds are intended to be used, to ensure liquidity and sound financial management.

If the value of our free reserves falls below three months of operating costs, the TSA Board of Trustees will consider reallocating designated funds which were originally intended for other activities and projects or, as a final resort, drawing from the endowment-like funds (see later sections). This would ensure the charity's long-term survival and stability.



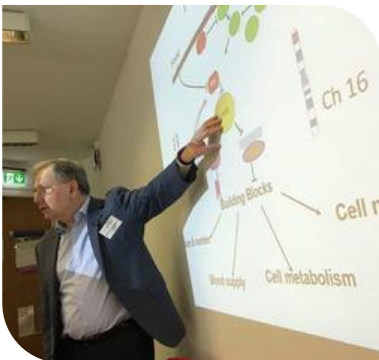
The event was fabulous and very informative.

- Teacher who completed TSA training course



The process was so easy from start to finish the conversation was so easy and I was treated like part of a big family

- TSA Support Line user



Investment policy

The TSA Board of Trustees has decided on a clear plan for the ongoing investment and management of the TSA's reserves to ensure long-term financial resilience, achieved while meeting the planned objectives of our current strategy. The TSA's investment policy follows best practice from the Charity Investment Governance Principles Guide.

A total returns strategy has been adapted as part of our investment planning. As of 2025, the 'endowment-like' designated funds are held within investment products currently managed by our investment partner, Brewin Dolphin. 27% of funds held with Brewin Dolphin are in cash products. 71% are in other investments, and the remaining 2% in other assets. This is done under a discretionary investment mandate.

Environment, Social and Governance factors have been considered in our investment policy. This has resulted in a restriction on investing in funds related to tobacco.

Our investment objective is to maximise total returns over the longer term and to provide a stable level of income to be generated with a medium level of risk. The level of risk applies to the portfolio as a whole, not to individual stocks.

In the year ended 31 December 2024, investment income from the year was **£15,969**, with an increase in the market value of those investments of **£50,981**. Over the longer term, our investment managers have consistently outperformed the benchmark. Their performance continues to be kept under review and Trustees have an annual review meeting with them. The Trustees have agreed a formal investment policy reflecting the investment objectives.



OUR FINANCIAL PLANS FOR THIS STRATEGIC PERIOD

As of Q3 / Autumn 2025, the TSA's fund allocation aims to be the following. This plan, agreed by the TSA Board of Trustees, is in-keeping with our constitution:

- **Non-designated funds (free reserves) (£214,000).** Equivalent to approximately 6 months running costs. At a sufficient level agreed by trustees, forming our reserves so we are financially stable and resilient, and to cover potential wind-up costs. These funds can be used at the discretion of the Board of Trustees towards our charitable aims and objectives
- **Designated funds (£135,000).** For major projects in our strategic plan for 2025 – 2027, with the allocation reflecting the business plan for the year. More details shared below
- **Restricted funds (£58,200).** For major projects within our latest strategic plan for 2025 – 2027, that we have gratefully received restricted funding to undertake
- **'Endowment-like' funds for vital ongoing activities (£920,000).** Providing some of the services and projects in our latest strategic plan that unlikely to receive funding elsewhere. 'Endowment-like' means we give a commitment to sensibly invest this fund so that the interest (income) can be used to improve lives in the TSC community

The 'Endowment-like' funds have been made possible thanks to the historical and recent gifts in Wills that we received from two kind individuals. **Although the projects within these funds are vital to improving the lives of people in the TSC community, it is unlikely that they could be funded from external funders or providers.** These projects include funding seedcorn TSC research grant rounds, led directly by the views of the TSC community, and benevolent grants to support those in the TSC community who are facing financial crisis.

Designated funds explained

We have identified a series of major projects that have been allocated designated funding as part of our strategy for 2025 -2027. Further details on these projects is in our Strategy Implementation Plan which demonstrates the charity's ambition to invest funds to grow our service offering for the TSC community. Projects include, but are not limited to:

- **Major TSC research projects**
 - All research funding decisions are made in partnership with the TSC Research Committee and the TSA Research Volunteer Network (ensuring patient and public involvement and engagement)
- **A new TSA website**
 - The existing website is now out of date and requires a much-needed update to ensure that we continue to have an accessible and impactful resource
- **TSA community events, including regional peer-support opportunities**
 - To ensure that both Outlook and Big Day events can take place in 2025, with both being significant costs to the TSA
 - A further pilot of regional peer-led events, allowing people to connect more often
- **TSC medical professional events and resources**
 - These events drive best practice in TSC care and management forward, providing specialist and non-specialist clinicians the opportunity to come together to discuss TSC
 - Specialist CPD-accredited medical training for clinicians less familiar with TSC

Designated projects are reviewed every 12 months, based on the strategic plan and period.

‘Endowment-like’ funds for ongoing activities explained

These designated funds are treated like an endowment. This means that we retain the capital but spend the income, allowing us to self-fund some vital activities from our strategic plan, for current and future beneficiaries, in a sustainable manner. Selected activities will be in areas that are incredibly important to our vision and mission. These activities would be unlikely to attract external funding, making it even more important that we have a way to self-fund them.

These projects are expected to continue year-on-year, allowing the TSA to access long-term funding for each activity. Not having these activities would have a significant negative impact on the TSC community. The projects in this fund are currently:

- **TSA seedcorn grant round**
 - Many areas of TSC research are undervalued and underfunded. Thanks to this fund, we can unlock research into areas of TSC unlikely to be funded by larger organisations
 - This **funds up to around 4 projects per year**, helping us to progress our understanding of TSC in new and important ways
 - Projects are assessed for suitability by the TSA Research Volunteer Committee
- **TSA benevolent grants**
 - TSC is a devastating condition that impacts all areas of daily life for individuals and their families, including significant financial poverty
 - The TSA Support Fund offers small but vital financial grants to people in the TSC community who are in financial hardship. The grants support a wide range of areas, from a new dishwasher to respite breaks. **Around 30 grants can be provided** every year
 - TSA travel bursaries give people the chance to attend TSA events that they otherwise could not afford, giving people an important opportunity to connect with others in the TSC community. The fund **enables up to 15 grants every year**

The decision to spend down any capital in this fund would only be considered under exceptional circumstances for either the charity or the TSC community. Such as:

- Charity reserves falling to below three months, as this may risk the charity's liquidity or ability to wind down if needed
- A significant opportunity to progress the charity's mission and values against our current strategy, such as vital research project that could change the course of TSC and unlikely to be funded elsewhere, or a very noteworthy support and information project

The TSA Board of Trustees has worked incredibly hard to develop a meaningful strategy to make best use of our funds. The Board is confident that the endowment-like funds will have a significant impact on the TSC community today and into the future.

This reserves and investment approach ensures the TSA can continue to expand vital services, invest in research and innovation, and deliver long-term impact for the TSC community.

GOVERNANCE AND OPERATIONS

In 2024, we began an ambitious project to make our governance and operations more data-driven. This work continues today, so we can be more evidence-based and values-based.

We've introduced new and improved ways to share feedback on how TSC affects people, most notably by proactively asking people more, whether in surveys, on the TSA Support Line or during events. We did this to better understand who in the TSC community we most often engage with and support. This includes gathering information on daily challenges with TSC, why people turn to the TSA, and broadly what life with TSC in the modern world is really like.

Gathering views more effectively will mean that the significant and ongoing projects we do for the TSC community will have a much bigger impact, as we can be more confident in the difference that they're making and what things the TSC community would like more focus on.

Risk management

Strategic planning and risk management are a central part of the ongoing work of the TSA's Board of Trustees and senior team. The TSA follows recommendations by the Charity Commission on risk management (document CC26).

The Trustees are also responsible for monitoring and overseeing the financial performance of the TSA, which includes:

- Reviewing and approving a business plan and accompanying budget each year
- Monitoring financial performance against the planned budget through regular finance reports which are scrutinised at each Board meeting
- Approving unbudgeted expenditure in line with the Board-approved scheme of delegation
- Regularly reviewing a three-year forecast to ensure that they are aware of the longer-term financial sustainability for the charity
- Overseeing the preparation of the statutory Annual Report and Accounts, ensuring compliance with accounting standards and the legal requirements
- Having responsibility for appointing and overseeing the external finance provider, independent examination and audit function
- Monitoring and reviewing the performance of the investment portfolio and reviewing and reappointing investment managers as appropriate
- Oversight of financial processes and policies

Risk register

A risk register of different categories (governance, operations, financial and external) is completed annually. It is regularly referred to by the TSA Board of Trustees and leadership team. It considers potential risks and their impact, existing prevention controls and how to further expand on these controls. The register discusses assurances that protect against risks, and horizon scans for future emerging trends. A scoring matrix calculates two figures: Each

risk's priority status with existing controls, and another figure with further measures taken. The following risks have been identified as the most significant to the charity:

- A Board of Trustees that lacks relevant skills or commitments. The TSA's policies in recruitment, training and succession planning protects against this risk
- Failure to achieve our financial plans. Stringent and ongoing budgets and forecasting helps to avoid this risk, as does proactive work to diversify income and monitor reserves
- Poor services outcomes. This would jeopardise us meeting our charitable objectives. Clarity in goals, a strategic plan and proactive support of the TSA team with training and growth opportunities reduces this risk

Having identified these risks, the Board of Trustees and senior leadership team now have clear plans and procedures in place to reduce the likelihood and impact of them.

Declarations of interest

All connected parties to the TSA are expected to make any potential declarations of interest as part of their ongoing activities with the charity. This includes TSA Trustees, the TSA team, our volunteers and supporters. Declarations are encouraged, in an open and transparent environment. For 2024, no shared potential conflicts were considered a major risk to the TSA or our community.

During TSA Board of Trustee Meetings, Trustees must make any new or existing potential declarations. Recent declarations include:

- Engagement with industry groups
- Involvement in a research steering group with an interest in TSC
- Sitting on an advisory panel for a TSC-focused clinical trial

The TSA receives donations, grants and sponsorship from a wide range of individuals and groups. This is vital to our operations and our work in improving the lives of people with TSC. The TSA ensures that our income management is guided by industry best practice, such as the guidance set out by the Charity Commission, National Council for Voluntary Organisation (NCVO) and the Association of Medical Research Charities (AMRC).

A significant area of support for the TSA is from pharmaceutical companies focused on TSC. Industry grants and sponsorships provide no influence, or shift focus, on TSA activities in any shape or form. In-line with best practice, the TSA also seeks multi-organisational sponsorship and grants for projects of interest to pharmaceutical groups. Pharmaceutical support for the TSA accounted for only around 12% of overall TSA income in 2024.

Going concern

The TSA Board of Trustees has reviewed strategic and financial risks of the charity. This has included the present and future risks as identified in the risk register, the budget projections for 2025, and the future financial forecasts. Having considered these areas, the TSA Board of Trustees considers that there are sufficient reserves held as of 18 August 2025 to manage those risks effectively for a period of at least 12 months. Accordingly, they continue to adopt the 'going concern' basis in preparing this annual report and its related accounts.

Monitoring our success and impact

We strongly encourage the TSC community to provide formal and informal feedback to us about our work and impact. This includes through surveys, focus groups and all other discussions with us. Feedback is regularly analysed by the TSA Board of Trustees and senior leadership team, with this information used to assess our effectiveness and progress against our strategic plan.

It is especially important to us to understand what we can do better and what are the most pressing challenges for the TSC community, so that we can tailor our work and have the biggest impact possible. For example, previous feedback indicated that additional opportunities to meet with others face-to-face would be beneficial, which led us to adapt our focus for TSA events.

The TSA Board of Trustees and senior leadership team meet on a regular basis to monitor the current year's business plan and planned goals against the wider strategy for 2025 – 2027. This helps to ensure that everything we do is aligned with our overarching aims and mission. To ensure that we are always working towards the aims and objectives of our latest strategy, a continually updated 'Results Framework tracker' is used to measure our work, including Key Performance Indicators (KPIs), potential barriers and means of achieving these aims.

For financial reporting, levels of liquidity, capital, interest and funds are continually monitored by TSA senior leadership and our investment partners. The TSA Treasurer and senior leadership team meet monthly to discuss the financial status of all funds as well as opportunities for future growth and investment to improve the lives of the TSC community.



In 2025, some of the things we plan to do are:

- Launch a special 'TSA Voices' feedback group, where people in the group will be asked to share their experiences or thoughts on specific projects or ideas that we have
- Introduce more ambitious feedback mechanisms, to tell us what we're doing well and could be improved
- Explore ways to reach and support a more diverse audience within the TSC community, such as those who we might not connect with right now

FINANCIAL REPORT 2024

Independent auditor's report

We have audited the financial statements of The Tuberous Sclerosis Association (the 'charity') for the year ended 31 December 2024 which comprise the Statement of financial activities, the Balance sheet, the Statement of cash flows and the related notes, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- Give a true and fair view of the state of the Charity's affairs as at 31 December 2024 and of its incoming resources and application of resources, including its income and expenditure for the year then ended
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- Have been prepared in accordance with Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and in other respects the requirements of the Charities Act 2011

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors' responsibilities for the audit of the financial statements section of our report. We are independent of the Charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the United Kingdom, including the Financial Reporting Council's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the Annual report other than the financial statements and our Auditors' report thereon. The Trustees are responsible for the other information contained within the Annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon. Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- The information given in the Trustees' report for the financial year for which the financial statements are prepared is consistent with the financial statements.
- The Trustees' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of our knowledge and understanding of the Charity and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' report.

We have nothing to report in respect of the following matters in relation to which Companies Act 2006 requires us to report to you if, in our opinion:

- Adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- The financial statements are not in agreement with the accounting records and returns; or
- Certain disclosures of Trustees' remuneration specified by law are not made; or
- We have not received all the information and explanations we require for our audit; or
- The Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the Trustees' report and from the requirement to prepare a strategic report

Responsibilities of Trustees

As explained more fully in the Trustees' responsibilities statement, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the Charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the Charity or to cease operations, or have no realistic alternative but to do so.

Auditors' responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditors' report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Our audit procedures have reviewed for evidence of management override, any ongoing legal cases, completeness of related party transactions, as well as on ongoing consideration of fraud and irregularities during the whole audit process.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our Auditors' report.

Other matters

Tuberous Sclerosis Association did not require an audit in the previous year. Therefore, the comparative figures are unaudited. Sufficient appropriate audit evidence that the opening balances do not contain misstatements that materially affect the current period's financial statements has been obtained.

Use of our report

This report is made solely to the Charity's trustees, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the Charity's trustees those matters we are required to state to them in an Auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity and its trustees, as a body, for our audit work, for this report, or for the opinions we have formed.

Laura Waycott FCA (Senior Statutory auditor). For and on behalf of Griffin Accountancy
Courtenay House
Pynes Hill

Exeter
EX2 5AZ

Date: 26 September 2025



Statement of Financial Activities including income and expenditure account

For the year ended 31 December 2024

		Unrestricted funds	Restricted funds	Total	Unrestricted funds	Restricted funds	Total
	Notes	2024 £	2024 £	2024 £	As restated 2023 £	2023 £	As restated 2023 £
Income from:							
Donations and legacies	3	614,432	7,350	621,782	392,577	90,547	483,124
Charitable activities	4	2,105	-	2,105	2,666	-	2,666
Investments	5	32,664	-	32,664	25,559	-	25,559
Total income		649,201	7,350	656,551	420,802	90,547	511,349
Expenditure on:							
Raising funds	6	153,957	-	153,957	84,073	-	84,073
Charitable activities	7	229,575	84,937	314,512	218,779	-	218,779
Total expenditure		383,532	84,937	468,469	302,852	-	302,852
Net gains/(losses) on investments		50,981	-	50,981	22,290	-	22,290
Net income/(expenditure) and movement in funds		316,650	(77,587)	239,063	140,240	90,547	230,787
Reconciliation of funds:							
Fund balances at 1 January 2024		969,951	90,547	1,060,498	829,711	-	829,711
Fund balances at 31 December 2024		1,286,601	12,960	1,299,561	969,951	90,547	1,060,498

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

Balance sheet

As at 31 December 2024


		2024		2023 As restated	
	Notes	£	£	£	£
Fixed assets					
Tangible assets	15		2,708		-
Investments	16		706,437		660,307
			<u>709,145</u>		<u>660,307</u>
Current assets					
Debtors	17	24,766		169,873	
Cash at bank and in hand		594,532		249,860	
		<u>619,298</u>		<u>419,733</u>	
Creditors: amounts falling due within one year	18				
		<u>(28,882)</u>		<u>(19,542)</u>	
Net current assets			590,416		400,191
Total assets less current liabilities			<u>1,299,561</u>		<u>1,060,498</u>
The funds of the Charity					
Restricted income funds	21		12,960		90,547
Unrestricted funds	22		1,286,601		969,951
			<u>1,299,561</u>		<u>1,060,498</u>

The entity was entitled to exemption from audit under section 477 of the Companies Act 2006. The members have not required the entity to obtain an audit for the year in question in accordance with section 476 of the Companies Act 2006. However, an audit is required in accordance with section 144 of the Charities Act 2011.

The Trustees acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and preparation of financial statements.

The financial statements have been prepared in accordance with the provisions applicable to entities subject to the small companies regime.

The financial statements were approved by the trustees on 26 September 2025.



Simon James (Treasurer, Tuberous Sclerosis Association)

Statement of cash flows

For the year ended 31 December 2024

		2024		2023	
	Notes	£	£	As restated	£
Cash flows from operating activities					
Cash generated from/(absorbed by) operations	25		310,618		(51,231)
Investing activities					
Purchase of tangible fixed assets		(3,461)		-	
Purchase of investments		(166,899)		(165,929)	
Proceeds from disposal of investments		171,750		170,619	
Investment income received		32,664		25,559	
Net cash generated from investing activities			34,054		30,249
Net cash generated from financing activities			-		-
Net increase/(decrease) in cash and cash equivalents			344,672		(20,982)
Cash and cash equivalents at beginning of year			249,860		270,842
Cash and cash equivalents at end of year			594,532		249,860

Notes to the financial statements

For the year ended 31 December 2024

1 Accounting policies

Charity information

The Tuberous Sclerosis Association is a charity and company limited by guarantee, incorporated in England and Wales. The registered office is Courtenay House, Pynes Hill, Exeter, EX2 5AZ.

1.1 Accounting convention

The financial statements have been prepared in accordance with the Charity's governing document, the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)". The Charity is a Public Benefit Entity as defined by FRS 102.

The financial statements are prepared in sterling, which is the functional currency of the Charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, [modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value]. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the Charity.

1.4 Income

Income is recognised when the Charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the Charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the Charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

Entitlement to research conference income is on receipt of the booking fee from the delegate.

Investment income comprises dividends and interest receivable for the year. Dividends on equity securities are recorded as revenue on the ex-dividend date. Interest income is recognised as it accrues, taking into account the effective yield on the investment.

Notes to the financial statements (continued)

For the year ended 31 December 2024

1 Accounting policies

(Continued)

1.5 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably. Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure. Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

Amortisation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Database costs	Over estimated useful life
----------------	----------------------------

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% on reducing balance
Computers	4 years straight line

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

The company has a policy not to capitalise assets with a cost below £250.

1.7 Fixed asset investments

Fixed asset investments are initially measured at transaction price excluding transaction costs, and are subsequently measured at fair value at each reporting date. Changes in fair value are recognised in net income/(expenditure) for the year. Transaction costs are expensed as incurred.

1.8 Impairment of fixed assets

At each reporting end date, the Charity reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.9 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

Notes to the financial statements (continued)

For the year ended 31 December 2024

1 Accounting policies

(Continued)

1.10 Financial instruments

The Charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments. Financial instruments are recognised in the Charity's balance sheet when the Charity becomes party to the contractual provisions of the instrument. Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the Charity's contractual obligations expire or are discharged or cancelled.

1.11 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received. Termination benefits are recognised immediately as an expense when the Charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

1.12 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

Notes to the financial statements (continued)

For the year ended 31 December 2024

2 Critical accounting estimates and judgements

In the application of the Charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates. The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

3 Income from donations and legacies

	Unrestricted funds	Restricted funds	Total	Unrestricted funds As restated 2023	Restricted funds 2023	Total As restated 2023
	2024 £	2024 £	2024 £	2023 £	2023 £	2023 £
Donations and gifts	277,373	-	277,373	155,603	90,547	246,150
Legacies	196,986	-	196,986	147,000	-	147,000
Grants	140,073	7,350	147,423	89,974	-	89,974
	<u>614,432</u>	<u>7,350</u>	<u>621,782</u>	<u>392,577</u>	<u>90,547</u>	<u>483,124</u>

4 Income from charitable activities

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Other trading activities		
Christmas cards and other sales	1,760	2,225
Training income		
Training income	345	441
	<u>2,105</u>	<u>2,666</u>

Notes to the financial statements (continued)

For the year ended 31 December 2024

5 Income from investments

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Income from listed investments	15,969	18,302
Interest receivable	16,695	7,257
	<u>32,664</u>	<u>25,559</u>

6 Expenditure on raising funds

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Fundraising and publicity		
Seeking donations, grants and legacies	5,926	2,054
Staging fundraising events	6,206	-
Other fundraising costs	14,532	62
Staff costs	110,199	66,282
Depreciation and impairment	405	-
Support costs	11,837	7,417
	<u>149,105</u>	<u>75,815</u>
Investment management	<u>4,852</u>	<u>8,258</u>
Total costs	<u>153,957</u>	<u>84,073</u>

Notes to the financial statements (continued)

For the year ended 31 December 2024

7 Expenditure on charitable activities

	Research 2024 £	Family Care and Support 2024 £	Total 2024 £	Research 2023 £	Family Care and Support 2023 £	Total 2023 £
Direct costs						
Depreciation and impairment	174	174	348	-	-	-
Subscriptions	819	1,643	2,462	1	-	1
Travel & Communications	887	69	956	-	-	-
IT & GDPR Services	915	10,068	10,983	871	2,824	3,695
Marketing & Media	73	73	146	-	-	-
Professional fees	-	900	900	-	500	500
Scan	2,640	-	2,640	-	10,332	10,332
Big Day	119	10,954	11,073	-	7,985	7,985
Training	541	7,603	8,144	2,229	2,014	4,243
Outlook events	645	1,935	2,580	575	1,726	2,301
Consultancy	-	5,600	5,600	-	-	-
	<u>6,813</u>	<u>39,019</u>	<u>45,832</u>	<u>3,676</u>	<u>25,381</u>	<u>29,057</u>
Grant funding of activities (see note 8)	36,934	4,900	41,834	(24,592)	9,300	(15,292)
Share of support and governance costs (see note 9)						
Support	104,378	112,171	216,549	88,117	112,791	200,908
Governance	5,136	5,161	10,297	2,053	2,053	4,106
	<u>153,261</u>	<u>161,251</u>	<u>314,512</u>	<u>69,254</u>	<u>149,525</u>	<u>218,779</u>
Analysis by fund						
Unrestricted funds	74,974	154,601	229,575	69,254	149,525	218,779
Restricted funds	78,287	6,650	84,937	-	-	-
	<u>153,261</u>	<u>161,251</u>	<u>314,512</u>	<u>69,254</u>	<u>149,525</u>	<u>218,779</u>

Notes to the financial statements (continued)

For the year ended 31 December 2024

8 Grants payable

	Research 2024 £	Family Care and Support 2024 £	Total 2024 £	Research 2023 £	Family Care and Support 2023 £	Total 2023 £
Grants to institutions:						
University of Bristol NHS Foundation Trust - Randomised Controlled Trial of ACT in TSC	6,171	-	6,171	-	-	-
University College London - The TSC1 and TSC2 Variation Databases	-	-	-	(226)	-	(226)
Institute of Medical Genetics, Cardiff	-	-	-	(1,370)	-	(1,370)
Research Department of Genetics, University College London	-	-	-	(513)	-	(513)
Epilepsy Research Institute UK	27,617	-	27,617	(22,483)	-	(22,483)
University of Manchester, Faculty of Life Sciences	(224)	-	(224)	-	-	-
Whitehead Institute	(185)	-	(185)	-	-	-
Cardiff University	(625)	-	(625)	-	-	-
Cardiff University	(620)	-	(620)	-	-	-
Institute of Psychiatry Psychology	(67)	-	(67)	-	-	-
Cardiff University	(65)	-	(65)	-	-	-
Other	4,932	-	4,932	-	-	-
	<u>36,934</u>	<u>-</u>	<u>36,934</u>	<u>(24,592)</u>	<u>-</u>	<u>(24,592)</u>
Grants to individuals	-	4,900	4,900	-	9,300	9,300
	<u>36,934</u>	<u>4,900</u>	<u>41,834</u>	<u>(24,592)</u>	<u>9,300</u>	<u>(15,292)</u>

Research Grants are awarded on an annual basis and are only renewed after an annual review. In accordance with the SORP, only the first year of the grant is charged against the relevant fund up to the committed amount of the grant. Negative balances represent the unclaimed elements of grants previously awarded, which have now expired.

Notes to the financial statements (continued)

For the year ended 31 December 2024

9 Support costs allocated to activities

	2024 £	2023 £
Staff costs	198,065	177,220
Staff training	-	299
Accommodation and room hire	-	(5,146)
Travel & Communications	927	(726)
Subscriptions	1,700	5,503
Accountancy	5,460	5,040
Sundries	5,560	5,293
IT and GDPR services	12,373	13,963
Insurance	2,693	5,540
Conference	-	1,339
Chief executive expenses	1,608	-
Governance costs	16,223	6,160
	<u>244,609</u>	<u>214,485</u>
Analysed between:		
Fundraising	17,763	9,471
Research	109,514	90,170
Family Care and Support	117,332	114,844
	<u>244,609</u>	<u>214,485</u>

10 Net movement in funds

	2024 £	2023 £
The net movement in funds is stated after charging/(crediting):		
Fees payable to the charity's auditor:		
- For the audit (2023 Independent Examination) of the charity's financial statements	6,900	1,800
- For other assurance services	-	1,920
Depreciation of owned tangible fixed assets	753	-
	<u>7,653</u>	<u>3,720</u>

11 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the Charity during the year. No trustee expenses were incurred during the year (2023: £Nil).

12 Employees

The average monthly number of employees during the year was:

	2024	2023
Fundraising	5	2
Family Support and Communications	2	4
Research	2	2
Total	<u>9</u>	<u>8</u>

Notes to the financial statements (continued)

For the year ended 31 December 2024

12 Employees**(Continued)**

Employment costs	2024	2023
	£	£
Wages and salaries	269,360	216,096
Social security costs	21,961	16,718
Other pension costs	16,943	10,688
	<u>308,264</u>	<u>243,502</u>

There were no employees whose annual remuneration was more than £60,000.

Remuneration of key management personnel

The remuneration of key management personnel was as follows:

	2024	2023
	£	£
Aggregate compensation	<u>116,600</u>	<u>105,000</u>

13 Gains and losses on investments

	Unrestricted funds	Unrestricted funds
	2024	2023
	£	£
Gains/(losses) arising on:		
Revaluation of investments	<u>50,981</u>	<u>22,290</u>

14 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

15 Intangible fixed assets

	Computers
	£
Cost	
At 1 January 2024 and 31 December 2024	<u>19,624</u>
Amortisation and impairment	
At 1 January 2024 and 31 December 2024	<u>19,624</u>
Carrying amount	
At 31 December 2024	<u>-</u>
At 31 December 2024	<u>-</u>

Notes to the financial statements (continued)

For the year ended 31 December 2024

16 Tangible fixed assets

	Fixtures and fittings £	Computers £	Total £
Cost			
At 1 January 2024	1,135	-	1,135
Additions	-	3,461	3,461
	<hr/>	<hr/>	<hr/>
At 31 December 2024	1,135	3,461	4,596
	<hr/>	<hr/>	<hr/>
Depreciation and impairment			
At 1 January 2024	1,135	-	1,135
Depreciation charged in the year	-	753	753
	<hr/>	<hr/>	<hr/>
At 31 December 2024	1,135	753	1,888
	<hr/>	<hr/>	<hr/>
Carrying amount			
At 31 December 2024	-	2,708	2,708
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

Notes to the financial statements (continued)

For the year ended 31 December 2024

17 Fixed asset investments

	Listed investments £	Total £
Cost or valuation		
At 1 January 2024	660,307	660,307
Additions	334,829	334,829
Valuation changes	50,981	50,981
Disposals	(339,680)	(339,680)
At 31 December 2024	706,437	706,437
Carrying amount		
At 31 December 2024	706,437	706,437
At 31 December 2023	660,307	660,307

Investments at fair value comprise:

	2024 £
Global Bonds	69,594
UK Bonds	44,600
Developed Asia ex. Japan Equities	44,579
Developed Europe ex. UK Equities	30,114
Emerging Equities	7,250
Global Equities	41,244
Japan Equities	21,233
North American Equities	240,225
UK Equities	133,963
Absolute Return	7,068
Global Property	16,974
Gold	13,352
Other Alternatives	20,902
Cash	15,339
	706,437

18 Debtors

	2024 £	2023 £
Amounts falling due within one year:		
Other debtors	3,415	5,471
Prepayments and accrued income	21,351	164,402
	24,766	169,873

Notes to the financial statements (continued)

For the year ended 31 December 2024

19 Creditors: amounts falling due within one year

	2024 £	2023 As restated £
Other taxation and social security	6,091	5,263
Trade creditors	3,568	8,238
Other creditors	1,999	1,482
Accruals and deferred income	17,224	4,559
	<u>28,882</u>	<u>19,542</u>

20 Retirement benefit schemes

	2024 £	2023 £
Defined contribution schemes		
Charge to profit or loss in respect of defined contribution schemes	16,943	10,688
	<u>16,943</u>	<u>10,688</u>

The Charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the Charity in an independently administered fund.

At 31st December 2024 £1,999 (2023 - £1,428) was payable to the fund and is included within creditors.

21 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 January 2024 £	Incoming resources £	Resources expended £	At 31 December 2024 £
Research	46,047	-	(33,787)	12,260
Sponsored events	44,500	-	(44,500)	-
Support activities	-	7,350	(6,650)	700
	<u>90,547</u>	<u>7,350</u>	<u>(84,937)</u>	<u>12,960</u>
Previous year:	At 1 January 2023 £	Incoming resources £	Resources expended £	At 31 December 2023 £
Research	-	46,047	-	46,047
Sponsored events	-	44,500	-	44,500
	<u>-</u>	<u>90,547</u>	<u>-</u>	<u>90,547</u>

Notes to the financial statements (continued)

For the year ended 31 December 2024

21 Restricted funds

(Continued)

A description of the purpose of the restricted funds is given below:

- Research - to enable, or directly fund, research into all aspects of TSC from a range of researchers and institutions. Including, but not limited to: Diagnosis, treatment and management of TSC; everyday challenges of TSC; and living well with TSC
- Sponsored events: A wide range of events, virtual and in-person, for the TSC community. This includes but not limited to: People directly living with TSC; carers and loved ones of people with TSC; and professionals on the condition, such as clinical, health, education and social care professionals
- Support activities: Actions and projects related to supporting people affected by TSC. This included but not limited to: People and families newly diagnosed with TSC; emotional and wellbeing support; certified medical information about TSC; ongoing support for people's daily lives with TSC

22 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 January 2024	Incoming resources	Resources expended	Gains and losses	At 31 December 2024
	£	£	£	£	£
Designated Endowment Fund	567,820	-	-	-	567,820
General funds	402,131	649,201	(383,532)	50,981	718,781
	<u>969,951</u>	<u>649,201</u>	<u>(383,532)</u>	<u>50,981</u>	<u>1,286,601</u>
Previous year:	At 1 January 2023	Incoming resources	Resources expended	Gains and losses	At 31 December 2023
		As restated	As restated		As restated
	£	£	£	£	£
Designated Endowment Fund	529,711	18,302	(2,483)	22,290	567,820
General funds	300,000	402,500	(300,369)	-	402,131
	<u>829,711</u>	<u>420,802</u>	<u>(302,852)</u>	<u>22,290</u>	<u>969,951</u>

23 Analysis of net assets between funds

	Unrestricted funds 2024	Restricted funds 2024	Total
	£	£	2024 £
At 31 December 2024:			
Tangible assets	2,708	-	2,708
Investments	706,437	-	706,437
Current assets/(liabilities)	577,456	12,960	590,416
	<u>1,286,601</u>	<u>12,960</u>	<u>1,299,561</u>

Notes to the financial statements (continued)

For the year ended 31 December 2024

23 Analysis of net assets between funds

(Continued)

	Unrestricted funds 2023 As restated £	Restricted funds 2023 £	Restricted funds 2023 As restated £
At 31 December 2023:			
Investments	660,307	-	660,307
Current assets/(liabilities)	309,644	90,547	400,191
	<u>969,951</u>	<u>90,547</u>	<u>1,060,498</u>

24 Related party transactions

There were no disclosable related party transactions during the year (2023 - none).

25 Cash generated from/(absorbed by) operations

	2024 £	2023 As restated £
Surplus for the year	239,063	230,787
Adjustments for:		
Investment income recognised in statement of financial activities	(32,664)	(25,559)
Fair value gains and losses on investments	(50,981)	(22,290)
Depreciation and impairment of tangible fixed assets	753	-
Movements in working capital:		
Decrease/(increase) in debtors	145,107	(166,487)
Increase/(decrease) in creditors	9,340	(67,682)
Cash generated from/(absorbed by) operations	<u>310,618</u>	<u>(51,231)</u>

26 Analysis of changes in net funds

The Charity had no material debt during the year.

27 Prior year adjustment

The following prior year adjustments have been made:

- An accrual for £147,000 of legacy income
- A reversal of an accrued grant dispersal of £22,483
- A £2,721 adjustment to agree the year-end cash at bank figure

The allocation of some of the costs was reviewed and amended during the year. As such, there has been some reallocation of costs compared to the 2023 published accounts, however there has been no change to the overall result in respect of this.

Notes to the financial statements (continued)

For the year ended 31 December 2024

28 Prior period adjustment**(Continued)****Changes to the balance sheet****At December 2023**

	As previously reported £	Adjustment £	As restated £
Current assets			
Debtors due within one year	22,873	147,000	169,873
Bank and cash	247,139	2,721	249,860
Creditors due within one year			
Other creditors	(36,762)	22,483	(14,279)
	<u>888,294</u>	<u>172,204</u>	<u>1,060,498</u>
Net assets			
	<u>888,294</u>	<u>172,204</u>	<u>1,060,498</u>
Income funds			
Restricted funds	90,547	-	90,547
Unrestricted funds	797,747	172,204	969,951
	<u>888,294</u>	<u>172,204</u>	<u>1,060,498</u>
Total equity	<u>888,294</u>	<u>172,204</u>	<u>1,060,498</u>

Changes to the profit and loss account**Period ended December 2023**

	As previously reported £	Adjustment £	As restated £
Donations and legacies	335,905	147,219	483,124
Investments	23,057	2,502	25,559
	<u>241,262</u>	<u>(22,483)</u>	<u>218,779</u>
Charitable activities			
	<u>58,583</u>	<u>172,204</u>	<u>230,787</u>
Net movement in funds	<u>58,583</u>	<u>172,204</u>	<u>230,787</u>

We're here for everyone affected by TSC
only thanks to the **amazing people and
groups** who kindly provide us with
regular and one-off donations

Help us to continue to be here for you
and others, now and the future:

tuberous-sclerosis.org/donate

Switchboard:

0300 222 5737

admin@tuberous-sclerosis.org

TSA Support Line:

0808 801 0700

support@tuberous-sclerosis.org

Webchat (tuberous-sclerosis.org)

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