



Tuberous Sclerosis Association Annual report 2025



Annual report and financial statements for the year ended 31 December 2025
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 ended 31 December 2025.

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 (1039549) 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 5 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 financial statements can be found on **pages 8-9**.

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

Independent Examiner: 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.

Frances Elmslie

Dr Frances Elmslie (Chair of the Board of Trustees)

August 2026

Statement of Trustees' responsibilities

The trustees, who are also the directors of The Tuberous Sclerosis Association for the purpose of company law, are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (UK Generally Accepted Accounting Practice).

Company law requires 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 the incoming resources and application of resources, including the income and expenditure, of the charitable company for that year.

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

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the Charities SORP
- Make judgements and estimates that are reasonable and prudent
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in operation

The trustees are responsible for keeping adequate accounting records that 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 Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006. 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.



We're here for everyone in the TSC community
only thanks to **people like you.**

Give a regular donation to the TSA:
tuberous-sclerosis.org/donate



Cole's story	05
About the TSA: Our goals, values and public benefit	06
A message from our Chair and Chief Executives	07
Meet your TSA team	08
• Board of Trustees	08
• TSA team	10
• Volunteers and Ambassadors	11
Our strategic period for 2025 – 2027	12
What we achieved in 2025	13
• Support and information	13
• Communications and events	16
• Working with TSC professionals	18
• Research	19
• Campaigning and advocacy	25
• Fundraising	26
• Governance, strategy and sustainability	28
Money matters	29
• Where money was used in 2025	29
• Financial overview 2025	30
• Our plans for financial resilience	30
• Reserves policy	31
• Investment policy	31
• Designated Investment Fund explained	32
Risk and compliance	33
• Risk management	33
• Risk register	33
• Declarations of interest	34
• Monitoring our success and impact	34
Financial report 2025	35
• Independent examiner's report	35
• Financial statements and notes	37

Legal and admin information

Trustees

- Dr Stacey Bissell
- Annemarie Cotton
- Dr Frances Elmslie
- Simon James
- Dr Chris Kingswood
- Jane Rogers
- Sanjay Sethi
- Martin Short (resigned 27 November 2025)
- Maxine Smeaton (resigned 27 January 2026)

Secretaries

- Dr Pooja Takhar
- Luke Langlands

Charity numbers

- 1039549 (England & Wales)
- SC042780 (Scotland)

Registered address

The TSA, Courtenay House, Pynes Hill, Exeter, EX2 5AZ

Independent examiner

Griffin Accountancy

COLE'S STORY

Nicola Daykin is a nurse and mum to three kids. When Nicola and Glyn's son was diagnosed with TSC, the TSA was there to support the family

"Cole was diagnosed with TSC at seven months old. Initially, the doctor said he had reflux and said I was being a paranoid mother. But, then Cole started to have infantile spasms (seizures). Before long, we received the life-changing diagnosis of TSC. He now has to cope with epilepsy, autism, ADHD, sleep problems and behavioural issues.

While life is clearly tough for Cole, I also worry about the impact on my daughters, Myla and Alarna, and how it's going to affect their lives as they grow up. Out of necessity, Cole commands a great deal of our attention, and I know that the girls don't get enough of our time. The siblings of children with TSC really are unsung heroes and deserve so much recognition for the part they play and the sacrifices they have to make. Days out and holidays are very difficult, in terms of finding something that suits everyone. The girls are brilliant with Cole, but every day is a 'Cole day'.

Fortunately, Glyn and I have always had the TSA to support us as a family. When Cole was initially diagnosed, all we received from the hospital was a letter. **We've relied heavily on the TSA for the wealth of knowledge and expertise they've shared with us.** They've even helped us to access a specialist clinic in Liverpool, which meant that Cole could get the best treatment possible. **I know that without the help of the TSA, Cole's quality of life would be decidedly worse.** We also used to go to the TSA community days. I'll always remember the lovely sense of warmth and the positive atmosphere at these TSA events, at a time when we felt quite alone.

I'll always be thankful for the work of the TSA. For Cole, Myla, Alarna, Glyn, our wider family and everyone in the TSC community."



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 into all aspects of the causes, management and treatment of TSC
- **Campaigns.** Influencing public policy and awareness to ensure that people with TSC get the support they deserve
- **Professional development.** Expanding knowledge of and expertise in TSC across 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. This is demonstrated even by this annual report, which surpasses reporting requirements for the TSA 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's an opportunity to reflect on our work throughout 2025, as well as what we're doing in 2026 and beyond.

Highlights of what we've recently accomplished include:

- Restarting our innovative programme to fund early career researchers, with a focus on studies that are highly impactful but unlikely to be funded elsewhere
- Launching a new range of TSC resources and guides, helping to support people with TSC whether they're newly diagnosed or have been on the TSC journey for many years
- Having a major role in the development of TSC registries, a key next step in improving diagnosis, care and management of TSC now and in the future

You can read more about some of the things our team achieved in 2025 on pages **13 - 28**.

This report covers the first year of our strategic plan for 2025 - 2027. Although highly ambitious, we truly believe that this strategic plan is achievable and reflects what the TSC community should expect and certainly deserves.

A key area of our work for the last few years has been on strengthening financial resilience. It's an incredibly challenging time for charities that are the size of the TSA, meaning that this continues to be a key pillar of focus for us. This includes 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 **29 - 32**, and our 2025 financial statements start from page **37**.

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 clearly and easily show our work, its impact, and the foundations that underpin everything we do.

What 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 who supported and worked with us over the past 12 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

TSA Board of Trustees

Dr Frances Elmslie (Chair)

Frances is Clinical Lead for South West Thames Centre for Genomics, based at London St George's Hospital, as well as Clinical Director of the South East Genomic Medicine Service Alliance. Frances leads the team that delivers the 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. Dr Elmslie is also a Co-Investigator for the Rare Disease Node in mTOR pathway disorders.



Dr Frances Elmslie

Annemarie Cotton (Vice Chair)

Annemarie is a parent to a young adult daughter with TSC and has been involved with the TSA for the past 20 years. Annemarie 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. Simon 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:

- Dr Stacey Bissell (Assistant Professor)
- Dr Chris Kingswood (Consultant Nephrologist)
- Jane Rogers (Nurse)
- Sanjay Sethi (Investment Manager)
- Maxine Smeaton (Charity consultant)

Company secretaries: Luke Langlands and Dr Pooja Takhar.

In 2025, Martin Short stepped down from the TSA Board of Trustees. Martin had a longstanding position in the charity, holding various board roles across many years. We're very thankful for Martin's contributions, which have benefitted countless people in the TSC community. The TSA Board of Trustees are actively recruiting for new people to join the board.

Board members have a wide range of backgrounds and skills. Six out of seven TSA Trustees either have a lived experience or professional focus on TSC. This, alongside our ongoing engagement with the TSC community, ensures that we're steered by the views, needs and challenges of individuals, families and professionals in the TSC community.

The professional experience of the Board ensures a strong level of knowledge that is applicable and useful to the ongoing work of the TSA. Board members are also encouraged to take up training and development opportunities to increase their knowledge and expertise.

A skills audit of trustees is performed every 12 months, allowing the Board to identify knowledge or background gaps. This helps to inform the board as part of any recruitment of new Trustees. 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, to ensure that we never lose our direct and vital connection to those affected by the impact of TSC every day. Candidates are considered only if they can demonstrate that they may fill skills gaps identified within skills audits.

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

The TSA Board of Trustees formally meets four times a year, typically virtually. However, the Board engages on a much more regular basis with the senior TSA team, ensuring that we are meeting the aims and objectives of our strategic plan. This includes the Joint Chief Executives holding monthly meetings with the Chair and Treasurer separately, with a set agenda covering key topics and any issues that have arisen.

“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

“The TSA Support Line is outstanding. I can't thank the team enough”
- Person with TSC

“What helped most was how quickly you responded during a very stressful time and how seriously you took my son's situation”
- Parent of child with TSC



TSA leadership

The TSA 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 help to ensure that the charity is built on strong foundations that enable the greatest impact possible. However, **this wouldn't be possible without the wider TSA team, to whom both Pooja and Luke are very grateful.**



Dr Pooja Takhar

The wider and vital TSA team

The TSA is immensely proud of our small but incredibly impactful and valued team. The team is made up of 10 individuals (seven full-time equivalent staff) achieving everything that we do for the TSC community.

We encourage a working environment based on kindness, respect and understanding. The charity ensures that its team truly appreciates the impact of TSC on individuals and families, and commits to providing salaries that are competitive with similar sized organisations. The great effort of the TSA team is acknowledged and celebrated, internally and externally.

New TSA team members 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 we feel that this is the best way for people to have the biggest impact as quickly as possible.



Luke Langlands



The TSA is proud to support people with TSC. However, being part of TeamTSA can also sometimes mean dealing with challenging circumstances. We offer a working environment that prioritises mental and physical health for our team. This includes an Employee Assistance Programme, providing mental health support and financial advice so the TSA 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 volunteer for the TSA or those recruited to become TSA Ambassadors have a vital role in everything that we do and achieve for the TSC community. In 2025, we started the work of refreshing our volunteer and ambassador programme. This includes developing a new range of opportunities for people to have more active roles in our work, across support and information, research and advocacy. This refresh will continue in 2026 and beyond.

We ask people taking a more active role in our work to sign a TSA Volunteer and Ambassador Agreement. This provides clear guidelines and expectations on their voluntary role, setting out what volunteers and ambassadors can expect from the TSA and what activities they might be asked to do. Signing the agreement is a pledge for volunteers and ambassadors to uphold the standards of the TSA, and for the charity to provide volunteers and ambassadors with what they need in their roles.



OUR 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: "Help for today and a cure for tomorrow."

We're focusing on 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 TSC-Associated Neuropsychiatric Disorders (TAND). With TSC clinics, champion great care and services
- **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 what our research priorities are
- **Support and information.** Ensure that everyone affected by TSC can receive support and 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.



“

I felt listened to, understood and supported.

- Parent of child with TSC

”

WHAT WE ACHIEVED IN 2025

Support and information

TSA Support Line

In 2025, the TSA Support Line continued to be central to our support and information projects. The support line experienced higher demand than in 2024, with **316 enquiries** across telephone (**130**), email (**123**), webchat (**25**), social media (**7**), web form (**29**) and post (**2**).

“
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

Some of the common reasons people contacted the TSA Support Line in 2025:

1. Emotional support
2. The physical impact of TSC
3. The TSA Support Fund
4. Accessing specialist TSC clinics
5. New diagnoses of TSC
6. TSC-Associated Neuropsychiatric Disorders

In 2025, we received lots of enquiries about accessing Hyftor (topical sirolimus), a medicine to treat bumps and marks on the face called facial angiofibromas, which are caused by TSC. Although Hyftor is not yet approved for funding all across the UK, we were successful in achieving access to Hyftor for many individuals who might benefit from it.

A gold standard support line

Helplines Partnership is a national membership body for organisations with a support line. Every three years, they review support lines for their quality, set against a range of standards and expectations that they set. In 2025, we applied for reaccreditation of the TSA Support Line.

We successfully achieved re-accreditation with Helplines Partnership. The assessor praised our mental health support provision, overall policies and procedures, and our support team's deep understanding of TSC.



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 2025, we received 43 TSA Support Fund applications, with 26 eligible and approved for support. Reasons for requests included:

1. Part funding of respite breaks or day trips
2. Adaptations to the home or other safety equipment
3. Household items, such as beds and white goods
4. Disability pushchairs or wheelchairs
5. Outdoor and sensory play equipment



“
The process of contacting your support line was so easy from start to finish. I was treated like part of a big family”

- TSA Support Line user

In recent years, we've seen a rise in enquiries to the TSA Support Fund. At the same time, the length of our application process and the amount of information we asked for were becoming barriers, making it harder for people to apply and receive the support they urgently need.

In response, **we simplified our processes in 2025 and reduced the paperwork required to apply.** We hope these changes will **make it easier for people to seek support and help ease the pressure on those already managing very busy workloads.**

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

- TSA Support Fund user

Some of the things we plan to do in 2026 are:

- Launch WhatsApp on the TSA Support Line, making our support team more accessible and our support quicker for the TSC community
- Replace the TSA website with a new one, so it's easier to use and is more fitting for the needs of the TSA and TSC community
- Focus more on upskilling the TSA support team on broader aspects of TSC that can be challenging, such as access to benefits and housing

Updating our TSA Welcome Packs

The TSA Welcome Pack is a vital resource for people in the TSC community. For individuals and families who are newly diagnosed, the pack is a potential lifeline that provides an overview of all things TSC, to help with taking your first steps on the TSC journey. For others, it's an important reminder that you're never alone with the condition.

We were told by the TSC community that more resources aimed at explaining TSC to children, and other resources to help with managing TSC in everyday lives, would be useful. **This is why in 2025 we updated our TSA Welcome Packs, better reflecting and supporting the needs and challenges of the TSC community.**

In 2025, we sent 20 TSA Welcome Packs to UK households. At the time of writing, **we've already surpassed this number for 2026.**



Our new range of resources is now available as part of TSA Welcome Packs. As well as more things for children and everyday life, our new welcome packs include ways to track ongoing health visits, an updated introduction to TSC, more ways to support people with learning difficulties, and a TSC medical card to keep handy.

“**I'm so impressed. My query was passed to a clinician and answered within 24 hours**”
- TSA Support Line user

Communications and events

Keeping you updated

In 2025, we had a target to significantly grow our social media presence. This included a new approach to the content we create and making posts more accessible. From January - December 2025, content interactions rose a staggering **405% on Facebook and 100% on Instagram**. Facebook also increased in **visits (121%), link clicks (45%) and followers (129%)**, while Instagram delivered particularly high growth in **reach (621%) and visits (326%)**.

Our monthly newsletter is a bite-sized view of all things TSA and TSC, making it easier for people who are short on time to keep updated. Around **3,000** people received this newsletter in 2025.

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. In 2025, we held **14 virtual and in-person events**.

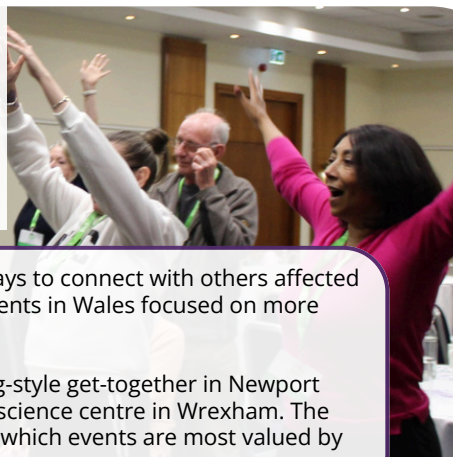
Outlook is our programme for adults with TSC. It's a way to make lifelong friends through a range of virtual and face-to-face opportunities, in an environment where being an adult with TSC is understood. **We welcomed 39 registrations for Outlook 2025**, held in Glasgow.

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 93 people register for Big Day 2025**, which took place in Reading.

The TSC community tell us that they want more simple ways to connect with others affected by the condition. In 2025, we launched a pilot series of events in Wales focused on more local and smaller get-togethers.

So far through the pilot, we've organised a coffee morning-style get-together in Newport and family visits to a farm in North Pembrokeshire and a science centre in Wrexham. The pilot will run throughout 2026, as we work to understand which events are most valued by the TSC community.

“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



“Very informative and engaging. It was good to talk about TSC with others”
- TSA event attendee

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

Showcasing the TSC community and the TSA

Many people have never heard of TSC or do not understand the huge impact that it has on individuals and families with the condition.

This is why in 2025 we commissioned two short films that we can use at third-party events and other wider opportunities. These films give us the opportunity to show the TSC community what our events are like and what to expect when attending them, as they were filmed at Big Day in 2025.



It's just wonderful to see all the community together.

Royal Chelsea Flower Show 2025

Landscape designers Jen Donnelly and Catherine Gibbon dedicated their Royal Chelsea Flower Show 2025 entry to the TSA, an incredible gesture that helped to raise awareness of TSC.

The beautiful garden, inspired by the need to find a place to breathe during challenging times, won a Gold award at the show! It was also visited by notable celebrities, including Sir David Suchet, Strictly... dancer Nadiya Bychkova and singer Alexandra Burke.

Jen and Catherine thought of the TSA, as Jen's son Alex has TSC.



Some of the things we plan to do in 2026 are:

- Reinvigorate our TSA Ambassador scheme, so that passionate people in the TSC community can represent the TSA at a range of events
- Continue with our pilot of local events in Wales
- Increase the digital focus of Outlook, our community of adults with TSC, so that more people can be involved across the UK
- Offer a special TSC Teens Art Club, making it possible for teenagers with TSC to come together creatively in a warm and open environment

Working with TSC professionals

A key part of our work 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 secretariat for the TSC Rare Disease Collaborative Network (RDCN), which brings together 23 TSC clinics across the UK. Now in its third year, the network enables clinical specialists to connect, share expertise, and strengthen best practice in TSC care. By promoting greater consistency in how TSC is diagnosed, treated and managed, the RDCN is helping to improve care for everyone in the TSC community, wherever they live in the UK.

A highlight of the TSC RDCN every year is the face-to-face meeting, held every September. In 2025, the meeting focused on first steps in updating the UK clinical guidelines for TSC. **41 professionals** registered for this event.

One significant benefit of the TSC RDCN is its regular virtual multidisciplinary team (MDT) meetings, allowing clinicians a space to discuss complex cases with other experts. As well as this, an annual TSC education session allows healthcare professionals to upskill on TSC.

All education-based events for the TSC RDCN are accredited for Continuing Professional Development (CPD) points, underlining their depth and impact for clinical professionals

First TSC clinical network meeting for nurses

TSC nurse specialists are at the heart of TSC care. It's only thanks to them that TSC clinics can operate.

We're proud to support TSC nurse specialists in any way that we can. **One suggestion was to host a face-to-face event exclusively for nurses, which we were delighted to do for the first time in 2025.**

The TSC Nurse Specialist Meeting 2025 took place in Birmingham, giving nurses the chance to connect with each other in a space especially for them. This results in better care and coordination of people with TSC. We plan to now host the meeting annually.



TSC clinicians are our valued allies

We do and achieve a lot in supporting TSC-focused professionals. However, this also works the other way around, with the TSA being incredibly thankful for the support that we receive from TSC clinicians.

In 2025, TSC specialist clinicians reviewed medical information that we produced for the TSC community. This helps ensure that all medical information we share with the TSC community is up-to-date, relevant and meaningful. We also consulted with TSC clinicians to help with many enquiries on the TSA Support Line.

Accredited TSC courses for professionals

The TSC community regularly tell us about the need for professionals unfamiliar with TSC to better understand the condition. Lots of professionals also get in contact with us directly about this challenge. This is why we run the world's first and only Continuing Professional Development (CPD) courses about TSC for education professionals and social care professionals.

In 2025, these courses were updated and improved, with more changes planned. **In 2025, 44 non-specialist professionals were upskilled on TSC through our training modules.**

100% of professionals agree that TSA training courses met their learning objectives

“

Fabulous. Very informative.”

- Teacher who completed TSA training course

“

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

- Teacher who completed TSA training course



Some of the things we plan to do in 2026 are:

- Once again be a key partner in updating the UK clinical guidelines for TSC, ensuring greater equality in TSC care
- Extend our CPD courses for non-specialist professionals to include medical professionals unfamiliar with TSC
- Create a more holistic support package for people with TSC, by encouraging TSC clinics to signpost to the TSC Support Line
- Grow the ongoing networking and knowledge-sharing we achieve with TSC clinics

Research

Launching the new TSA Research Strategy

In 2025, we **launched our new research strategy**, an important milestone for the TSA. The strategy was developed through a genuinely collaborative process and was co-designed with people affected by TSC and informed by leading clinicians and researchers.

Lived experience of TSC played a central role in developing our new research strategy, with input gathered through community ideas boards, ongoing conversations with individuals, families and caregivers, and wide-ranging engagement with the research community. This work was underpinned by a comprehensive review of recent scientific progress, enabling us to set a clear, informed direction for future research investment and ensuring that the priorities of the TSC community remain at the heart of everything we do.

Funding TSC research

As the only UK-wide charity dedicated solely to investing in TSC research, the TSA plays a vital role in advancing scientific understanding. In 2025, we committed over **£39,000** to research grants, supporting studies that improve the lives of people affected by TSC.

In 2025, the Board of Trustees reaffirmed its commitment to honouring all ongoing research obligations. To ensure continuity and stability across our research programme, the Board agreed to utilise the Designated Investment Fund to meet the costs of our active grants.

TSA Grant Round 2025/26

In 2025, **we launched the 2025/26 Grant Round, offering both seedcorn awards and a PhD studentship focused on a TSC registry**. Seedcorn research grants are early-stage funding awards designed to help researchers develop new projects, pilot studies, or international partnerships.

The remit for this round was shaped by the priorities set out in our new research strategy, ensuring that funded projects directly address unmet needs and the areas most important to the TSC community. Following a robust and extensive peer-review process, the TSA's Research Committee (RESCOM) recommended funding four seedcorn awards alongside the PhD studentship, continuing our commitment to nurturing early-stage ideas and supporting future TSC research leaders.



Our live grants for 2025

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.
Dr Liezl Schlebusch	University of Cape Town	Well-Beans for Caregivers Programme 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. Co-funded by TANDem Consortium.

Lead researcher	Institution	Research project
Ms Shoba Srivastava	University of Cape Town	TAND in India 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. Rigorous work by the TSA, as part of the funding application, confirmed that the research will not result in committed funds being used beyond the remit and focus of the research itself. Co-funded by TANDem Consortium.
Dr Stacey Bissell	University of Birmingham	Exploring Sleep experiences in people with TSC (e-Slept) 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. Co-funded by TANDem Consortium.

The TSA now has an innovative investment strategy that helps to enable new research into all areas of TSC. Crucially, the research that we fund is **focused on areas that the TSC community tell us are the most important**.

The projects we select are often funded through 'seedcorn grants', which largely enable important research that is unlikely to be funded elsewhere. Read more about this on **pages 20 and 32**.



Lead researcher	Institution	Research project
Dr Amanda Almacellas Barbanøj	University College London	Investigating new targets for TSC treatments 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. Co-funded by Epilepsy Research Institute UK.

TSC Research Volunteer Network

We believe that involving people in the TSC community in TSC research, called ‘Patient and Public Involvement and Engagement’ (PPIE), is vital in improving our understanding of TSC. Those affected are experts in their own experiences, and working with them ensures research focuses on what matters most and delivers real impact.

The TSC Research Volunteer Network now has **40 members**, including people with TSC, parents, carers and siblings. In 2025, they helped shape research by:

- Supporting project teams to refine protocols, lay summaries and outcome measures
- Providing letters of support and acting as co-applicants on multiple research bids (including MRC-funded grants and University of Birmingham schemes)
- Contributing to work on biomarkers, AI-supported rare epilepsy diagnostics and national clinical guideline updates

It is going to become increasingly important for those funding research into TSC to demonstrate that PPIE has been seriously considered and implemented. Although this is an ever-developing area of research, the TSA anticipated this while PPIE was in its infancy. The result is a well-established and highly impactful TSC Research Volunteer Network that will continue to make a real difference in TSC research.

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

International collaborations and influence

In 2025, the TSA strengthened its global research role at the International TSC Research Conference 2025, where we presented, led sessions and contributed to key scientific discussions. We also supported collaboration across related conditions through our role on the mTOR Pathway Diseases Node Advisory Board.

The TSA also helped develop a multi-country Marie Skłodowska-Curie Actions (MSCA) Doctoral Network application, ensuring lived experience is included in future PhD projects and securing our place as a named partner.

Our role in clinical trials and working with industry

One of the most important things the TSA does is work with partners in the pharmaceutical and medical industry so that new and innovative medicines and therapies can be developed for better TSC care. This continued in 2025, when we provided trusted pharmaceutical companies with insight into what life is like with TSC and supported the development of new potential treatments.

In 2025, we remained actively involved in clinical research. This included:

- Supporting two UK-based sites chosen for clinical trials
- Representing the TSC community on the EpiCom Clinical Trial Steering Committee
- TSA staff co-authoring a scientific paper showing how EpiCom happened
- Helping to secure funding for the 'Metformin in TSC' clinical trial, with the TSA supporting protocol development and ensuring the study reflects the needs of people affected by TSC



Campaigning and advocacy

Improving access to treatments and specialist care

The TSA works hard so that the voices, needs and expectations of the TSC community are heard clearly and acted upon across a range of opportunities.

In 2025, we represented the TSC community in the NHS funding review for Fenfluramine (Fintepla), used to treat seizures in Lennox–Gastaut syndrome, a condition that affects some people with TSC. The TSA was the only charity or community group who took the opportunity to be involved in the consultation, underlining the steps we take to improve TSC care.

Thanks to our involvement, the perspectives and lived experiences of people affected by TSC were genuinely considered, helping to place the TSC community at the centre of decisions that directly influence their health and wellbeing.

Fighting for the needs of the TSC community in national policy

The TSA plays an active role in shaping national thinking on issues central to TSC and the wider rare disease community, contributing to a broad range of expert workshops and consultations.

In 2025, our advocacy work included participation in high level discussions on the policy and political landscape for rare epilepsies, where the TSA provided insights that helped build a shared sector understanding of barriers to treatment and care. This work also informed follow-up activities led by UCB Pharma and Costello Medical.

The TSA strengthened its international advocacy profile through active participation in the 23rd Orphan Drugs and Rare Diseases Global Congress, a leading forum for rare disease research, policy and innovation. The congress provided an important platform to champion the needs of people with TSC, contribute to discussions on access to innovative therapies, and build strategic relationships to support the development of future treatments.

At a national level, we contributed to conversations on genomics, engaging in discussions on how advances in genomic technologies can accelerate the development of therapies for rare genetic conditions. The TSA also supported sector-wide calls for improved newborn screening, contributing to work led by the Specialised Healthcare Alliance in response to widespread concern among patient groups about delays in expanding heel prick screening panels.

Some of the things we plan to do in 2026 are:

- Advance TSC research and clinical knowledge by organising and funding another seedcorn grant round
- Support the launch of the TAND Toolkit, a highly anticipated app to help support research into TSC-Associated Neuropsychiatric Disorders (TAND)
- Further develop the TSC Research Volunteer Network, ensuring people affected by TSC can meaningfully shape research priorities, study design, and advocacy initiatives
- Take an active role in upcoming clinical trials for potential TSC medicines
- Create new opportunities for the TSC community to better connect with researchers, in ways that help people to understand the amazing new studies that the TSA funds

Fundraising

We're incredibly fortunate to have a dedicated and generous community of supporters and fundraisers who enable us to be there for everyone affected by TSC. Our heartfelt thanks to each and every one of you who fundraised or donated to us in 2025.

London Marathon 2025

The iconic London Marathon is one of our flagship challenge events, giving us a major opportunity to fundraise and also raise awareness of TSC. 2025's event welcomed seven brave TSA runners, raising an incredible **£23,000**.

Challenge events

The London Marathon is just one of the challenges that dedicated fundraisers take part in on our behalf. In 2025, amazing individuals and groups walked, ran, swam, skydived and took part in countless other heroic activities to support the TSC community. Including the marathon, this raised more than **£70,000**. We're extremely thankful to everyone involved.

Big Give Christmas Challenge 2025

We were once again successful in applying to take part in the annual Big Give Christmas Challenge. With the incredible generosity of our pledgers and donors, this was our most successful year yet! We brought in more than **£13,000** to help towards our TSC community events programme.

In memory giving

We're always touched when people raise funds for the TSA in memory of loved ones. We acknowledge and appreciate just how personal and important these gifts are and we aim to treat these donations and donors with the utmost respect and appreciation. We received more than **£19,000** through these gifts during 2025, from kind people going through very difficult times.

Trusts and foundations

Growing income received from trusts and foundations is a major focus for the TSA, as this support will help to enable our long-term sustainability. In 2025, we were successful in generating **£63,000** in restricted and unrestricted grants from trusts and foundations.



Some of the things we plan to do in 2026 are:

- Launch our first ever research fundraising campaign in conjunction with our new three-year research strategy
- Develop a robust corporate giving strategy, in order to target and secure high-profile corporate partnerships
- Deliver the second Superhero Summer campaign, bringing together moving stories from our community and encouraging UK-wide community fundraising events.

Superhero Summer

In 2025, we launched Superhero Summer, bringing the TSC community together through fundraising, celebration and awareness-raising. Throughout the summer, our supporters unleashed their inner heroes in a range of inclusive events and challenges, as well as organising their very own heroic events.

A key part of the campaign was 'Heroes Among Us', with the TSC community nominating their own heroes who demonstrated exceptional kindness, resilience and strength. These everyday heroes were rewarded with certificates, medals and letters of recognition! The mission continues in 2026!



Governance, strategy and sustainability

We proactively take extra steps to make sure that our operational foundations reflect charity sector best practice, that we can clearly explain and plan out our strategy and goals, and that we do everything we can to safeguard the long-term survival of the charity.

Ensuring strong foundations, so we can then achieve more

Operations and governance mean how we do things and the standards we hold ourselves to. It's the 'behind the scenes' work, not seen by those outside the charity, yet still very important. We updated our policies and introduced new ones, including a special seizure policy to help ensure people with TSC-related epilepsy are safe at our virtual and in-person events.

Improving how we gather and use feedback

We can be a successful charity only if we're adapting to and acting upon the needs of the TSC community. In 2025, we worked hard to improve the ways that we listen to feedback from the TSC community for all of our projects and outputs.

Making sure we stay fully focused on our strategic goals

It's important to make sure that everything we do takes us a step closer to the aims and objectives of our strategy (see [page 12](#)). We started the significant task of creating a 'Theory of Change' for the TSA, which acts as a strategic roadmap that connects even the smallest actions we do every day to the ultimate aim of a cure for TSC.

Reaching a more diverse TSC community

TSC affects everyone, from all backgrounds and experiences. However, the TSA identified that it wasn't reaching everyone in the TSC community, especially those from minority backgrounds. In 2025, we set about changing that.

Our special TSC Together campaign highlighted the many different people in the TSC community, encouraging people to engage with the TSA no matter where they're from or what their background is.



Some of the things we plan to do in 2026 are:

- Continue to improve how we listen and act upon the needs of the TSC community, through improved feedback opportunities
- Further develop our Theory of Change, so it shows how everything we do connects to our strategic plan and why all our projects are so important
- Further embed financial analysis tools and financial management steps, so that we can better plan for the future

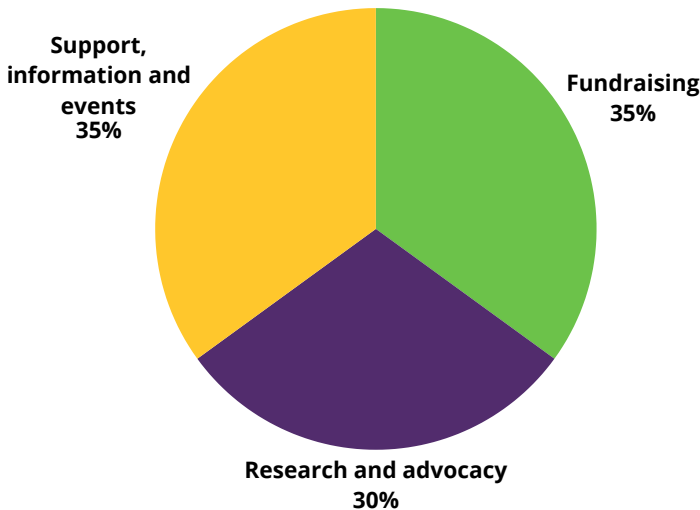
MONEY MATTERS

Where money was used in 2025

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 expenditure as possible is used where it's going to make a big 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.

In 2025 we had a roughly even split across spend in our different teams and projects. 35% 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.

We brought in more than twice as much income as we spent, with **a ratio of £1 fundraising spend leading to £2.26 of income**. This is down from 2024, which was closer to a 1:5 ratio. We believe this drop is because of a significant reduction in legacy income, which is hard to predict.



Financial overview at the end of 2025

The TSA has developed a clear and novel way of maximising our funds so that they help us to meet our charitable aims and objectives. You can read more about this below.

At the end of 2025, the TSA had total funds of **£1,320,551**. This consisted of:

- **Non-designated funds (£305,684)**
 - This forms our reserves so we are financially stable and resilient, giving us something towards a 'rainy day'. These funds can be used at the discretion of the TSA Board of Trustees towards our charitable aims and objectives. Read more on [page 31](#)
- **Designated investment funds (£980,343)**
 - Sensible investments that enable vital major projects in our latest strategic plan. We aim to spend the income, while not touching the capital (original amount). This helps us to be more sustainable and financially resilient. Read more on [page 32](#)
- **Other designated funds (£14,830)**
 - Allocated to major projects within our latest strategic plan for 2025 - 2027
- **Restricted funds (£19,694)**
 - Funds allocated to specific projects and nothing else. The funds can only be used for the allocated purpose, not for anything else at all

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

The total income for the year was **£477,773**. This is down from 2024's total of £656,551, when we received a large legacy gift. However, total investment gains were **£82,303** (2024: £50,981). This led to a surplus for 2025 of **£20,990** (2024: £239,063). Therefore, the surplus was possible thanks to the TSA's innovative investment strategy, made possible through our designated investment funds helping to fuel vital major TSA projects while making us more sustainable.

Our plans for financial resilience

It's an incredibly challenging time for small charities like the TSA, with overall giving in the UK reduced by £1.4 billion in 2025 compared to the previous year. This is why innovative strategies, such as the TSA's careful investing of funds to create a stable income, are so vital.

Although 2025 was a surplus year, the TSA Board of Trustees anticipates several years of managed deficits in the coming years, as we negotiate a challenging fundraising environment while also investing in vital major and ongoing projects to improve the lives of people with TSC. The TSA Board of Trustees is doing everything that it can to ensure that the TSA is here not only today but also for as long as we seek a cure for TSC.

The TSA Board of Trustees and senior leadership have an in-depth and active financial resilience plan to respond to the ongoing economic challenges of the UK and beyond. 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.



Non-designated reserves and reserves policy

The TSA Board of Trustees has agreed to hold up to the equivalent of six months of reserves in non-designated funds, which is around **£270,000**. Six months of operational reserves allows the charity to cover operating deficits and unexpected drops in income, while ensuring liquidity for ongoing costs. It also means that we can maximise restricted and designated funds for vital projects aligned with our strategic plan. The Trustees and senior leadership team expect the currently held level of non-designated reserves to drop in future years, as it now slightly exceeds the target amount.

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 the 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. This would ensure the charity's long-term survival and stability.

This overall approach strengthens the TSA's resilience while ensuring funds remain readily available to support key activities that help us achieve our vision and mission.

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 adopted 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. 68% of funds held in Brewin Dolphin are in equities, while 17% are in bonds and 3% are in cash. The remaining 12% are in other assets. This is done under a discretionary investment mandate.

Environmental, 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 2025, bank interest and investment income was **£35,721**, with an increase in the market value of investments of **£81,332**. 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.



Designated Investment Fund explained

It's an extremely challenging time for UK charities, with income generation an ongoing issue. This is partly why the TSA's Board of Trustees set up our Designated Investment Fund. These designated funds, which are invested with expert investment managers, allow us to self-fund vital activities in our strategic plan in a sustainable manner. This is because we aim to retain the original sum (capital) while spending the income. The original sum invested in the Designated Investment Fund was received thanks to two large legacy gifts from previous years.

Activities selected to be funded through the Designated Investment Fund are in areas that are incredibly important to our vision and mission. **Despite being important, 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 2 – 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 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 will enable 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 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 a vital research project that could change the course of TSC and is 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 Designated Investment Fund will have a significant impact on the TSC community today and into the future.



RISK AND COMPLIANCE

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 and closely monitored by the TSA Board of Trustees and senior 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 protect against this risk
- Failure to achieve our financial plans. Stringent and ongoing budgets and forecasting help to avoid this risk, as does proactive work to diversify income and monitor reserves
- Poor service 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 help to reduce 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 must 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. During 2025, no shared potential conflicts were considered a major risk to the TSA or our community.

During TSA Board of Trustees 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 income is vital to operations and impact. The TSA ensures that income management is led by industry best practice, such as guidance by the Charity Commission, National Council for Voluntary Organisations (NCVO) and the Association of Medical Research Charities (AMRC).

The TSA receives support from pharmaceutical companies focused on TSC. Industry grants and sponsorships do not influence TSA activities or shift our focus in any way. In line with best practice, the TSA 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 2025.

Monitoring our success and impact

We strongly encourage the TSC community to provide formal and informal feedback about our work and impact. This includes surveys, focus groups and face-to-face discussions. Feedback is regularly analysed by the TSA team and Board of Trustees, 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 the biggest challenges are for the TSC community, so that we can tailor our work and have the biggest impact possible. For example, previous feedback said 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.

FINANCIAL REPORT 2025

Independent examiner's report to the Trustees of The Tuberous Sclerosis Association ('the Charity')

I report to the charity Trustees on my examination of the accounts of the Charity for the year ended 31 December 2025.

Responsibilities and basis of report

As the Trustees of the Charity you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the 2011 Act').

I report in respect of my examination of the Charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Since the Charity's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the ICAEW, which is one of the listed bodies.

Your attention is drawn to the fact that the Charity has prepared the accounts in accordance with 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) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has been withdrawn.



I understand that this has been done in order for the accounts to provide a true and fair view in accordance with the Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Charity as required by section 130 of the 2011 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

This report is made solely to the Charity's Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. My work has been undertaken so that I might state to the Charity's Trustees those matters I am required to state to them in an Independent examiner's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the Charity and the Charity's Trustees as a body, for my work or for this report.

Signed:

Dated: 09/09/2026



Laura Waycott

FCA

Griffin
Chartered Accountants
Courtenay House
Pynes Hill
Exeter
EX2 5AZ



THE TUBEROUS SCLEROSIS ASSOCIATION

STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2025

	Note	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025 £	Total funds 2024 £
Income from:					
Donations and legacies	4	293,058	145,127	438,185	621,782
Charitable activities	5	3,867	-	3,867	2,105
Investments	6	35,721	-	35,721	32,664
Total income		332,646	145,127	477,773	656,551
Expenditure on:					
Raising funds	7	211,331	-	211,331	153,957
Charitable activities	9	189,362	138,393	327,755	314,512
Total expenditure		400,693	138,393	539,086	468,469
Net (expenditure)/income before net gains on investments		(68,047)	6,734	(61,313)	188,082
Net gains on investments		82,303	-	82,303	50,981
Net movement in funds		14,256	6,734	20,990	239,063
Reconciliation of funds:					
Total funds brought forward		1,286,601	12,960	1,299,561	1,060,498
Net movement in funds		14,256	6,734	20,990	239,063
Total funds carried forward		1,300,857	19,694	1,320,551	1,299,561

The Statement of financial activities includes all gains and losses recognised in the year.

The notes on pages 40 to 61 form part of these financial statements.

THE TUBEROUS SCLEROSIS ASSOCIATION
REGISTERED NUMBER: 02900107

BALANCE SHEET
AS AT 31 DECEMBER 2025

	Note	2025 £	2024 £
Fixed assets			
Tangible assets	15	1,843	2,708
Investments	16	980,343	706,437
		<u>982,186</u>	<u>709,145</u>
Current assets			
Debtors	17	61,103	24,766
Cash at bank and in hand		293,233	594,532
		<u>354,336</u>	<u>619,298</u>
Current liabilities			
Creditors: amounts falling due within one year	18	(15,971)	(28,882)
Net current assets		<u>338,365</u>	<u>590,416</u>
Total assets less current liabilities		<u>1,320,551</u>	<u>1,299,561</u>
Net assets excluding pension asset		<u>1,320,551</u>	<u>1,299,561</u>
Total net assets		<u><u>1,320,551</u></u>	<u><u>1,299,561</u></u>
Charity funds			
Restricted funds	19	19,694	12,960
Unrestricted funds	19	1,300,857	1,286,601
Total funds		<u><u>1,320,551</u></u>	<u><u>1,299,561</u></u>

THE TUBEROUS SCLEROSIS ASSOCIATION

BALANCE SHEET (CONTINUED)
AS AT 31 DECEMBER 2025

The Company was entitled to exemption from audit under section 477 of the Companies Act 2006.

The members have not required the company to obtain an audit for the year in question in accordance with section 476 of Companies Act 2006.

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 and authorised for issue by the Trustees on
and signed on their behalf by:

Simon James

08/09/2026

S James
(Treasurer)

The notes on pages 40 to 61 form part of these financial statements.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

1. General information

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

2. Accounting policies

2.1 Basis of preparation of financial statements

The financial statements have been prepared in accordance with the Charities SORP (FRS 102) - 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) (effective 1 January 2019), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

The Tuberous Sclerosis Association meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy.

2.2 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.

2.3 Income

All income is recognised once the Company has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

The recognition of income from legacies is dependent on establishing entitlement, the probability of receipt and the ability to estimate with sufficient accuracy the amount receivable. Evidence of entitlement to a legacy exists when the Company has sufficient evidence that a gift has been left to them (through knowledge of the existence of a valid will and the death of the benefactor) and the executor is satisfied that the property in question will not be required to satisfy claims in the estate. Receipt of a legacy must be recognised when it is probable that it will be received and the fair value of the amount receivable, which will generally be the expected cash amount to be distributed to the Company, can be reliably measured.

Grants are included in the Statement of financial activities on a receivable basis. The balance of income received for specific purposes but not expended during the period is shown in the relevant funds on the Balance sheet. Where income is received in advance of entitlement of receipt, its recognition is deferred and included in creditors as deferred income. Where entitlement occurs before income is received, the income is accrued.

Income tax recoverable in relation to investment income is recognised at the time the investment income is receivable.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

2. Accounting policies (continued)

2.4 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. 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 allocated on the portion of the asset's use.

Expenditure on raising funds includes all expenditure incurred by the Company to raise funds for its charitable purposes and includes costs of all fundraising activities events and non-charitable trading.

Expenditure on charitable activities is incurred on directly undertaking the activities which further the Company's objectives, as well as any associated support costs.

Grants payable are charged in the year when the offer is made except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attaching are fulfilled. Grants offered subject to conditions which have not been met at the year end are noted as a commitment, but not accrued as expenditure.

All expenditure is inclusive of irrecoverable VAT.

2.5 Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the Company; this is normally upon notification of the interest paid or payable by the institution with whom the funds are deposited.

2.6 Gift Aid

In the case of a Gift Aid payment made within the Group, income is accrued when the payment is payable to the Parent Company under a legal obligation. Measurement is at the fair value receivable, which will normally be the transaction value.

Where the right to receive Gift Aid has been established, the amount receivable is recognised as investment income in the Statement of financial activities.

2.7 Tangible fixed assets and depreciation

Tangible fixed assets costing £250 or more are capitalised and recognised when future economic benefits are probable and the cost or value of the asset can be measured reliably.

Tangible fixed assets are initially recognised at cost. After recognition, under the cost model, tangible fixed assets are measured at cost less accumulated depreciation and any accumulated impairment losses. All costs incurred to bring a tangible fixed asset into its intended working condition should be included in the measurement of cost.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

2. Accounting policies (continued)

2.7 Tangible fixed assets and depreciation (continued)

Depreciation is charged so as to allocate the cost of tangible fixed assets less their residual value over their estimated useful lives, .

Depreciation is provided on the following bases:

Fixtures and fittings	- 25% reducing balance
Computer equipment	- 4 years straight line

2.8 Investments

Fixed asset investments are a form of financial instrument and are initially recognised at their transaction cost and subsequently measured at fair value at the Balance sheet date, unless the value cannot be measured reliably in which case it is measured at cost less impairment. Investment gains and losses, whether realised or unrealised, are combined and presented as 'Gains/(Losses) on investments' in the Statement of financial activities.

2.9 Debtors

Trade and other debtors are recognised at the settlement amount after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

2.10 Cash at bank and in hand

Cash at bank and in hand includes cash and short-term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

2.11 Liabilities and provisions

Liabilities are recognised when there is an obligation at the Balance sheet date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably.

Liabilities are recognised at the amount that the Company anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide.

Provisions are measured at the best estimate of the amounts required to settle the obligation. Where the effect of the time value of money is material, the provision is based on the present value of those amounts, discounted at the pre-tax discount rate that reflects the risks specific to the liability. The unwinding of the discount is recognised in the Statement of financial activities as a finance cost.

2.12 Financial instruments

The Company only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

2. Accounting policies (continued)

2.13 Pensions

The Company operates a defined contribution pension scheme and the pension charge represents the amounts payable by the Company to the fund in respect of the year.

2.14 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Company and which have not been designated for other purposes.

Designated funds comprise unrestricted funds that have been set aside by the Trustees for particular purposes. The aim and use of each designated fund is set out in the notes to the financial statements.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the Company for particular purposes. The costs of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

Investment income, gains and losses are allocated to the appropriate fund.

3. Critical accounting estimates and areas of judgment

Estimates and judgments are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

Critical accounting estimates and assumptions:

The Company makes estimates and assumptions concerning the future. The resulting accounting estimates and assumptions will, by definition, seldom equal the related actual results. There are no critical accounting estimates or assumptions.

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

4. Income from donations and legacies

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025 £
Donations	218,522	18,427	236,949
Legacies	29,503	-	29,503
Grants	45,033	126,700	171,733
	<u>293,058</u>	<u>145,127</u>	<u>438,185</u>
	Unrestricted funds 2024 £	Restricted funds 2024 £	Total funds 2024 £
Donations	277,373	-	277,373
Legacies	196,986	-	196,986
Grants	140,073	7,350	147,423
	<u>614,432</u>	<u>7,350</u>	<u>621,782</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

5. Income from charitable activities

	Unrestricted funds 2025 £	Total funds 2025 £
Christmas Cards & Other Sales	3,577	3,577
Training Income	290	290
	3,867	3,867
	<i>Unrestricted funds 2024 £</i>	<i>Total funds 2024 £</i>
Christmas Cards & Other Sales	1,760	1,760
Training Income	345	345
	2,105	2,105

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

6. Investment income

	Unrestricted funds 2025 £	Total funds 2025 £
Income from listed investments	21,085	21,085
Interest receivable	14,636	14,636
	<u>35,721</u>	<u>35,721</u>
	Unrestricted funds 2024 £	Total funds 2024 £
Income from listed investments	15,969	15,969
Interest receivable	16,695	16,695
	<u>32,664</u>	<u>32,664</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

7. Expenditure on raising funds

Fundraising trading expenses

	Unrestricted funds 2025 £	Total funds 2025 £
Seeking Donations, Grants and Legacies	7,406	7,406
Staging Fundraising Events	12,997	12,997
Other Fundraising Costs	29,321	29,321
Investment Management	7,843	7,843
Staff Costs	153,227	153,227
Depreciation	537	537
	<u>211,331</u>	<u>211,331</u>

Fundraising trading expenses (continued)

	Unrestricted funds 2024 £	Total funds 2024 £
Seeking Donations, Grants and Legacies	5,926	5,926
Staging Fundraising Events	6,206	6,206
Other Fundraising Costs	14,532	14,532
Investment Management	4,852	4,852
Staff Costs	122,036	122,036
Depreciation	405	405
	<u>153,957</u>	<u>153,957</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2025

8. Analysis of grants

	Grants to Institutions 2025 £	Grants to Individuals 2025 £	Total funds 2025 £
Grants, Research	34,200	-	34,200
Grants, Family Care & Support	-	9,933	9,933
	<u>34,200</u>	<u>9,933</u>	<u>44,133</u>
	<i>Grants to Institutions 2024 £</i>	<i>Grants to Individuals 2024 £</i>	<i>Total funds 2024 £</i>
Grants, Research	36,934	-	36,934
Grants, Family Care & Support	-	4,900	4,900
	<u>36,934</u>	<u>4,900</u>	<u>41,834</u>

The Company has made the following material grants to institutions during the year:

	2025 £	2024 £
Name of institution		
University of Bristol NHS Foundation Trust - Randomised Controlled Trial of ACT in TSC	1,644	6,171
Epilepsy Research Institute UK	32,556	27,617
University of Manchester, Faculty of Life Sciences	-	(224)
Whitehead Institute	-	(185)
Cardiff University	-	(1,310)
Institute of Psychiatry Psychology	-	(67)
Other	-	4,932
	<u>34,200</u>	<u>36,934</u>
	<u>34,200</u>	<u>36,934</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

9. Analysis of expenditure on charitable activities

Summary by fund type

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £
Research	101,670	34,200	135,870
Family Care & Support	87,692	104,193	191,885
	<u>189,362</u>	<u>138,393</u>	<u>327,755</u>
	<u><u>189,362</u></u>	<u><u>138,393</u></u>	<u><u>327,755</u></u>
	<i>Unrestricted funds 2024 £</i>	<i>Restricted funds 2024 £</i>	<i>Total 2024 £</i>
Research	236,806	33,787	270,593
Family Care & Support	39,619	4,300	43,919
	<u>276,425</u>	<u>38,087</u>	<u>314,512</u>
	<u><u>276,425</u></u>	<u><u>38,087</u></u>	<u><u>314,512</u></u>

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

10. Analysis of expenditure by activities

	Activities undertaken directly 2025 £	Grant funding of activities 2025 £	Support costs 2025 £	Total funds 2025 £
Research	19,947	34,200	81,723	135,870
Family Care & Support	20,705	9,933	161,247	191,885
	<u>40,652</u>	<u>44,133</u>	<u>242,970</u>	<u>327,755</u>

	Activities undertaken directly 2024 £	Grant funding of activities 2024 £	Support costs 2024 £	Total funds 2024 £
Research	6,813	36,934	226,846	270,593
Family Care & Support	39,019	4,900	-	43,919
	<u>45,832</u>	<u>41,834</u>	<u>226,846</u>	<u>314,512</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

10. Analysis of expenditure by activities (continued)

Analysis of direct costs

	Research 2025 £	Family Care & Support 2025 £	Total funds 2025 £
Depreciation	138	190	328
Subscriptions	1,098	481	1,579
Travel & Communications	2,217	10	2,227
IT & GDPR Services	3,844	6,194	10,038
Marketing & Media	2,021	2,133	4,154
Scan	887	888	1,775
Big Day	6,625	5,568	12,193
Training	169	2,157	2,326
Outlook Events	2,948	2,949	5,897
Consultancy	-	135	135
	<u>19,947</u>	<u>20,705</u>	<u>40,652</u>

	Research 2024 £	Family Care & Support 2024 £	Total funds 2024 £
Depreciation	174	174	348
Subscriptions	819	1,643	2,462
Travel & Communications	887	69	956
IT & GDPR Services	915	10,068	10,983
Marketing & Media	73	73	146
Professional Fees	-	900	900
Scan	2,640	-	2,640
Big Day	119	10,954	11,073
Training	541	7,603	8,144
Outlook Events	645	1,935	2,580
Consultancy	-	5,600	5,600
	<u>6,813</u>	<u>39,019</u>	<u>45,832</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

10. Analysis of expenditure by activities (continued)

Analysis of support costs

	Total funds 2025 £	<i>Total funds 2024 £</i>
Staff costs	206,837	186,228
Subscriptions	696	1,700
Travel & Communications	597	927
IT & GDPR Services	5,973	6,447
Accountancy	5,560	5,460
Sundries	8,960	5,560
Insurance	1,111	2,693
Chief Executive Expenses	172	1,608
Sundries	102	-
Governance Costs	12,962	16,223
	242,970	226,846

11. Independent examiner's remuneration

	2025 £	<i>2024 £</i>
Fees payable to the Company's independent examiner for the independent examination of the Company's annual accounts (2024 Audit Fee)	1,950	6,900
Fees payable to the Company's independent examiner in respect of: All accountancy services not included above	13,904	753

12. Staff costs

	2025 £	<i>2024 £</i>
Wages and salaries	306,658	269,360
Social security costs	22,979	21,961
Contribution to defined contribution pension schemes	30,427	16,943
	360,064	308,264

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2025

12. Staff costs (continued)

The average number of persons employed by the Company during the year was as follows:

	2025 No.	2024 No.
Fundraising	4	5
Family Support & Communications	4	2
Research	2	2
	10	9

No employee received remuneration amounting to more than £60,000 in either year.

The key management personnel of the Charitable Company are the Joint Chief Executives. The total employee benefits, including employer pension contributions, of the key management personnel of the charity is £131,572 (2024: £116,000).

13. Trustees' remuneration and expenses

During the year, no Trustees received any remuneration or other benefits (2024 - £NIL).

During the year ended 31 December 2025, expenses totalling £134 were reimbursed or paid directly on behalf of a Trustee (2024 - £NIL to Trustee). The expense was in relation to travel costs.

THE TUBEROUS SCLEROSIS ASSOCIATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

14. Intangible assets

	Computer software £
Cost	
At 1 January 2025	19,624
At 31 December 2025	<u>19,624</u>
Amortisation	
At 1 January 2025	19,624
At 31 December 2025	<u>19,624</u>
Net book value	
At 31 December 2025	<u><u>-</u></u>
<i>At 31 December 2024</i>	<u><u>-</u></u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

15. Tangible fixed assets

	Fixtures and fittings £	Computer equipment £	Total £
Cost or valuation			
At 1 January 2025	1,135	3,461	4,596
At 31 December 2025	<u>1,135</u>	<u>3,461</u>	<u>4,596</u>
Depreciation			
At 1 January 2025	1,135	753	1,888
Charge for the year	-	865	865
At 31 December 2025	<u>1,135</u>	<u>1,618</u>	<u>2,753</u>
Net book value			
At 31 December 2025	<u>-</u>	<u>1,843</u>	<u>1,843</u>
<i>At 31 December 2024</i>	<u>-</u>	<u>2,708</u>	<u>2,708</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

16. Fixed asset investments

	Listed investments £
Cost or valuation	
At 1 January 2025	706,437
Additions	635,542
Disposals	(644,968)
Revaluations	81,332
Cash invested	202,000
At 31 December 2025	<u>980,343</u>
Net book value	
At 31 December 2025	<u>980,343</u>
At 31 December 2024	<u>706,437</u>

	2025 £
Investments at fair value comprise:	
Global Bonds	92,610
UK Bonds	66,179
Developed Asia ex. Japan Equities	60,463
Developed Europe ex. UK Equities	57,725
Emerging Equities	10,364
Global Equities	51,544
Japan Equities	25,131
North America Equities	326,396
UK Equities	167,321
Absolute Return	9,229
Global Property	25,011
Gold	27,286
Other Alternatives	24,164
Cash	36,920
	<u>980,343</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025**

17. Debtors

	2025	2024
	£	£
Due within one year		
Other debtors	3,343	3,415
Prepayments and accrued income	57,760	21,351
	<u>61,103</u>	<u>24,766</u>

18. Creditors: Amounts falling due within one year

	2025	2024
	£	£
Trade creditors	9,222	3,568
Other taxation and social security	77	6,091
Other creditors	3,307	1,999
Accruals and deferred income	3,365	17,224
	<u>15,971</u>	<u>28,882</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

19. Statement of funds

Statement of funds - current year

	Balance at 1 January 2025 £	Income £	Expenditure £	Transfers in/out £	Gains/ (Losses) £	Balance at 31 December 2025 £
Unrestricted funds						
Designated funds						
TSA Seecorn Research	-	-	(22,714)	22,714	-	-
TSA Support Fund and Travel Bursaries	-	-	(10,677)	13,007	-	2,330
New Website	-	-	(12,500)	25,000	-	12,500
TSA Community Events	-	-	(30,000)	30,000	-	-
TSA Support Line	-	-	(6,000)	6,000	-	-
Investment Fund	567,820	-	-	330,220	82,303	980,343
	<u>567,820</u>	<u>-</u>	<u>(81,891)</u>	<u>426,941</u>	<u>82,303</u>	<u>995,173</u>
General funds						
General Funds	718,781	332,646	(318,802)	(426,941)	-	305,684
Total Unrestricted funds	<u>1,286,601</u>	<u>332,646</u>	<u>(400,693)</u>	<u>-</u>	<u>82,303</u>	<u>1,300,857</u>
Restricted funds						
Research	12,260	144,127	(136,693)	-	-	19,694
Support Activities	700	1,000	(1,700)	-	-	-
	<u>12,960</u>	<u>145,127</u>	<u>(138,393)</u>	<u>-</u>	<u>-</u>	<u>19,694</u>
Total of funds	<u>1,299,561</u>	<u>477,773</u>	<u>(539,086)</u>	<u>-</u>	<u>82,303</u>	<u>1,320,551</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

19. Statement of funds (continued)

The specific purposes for which the funds are to be applied are as follows:

Designated Funds:-

TSA Support Fund and Travel Bursaries

Fund to provide grants to people in the TSC community facing financial pressures.

New Website

Fund for the development of a new website for the Charity.

Investment Fund

Investment fund which is used to fund the Charity's objectives.

Unrestricted Funds:-

Comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how these may be used. Includes an investment fund which is used to fund the Charity's objectives.

Restricted:-

Research

To enable, or directly fund, research into all aspects of TSC from a range of researchers and institutions. This includes, but is not limited to; Diagnosis, treatment and management of TSC; everyday challenges of TSC; and living well with TSC.

Support Activities

Actions and projects related to supporting people affected by TSC. This includes, but is 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.

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2025

19. Statement of funds (continued)

Statement of funds - prior year

	<i>Balance at 1 January 2024 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Gains/ (Losses) £</i>	<i>Balance at 31 December 2024 £</i>
Unrestricted funds					
Designated funds					
TSA Seecorn Research	567,820	-	-	-	567,820
General funds					
General Funds	402,131	649,201	(383,532)	50,981	718,781
Total Unrestricted funds	969,951	649,201	(383,532)	50,981	1,286,601
Restricted funds					
Research	46,047	-	(33,787)	-	12,260
Pharma education grants	44,500	-	(44,500)	-	-
Support Activities	-	7,350	(6,650)	-	700
	90,547	7,350	(84,937)	-	12,960
Total of funds	1,060,498	656,551	(468,469)	50,981	1,299,561

THE TUBEROUS SCLEROSIS ASSOCIATION

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2025

20. Analysis of net assets between funds

Analysis of net assets between funds - current year

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025 £
Tangible fixed assets	1,843	-	1,843
Fixed asset investments	980,343	-	980,343
Current assets	334,642	19,694	354,336
Creditors due within one year	(15,971)	-	(15,971)
Total	1,300,857	19,694	1,320,551

Analysis of net assets between funds - prior year

	Unrestricted funds 2024 £	Restricted funds 2024 £	Endowment funds 2024 £	Total funds 2024 £
Tangible fixed assets	-	-	2,708	2,708
Fixed asset investments	-	-	706,437	706,437
Current assets	-	12,960	606,338	619,298
Creditors due within one year	-	-	(28,882)	(28,882)
Total	-	12,960	1,286,601	1,299,561

21. Pension commitments

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. During the year payments of £30,427 (2024: £16,943) were made to the fund. At the year end £3,307 (2024: £1,999) was payable to the fund and is included within creditors.

22. Related party transactions

The Company has not entered into any related party transaction during the year, nor are there any outstanding balances owing between related parties and the Company at 31 December 2025.

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 in 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)

Tuberous Sclerosis Association is a registered charity in
England and Wales (1039549) and Scotland (SC042780), and
is a company limited by guarantee registered in England and
Wales (no. 02900107).

t**sa**
tuberous sclerosis
association