

**REGISTERED COMPANY NUMBER: 02900107 (England and Wales)**  
**REGISTERED CHARITY NUMBER: 1039549**

**THE TUBEROUS SCLEROSIS ASSOCIATION**

**Unaudited Financial Statements for the Year Ended 31 December 2023**

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# **THE TUBEROUS SCLEROSIS ASSOCIATION**

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**THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)**

**Report of the Trustees  
for the year ended 31 December 2023**

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 December 2023. The trustees have adopted the provisions of 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).

**Report of the Trustees  
for the year ended 31 December 2023**

**OBJECTIVES AND ACTIVITIES**

**Objectives and aims, including public benefit**

The Tuberous Sclerosis Association (TSA) was launched in 1977 with a membership of 50 families and funds of just £25. We have grown from a round robin support letter to a professional organisation providing support to families affected by Tuberous Sclerosis Complex (TSC) across the UK.

Tuberous Sclerosis Complex (TSC) is a rare genetic condition that causes growths to develop in different organs around the body, such as the brain, lungs, kidneys, eyes, heart and skin. These growths are sometimes referred to as benign (non-cancerous) tumours. When they cause problems, it is mainly because of their size and where they are growing in the body.

**TSC in numbers:**

- Every month around 10 babies are born with TSC in the UK
- 80% of people with TSC have epilepsy which typically starts in infancy and is difficult to control using epilepsy medication
- 5 out of every 10 people with TSC have learning disabilities with around 3 in 10 people have profound learning disabilities and need life-long support from their families or live in residential care
- 90% of people living with TSC develop TSC-Associated Neuropsychiatric Disorders (TAND). This includes autism spectrum disorder, attention deficit hyperactivity disorder, behaviours that can challenge, depression, anxiety and sleep disorders

Every new diagnosis of TSC marks the start of an unexpected journey for the individual and family affected. The TSA is here to provide support on every step of the way.

The Trustees confirm that they have complied with their duty, under the Charities Act 2011, to have regard to the Charity Commission's published public benefit guidelines in determining the activities undertaken by the Association.

**SUMMARY OF ANNUAL PERFORMANCE: 2023**

The TSA has continued to deliver on its strategic priorities:

- Supporting the TSC community in all aspects of the condition
- Being at the forefront of the TSC research agenda
- Reducing the charity's operating deficit

**OBJECTIVES AND ACTIVITIES**

**Purpose and Strategy**

The TSA has 3 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 problems caused by TSC

The TSA is approaching the end of its 5 year strategy (2019-23) which sets out a clear vision of a world where TSC and its effects are conquered and continues the charity's mission to provide help for today and a cure for tomorrow.

During this strategy we plan to:

- REACH more people - significantly increase the number of people being supported by the TSA by 2023
- Drive more REseArCH - stimulate at least the same amount of investment in TSC research during 2019-2023 as was invested by the TSA over the last five years
- Continue to balance the TSA's finances - having invested in research in recent years, we need to reduce expenditure and grow income so that the charity is sustainable in the long-term

**Report of the Trustees  
for the year ended 31 December 2023**

The Aims, Objectives, Enablers and Values that deliver the strategy

Our strategic aims are to:

- Positively impact on the health and wellbeing of people living with TSC, families and carers
- Lead research into tools, technologies and treatments which eliminate the effects of TSC
- Lead innovation in the integration of medical and social care

Our strategic objectives (how we will do it) are to:

- Deliver quality, easily accessible and timely information about TSC and living with the condition
- Provide opportunities for people with TSC and their families to connect, support and learn together
- Build the knowledge and expertise of professionals working with people with TSC
- Drive the research agenda to improve outcomes and quality of life for people with TSC
- Expand our understanding of the condition to accelerate diagnosis, intervention and development of new treatments
- Disseminate and use evidence to influence NHS policy and practice
- Campaign for better access to treatments and care from the NHS
- Support the development of centres of excellence for supporting people with TSC and their families
- Pilot, then roll out, innovative approaches to whole person, family and carer support

Our strategic enablers that make it possible are:

- Effective teamwork by staff working together to achieve a shared vision
- High-quality, integrated financial management
- Digital transformation and smart working to reach more people
- An enterprising approach to income generation to drive more research
- Having values that are inclusive, ambitious and effective

### **2023 Business Plan**

The first four years of our 2019-2023 strategy saw the TSA significantly reduce expenditure to address the charity's structural deficit, while simultaneously improving the quality of our services and increasing our reach in the TSC community.

As a result of the cost-of-living crisis and working with a smaller team than originally envisaged at the start of the current strategy period and beyond, we continued to focus our resource on a smaller number of strategic objectives in 2023 to help the TSA community and the professionals who work with them. These were:

#### **Ensuring that the TSA is on solid ground across all teams, with a view to long-term stability-**

- Recruit a new fundraising team (Head of Fundraising and Fundraising Officer) and establish a clear fundraising strategy across all income streams for the immediate and long-term
- Recruit new hires across TSA teams, providing stronger foundations and resilience for a healthier and happier charity that also mitigates risk of future exits
- Ensure that the TSA's internal practices and structures are up-to-date and easy to follow, including access to all banking and other procedures

#### **Providing access to good quality, accessible and timely information**

- Develop further support materials and resources for the TSC community. Namely, an improved 'TSA Welcome Pack' to make the first steps of a TSC diagnosis easier
- Continue to build and improve the TSA website and social media channels, working to achieve the Patient Information Forum accreditation as a kite-mark of service quality
- Undergo an audit of the TSA's website, updating and removing content as needed to better represent the digital-first TSA and TSC community

**Report of the Trustees  
for the year ended 31 December 2023**

**Providing the opportunity for people with TSC to connect, support and learn together**

- Explore opportunities for virtual peer-to-peer support, such as in the form of virtual events, one-to-one discussions or other forums
- Deliver a slimmed-down Big Day which had to be postponed from November 2022 to May 2023 due to rail strikes. Big Day will allow the TSC community to connect face-to-face, with the focus on networking and feeling like part of a community
- Deliver a face-to-face Outlook event, connecting adults mildly affected by TSC
- Continue to deliver ambitious calendar of virtual events, ensuring that geographical location is not a barrier to the TSA

**Capacity-build the knowledge and expertise of professionals working with people with TSC**

- Launch the NHS England-partnered TSC Rare Disease Collaborative Network (RDCN). If application unsuccessful, work on appeal process to ensure the right decision is made
- Further solidify relationship with NHS TSC clinicians through regular educational communications focused on improving diagnosis, care and management of TSC
- Support the NHS TSC Clinics Network through a range of activities including a virtual annual NHS TSC Clinics Education Day

**Driving the research agenda with the aim of improving outcomes and quality of life for people living with TSC**

- Work with Epilepsy Research UK on the successful application to the joint-funded 'Emerging Leader' award
- Support review of the UK guideline on identifying and managing TSC, so it is consistent with updated international guidelines and incorporates UK guidance on new treatments
- Continue to grow TSA's research volunteer network to drive patient-centric research and increase investment in TSA research through patient and public involvement and engagement

**Campaigning for better access to treatments and care**

- Continue to work with pharmaceutical partners and foster strong relationships in anticipation of pipeline product launches (i.e., topical sirolimus treatment for facial angiofibromas)
- Should NICE reject Epidyolex (cannabidiol) funding application for TSC-related epilepsy after second appraisal: Work with key stakeholders – including the TSC community – to appeal to NICE in order to get the decision that the TSC community deserve
- Should NICE accept Epidyolex (cannabidiol) funding application for TSC-related epilepsy: Work with stakeholders to ensure that access to medicine and awareness of its availability is done efficiently

Strategic enablers

We will focus on:

**High-quality, integrated financial management**

- TSA leadership to continue to develop financial management skills, improving confidence and capabilities that will benefit the charity

**Digital transformation and smart working to reach more people**

- Further encourage greater use of digital platforms across community, further reducing costs and resourcing
- Continue our journey to working smarter, with more automation and streamlining across outputs
- Put our IT provider out to tender to see if it is possible to make savings in what has become a more competitive market due to the increase in home-workers following covid
- Audit the charity's current IT infrastructure and explore alternative options for cost-saving including a potential move from remote desktop set-up to a cloud based file sharing system
- Embrace third-party fundraising platforms and networks, maximising return on investment and resourcing

**An enterprising approach to income generation to drive more research**

- Continue to develop opportunities from alternative sources, including sponsorship by pharmaceutical companies
- Have a greater focus on trusts and foundations, opening new opportunities for income across small, medium and large applications
- Reconnect with medium and major donors, encouraging ongoing giving with focused campaign
- Audit of community fundraising activities to understand return on investment against high level of resourcing, such as the NHS TSC Clinics Virtual Challenge
- Migrate to a more efficient Customer Relationship Management (CRM) system, allowing us to work more efficiently and in a way that is more impactful

**Report of the Trustees  
for the year ended 31 December 2023**

**STRATEGIC REPORT**

Despite structural changes in the team and the challenges of the cost-of-living crisis impacting the charity's income generation, the TSA's Trustees and staff continue to be ambitious about what we want to achieve for individuals living with TSC and their families. We are determined that the current financial climate will not stop us being here for anyone affected by TSC.

Our mission is to provide help for today and a cure for tomorrow.

The Trustees monitor performance against three headline indicators and a broader set of key performance indicators to determine the progress of our current 5-year strategy.

**Reaching more people**

It is estimated that there are between 3,700 to 11,000 people living with TSC in the UK. In 2018 there were 3,394 people in contact with the charity including people living with TSC, their families, carers and friends. In 2023, 4,536 people made up of those living with TSC, their families, carers and friends were in contact with the charity. This was 30 per cent higher than at the start of the strategy.

The TSA Support Line continued to provide vital support and advice by telephone and email to people living with TSC across the UK. 270 people contacted the TSA Support Line for support in 2023. 22,000 users visited our website for information in 2023. 3,040 people are subscribed to receive email updates from us.

**Driving more research**

The TSA continued to drive the research agenda by jointly funding research and supporting researchers.

2023 saw the start of new study jointly funded with Epilepsy Research Institute. The Fellowship Award is a major opportunity to push TSC-related epilepsy research further, widening its scope and giving Dr Amanda Almacella Barbanj (University College London) the opportunity to become a leader in TSC research. Dr Barbanj's research will allow us to better understand the relationship between TSC and epilepsy. The hope is that this will then mean that new ways to treat and manage TSC-related epilepsy will be unlocked, such as medicines and therapies. This could mean that people have fewer and less severe seizures, reducing the impact of TSC on everyday life. This is an exciting opportunity for TSC-related epilepsy research to extend beyond the 'walls' of TSC, into researchers and experts who may not have otherwise encountered or focused on the condition previously.

**Balancing the books**

Enabling and funding world-leading research into the diagnosis, treatment and management of TSC will always be a central pillar of the TSA. However, the Trustees made the difficult decision that for the TSA to be sustainable, it must raise sufficient funds to ensure that the charity is making a surplus before any further research commitments are made. All existing research commitments continue to be met, and the charity continues to have an important role in TSC research more broadly.

The Trustees' goal is to retain our reserves at a sensible level to give us the best possible opportunity to grow the charity from 2024 and deliver the ambitions set out in the next strategy period.

**Report of the Trustees  
for the year ended 31 December 2023**

**OBJECTIVES AND ACTIVITIES**

**PERFORMANCE:**

Support and information, events and communications

The TSA remains focused on flexibly reaching more people impacted by TSC, respecting geographical and cultural diversity.

We continue to provide the TSA Support Line to everyone in the TSC community. This enables people across the UK to contact our small support team confidentially by telephone, chat, email and post (9am to 5pm on Monday to Friday each week). We were contacted by around 25 people each month in 2023 asking for support, information or a listening ear. Reasons for contacting the TSA Support Line varied, from new diagnoses, specific questions about medicines or treatments, or just wanting to talk to someone with a listening ear.

We continued to provide proactive information and resources through our other various challenges. This includes our website (<https://tuberous-sclerosis.org/>), popular social media channels, community magazine (called Scan), email newsletter updates and our virtual and face-to-face events. We continually evolve all information and support materials that we offer, ensuring that remains up-to-date and relevant.

2023 marked the launch of the TSA's professional training courses – one for education professionals and one for social care professionals. These courses are the first of their kind anywhere in the world, providing training to people previously unfamiliar with TSC across a range of topics and areas. The training courses are fully certified for Continual Professional Development (CPD) points, meaning that professionals can use them as part of their required annual training and development.

13 professionals signed up for the online training courses upon their launch during 2023. Feedback for the course was overwhelmingly positive and thankful. The cost of purchasing access to the training for every professional means that the training courses were self-funded during 2023.

Throughout 2023, we organised regular virtual events focused on the concerns that people shared on the TSA Support Line. These events were recorded and shared online so they were accessible for families with caring responsibilities. Virtual events in 2023 included:

- Events focused on health aspects of TSC, such as TSC and epilepsy, TSC and pregnancy and the ketogenic diet
- Practical advice, such as Wills and future planning, Education Health and Care plans, and TSC research
- Special clinic meetings focused on specific NHS TSC Clinics

Across 2023, there were 253 people who registered for our virtual events.

2023 also saw the return of our popular face-to-face events. Outlook is our group for adults mildly affected by TSC. We welcomed 35 'Outlookers' to Outlook 2023 which took place in Leicester. Big Day, our biggest event of the year where everyone in the TSC community is invited, took place in Manchester with 90 people in attendance. We look forward to hosting these events in 2024.

2023 saw an unprecedented demand for the TSA Support Fund. The fund provides small discretionary grants to those in the TSC community facing financial crisis. The TSA Support Fund is available to people affected by TSC who are in benefit of benefits. The fund provides support for a range of things, such as household items, respite leave or emergency repairs. We awarded £9,600 in grants from the TSA Support Fund to 33 individuals and families.

In January 2023, NHS England accepted our application for the NHS TSC Clinic Network to be formally recognised as a Rare Disease Collaborative Network (RDCN). This means that the network and all clinics who were part of the application will be able to have a much stronger role and capability in: (i) Improving understanding and awareness of TSC in the NHS; (ii) standardising clinical and care pathways; and (iii) maintaining best practice and education amongst TSC specialists and non-specialists. Providers in the TSC RDCN will also be recognised as leaders in TSC diagnosis, care and management. In addition, it is hoped that all clinics part of the network may in the future be possibly eligible for future funding opportunities, if ever available.



**Report of the Trustees  
for the year ended 31 December 2023**

Following approval by NHS England of the TSC RSCN, the TSA hosted its first NHS TSC Clinic Lead meeting of the year in May 2023, followed by a face-to-face event for clinic leads in October. The TSA hosted further hosted two vital meetings virtually: TSC RDCN Nurse Specialists Meeting, first TSC clinical networking event focused exclusively on TSC specialist nurses; and the annual NHS TSC Clinics Education Meeting.

Two issues of the TSA's popular community magazine, Scan, were published in 2023. The magazine is an important element of the TSA's support and information, providing an update to households on key TSC news and TSA projects. Scan was delivered to around 2,000 households in 2023

Research and advocacy

Our research team is committed to driving more research to give people living with TSC and their families hope for the future. The TSA is the only UK charity dedicated to supporting TSC research, with an in-year research grant commitment in 2023 of £13,268. The charity's Trustees remain determined to honour the research grant commitments that we have made and decided that the Designated Endowment Fund would be used to cover the cost of our ongoing research grants programme.

The TSA's research portfolio of previously committed grants in 2023 consists of 5 live grants (2 of which are jointly funded). Our portfolio of ongoing projects is worth £43,072.14.

**Live grants table 2023**

Reference	Investigator	Institution	Title and purpose of grant	Co-funder
2018-S02 Dunlop	Dr Elaine Dunlop	Cardiff University	<b>Characterising the role of exosomes in TSC</b> We know that TSC cysts surround and hijack healthy cells, in turn helping the cysts grow. This project plans to collaborate with world leading TSC experts to help better understand exactly how TSC cysts communicate with healthy cells. It is hoped that this research could help to reveal new ways of preventing TSC cysts from growing, thereby helping to develop better strategies for treating and managing TSC.	
2018-S04 Tee	Professor Andrew Tee	Cardiff University	<b>Understanding the limits of everolimus and rapamycin</b> This project is investigating the limits of everolimus and rapamycin, specifically, why these treatments are not 100% effective and why not all TSC tumours respond to treatment with them. The team are currently examining how TSC tumour cells in the lab respond to a series of new drugs in clinical development and will compare the effects with existing treatments. It is hoped that this research will help to find better and more effective treatments for TSC patients.	

Report of the Trustees  
for the year ended 31 December 2023

2019-F01 Tye	Dr Charlotte Tye	Kings College London	<p><b>Designing a protocol to measure the developmental trajectory of infants with Tuberous Sclerosis</b></p> <p>The EDiTS study team have developed a home-based assessment to better monitor and understand social and non-social attention in toddlers with TSC. This early intervention solution already indicated a dramatic improvement in social behaviour linked to autism spectrum disorder. The EDiTS study is ongoing and aims to pave the way for the design of more early interventions to improve the long-term quality of life for patients with TSC.</p>	
2019-P01 Dunlop	Dr Elaine Dunlop	Cardiff University	<p><b>A model of cell invasion in TSC-LAM</b></p> <p>One of the current priorities in TSC research is to develop a model of the human circulatory system using human cells, so that scientists can study LAM in more detail. LAM (or 'lymphangioliomyomatosis') is a condition affecting around 35-40% of females who live with TSC. LAM is caused by TSC cells moving from different parts of the body to the lungs, causing cysts. This new project aims to create a LAM model. If the research is successful, it will give scientists a better understanding of why TSC LAM happens and why some cells invade the lungs whilst others do not.</p>	US Ministry of Defence
2019-P02 Amin	Dr Sam Amin and Dr Ingram Wright	University of Bristol	<p><b>Better understanding the accessibility of mental health services for children and young people with TSC</b></p> <p>This project aims to develop an understanding of appropriate and effective ways for children and young people with TSC to access available 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.</p>	Anonymous major donor

**Report of the Trustees  
for the year ended 31 December 2023**

**TSC Research Volunteer Network**

In 2023, 7 new volunteers signed up to be a part of the TSC Research Volunteer Network – the TSA’s patient and public involvement and engagement programme. Established in 2021, the network aims to encourage and empower people living with TSC and their families to help shape the future of TSC research. The network now has a total of 39 volunteers, including individuals with TSC, parents and siblings.

Throughout 2023, the TSA offered a range of opportunities to volunteers, including:

- Attending the All Party Parliamentary Group on Rare, Genetic and Undiagnosed conditions on issues such as improving diagnosis, increasing awareness of rare conditions, access to treatments, healthcare and delivery
- Helping TSC researchers apply for funding from major funders. This was done by reading summaries of the researcher’s work and participating in focus groups and 1:1 meetings with researchers, to ensure that the work was impactful and meaningful to people who are affected by TSC on a daily basis
- Co-producing an upcoming stage 4 clinical trial
- Acting as co-applicants on a large funding application
- Participating in focus groups to refine the design of research protocols. This was done for both clinical trials and qualitative research studies
- Giving feedback on draft information leaflets written by a pharmaceutical company conducting a trial into TSC medicine. The leaflets will help explain the studies and how to be a part of them.
- Reviewing different leaflets and other documents on behalf of TSC researchers working on TSC projects. This helped ensure that content was written in a way that was easy to understand for non-researchers

**New treatments for TSC**

In early 2023, cannabidiol (brand name Epidyolex®) was approved for use in TSC-related epilepsy in England after ongoing campaigning by the TSA. This means that people living with TSC across all UK nations now have access to this new medicine, following similar campaigns by the TSA to previously get access to the medicine in other UK nations. Decision-makers in England noted the “real difference” that the input of the TSA and the TSC community had on the approval process.

**Advocacy**

We formed successful alliances with other charities and worked with them on a range of activities and initiatives with the common aim to raise the profile and importance of rare disease with parliamentarians and policy makers.

During 2023 we continued to work closely with colleagues from the Specialised Healthcare Commissioning Alliance (SHCA). We worked with the UK Rare Diseases Forum and Genetic Alliance UK to raise awareness of the need to the views of patients and families when making decisions about treatments for rare diseases. We continued to be a member of the Embracing Complexity Coalition to raise awareness of the need for joined up support from health and social care for complex conditions, and the Council for Disabled Children to improve access to services for children living with TSC and their families. We attended the Westminster All Party Parliamentary Group (APPG) on Rare, Genetic and Undiagnosed conditions meeting on 16 May 2023 at the Houses of Parliament. The APPG focuses on issues such as improving diagnosis, increasing awareness of rare conditions, access to treatments, healthcare and delivery. The aim of the meeting was to speak to MPs about the Coordinating Care report that Genetic Alliance UK launched for Rare Disease Day.

The TSA was invited to attend a roundtable, a co-created joint event between UKRET and Genomics England (GEL), facilitated by GEL’s Patient Engagement initiative to discuss the challenges and experiences of charities like the TSA in order to develop a meaningful conversation and roadmap to facilitate future working relationship.

**Report of the Trustees  
for the year ended 31 December 2023**

Income Generation

The last few years have been unprecedented for many charities, with the TSA being no exception. UK businesses and charities were optimistic that 2023 would be a year of replenishment and returning to normality following the devastating consequences of Covid-19. However, fresh challenges through rapidly rising inflation and a major cost of living crisis put strain on people which led to: Reduced means for people to give to charities (either directly through donations due to personal financial challenges, or in fundraising due to resourcing challenges of this); greater numbers of applications to grant-making trusts and foundations, diluting this important income stream; and charities being unable to take greater risks in fundraising, reducing innovation. As a rare disease charity whose supporter base is smaller than others, the TSA continued to feel these financial challenges even harder than most charities. Throughout 2023 the TSA's small and dedicated team continued to work incredibly hard to mitigate risks to the charity's income whilst minimising expenditure.

We are extremely grateful to the following grant-making trusts and foundations for their crucial unrestricted support towards core costs throughout 2023: The Swann-Morton Foundation (£1,000), Frazer Trust (£2,000), The Masterserve Foundation (£6,411.63), The Beechwood Trust (£2,000), AK&AJ Barnett Charitable Trust (£3,000), The Rest Harrow Trust (£3,000).

In addition, we received unrestricted sponsorship from Jazz Pharmaceuticals (£22,500), PlusUltra Pharma (£22,500) and Marinus Pharmaceuticals (£8,000) which was a welcome boost for the charity. This sponsorship was for different areas of our work, including our work as secretariat on the NHS TSC Rare Disease Collaborative Network, our clinical events and our community events.

We would also like to thank the following trusts who have supported us with restricted funding to enable us to continue to develop specific areas of our work: The Meikle Foundation (£2,000) for our ongoing work in Scotland and The Bailey Thomas Trust (£2,000) who generously contributed funds to assist with the TSC Together project. The Reed Foundation (£1,500) and The Hobson Foundation (£4,000) who both kindly enabled us to develop our support services training modules. The Hospital Saturday Fund (£2,000) for generously contributed funds to develop our mental wellbeing research project, and Jeans for Genes (£4,000) for funds that enabled us to provide specialist creche services at our Big Day event.

The generosity of grant-making trusts and foundations who supported us in 2023 enabled us to continue to deliver our vital services to the individuals and families impacted by TSC.

Our sincere thanks go to our corporate supporters. Equistone Partners Europe who continue to support us with a generous donation of £1,000, and who also allowed use of their London office space for our TSA team away day. We are also grateful for the continued support of Aubrey Allen who generously donated £1,000.

The TSA would like to thank the amazing people who took part in the 2023 TCS London Marathon. We are in awe of the dedication and time they all gave to train for such an iconic event, and we are thrilled that our team of runners raised a fantastic £22,670.

The TSA would also like to thank Ian Gould for his generous donation of £9,142, raised during his captaincy at Nuneaton Golf Club during 2022.

Leaving a gift in a Will is a wonderful and powerful gesture that enables a person to support the TSA even when they are no longer here. For the family left behind, they are able to take great comfort that their loved one has left behind a legacy to be proud of. We would like to formally record a huge thank you to everyone who supported us in this way. In-memory donations and legacies raised £15,412 for the TSA this year.

Facebook donations have become popular with fundraisers as they are an easy way to support the TSA and raise money for milestone celebrations, such as birthdays and anniversaries. Throughout 2023, this income stream raised over £6,700 for the TSA.

In 2023, the TSA introduced the TSA Lottery, a new way for the TSC community to choose to generously give to the charity. This income stream was setup in partnership with Unity Lottery, and carefully organised to ensure high levels of best practice and compliance as expected with lottery products. In 2023, we had 60 players take part in the TSA Lottery, with a total income raised of £1,253.

In December 2023, the TSA's Big Give Challenge raised vital funds for our TSA Support Fund. The fund offers a lifeline to individuals and families affected by TSC when the financial implications of the condition become too much to carry and they need financial assistance. We met our target to raise £4,350 for the TSA Support Fund through the Big Give Christmas Challenge. This target was then doubled by the Big Give and the Reed Foundation, and with additional supporter donations an overall total of £10,470 was raised.

**Report of the Trustees  
for the year ended 31 December 2023**

Every year, the TSA is proud to run a design competition as part of our festive card design offerings. This year's winner was Jasmine Ferguson, a little girl with TSC who submitted a wonderful Santa Claus design. The response to our 2023 Christmas cards was fantastic, raising £1,740 for the TSA.

Despite the challenges so many people faced throughout 2023, our fundraisers dug deep and went above and beyond for the TSA. We have a growing number of individuals who raised money by taking part in outdoor activities such as fun runs, other walking and running events and cycle rides. Other fundraisers enjoyed organising activities such as bingo nights and gala dinners. We hope 2024 will provide a year of steady growth and stability within the TSA as we look to sustainably generate income from more diverse and varied sources.

Investment policy

The Trustees have appointed investment managers to manage the Association's investment portfolio under a discretionary investment mandate. 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 rather than to individual stocks.

In the year ended 31 December 2023, the total return on the portfolio was 6.55%. 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 objective stated above.

In Q3 2024 Trustees will review how much cash the charity is holding and decide whether to reinvest the cash remaining with our investment managers, move it into an account to attracting a higher rate of interest, or divide this cash so that some can be reinvested and some can be moved into higher interest accounts.

**FINANCIAL REVIEW**

**Financial position**

**Grant making policy**

Research grants are given by the TSA for purposes directly concerned with furthering an understanding of TSC and its treatment. The TSA is a member of the Association of Medical Research Charities (AMRC) and follows AMRC policy in the conditions attached to awarding grants. All applications are peer reviewed.

Benevolent grants through the TSA Support Fund are given to individuals and families facing the financial impact of TSC. The TSA Support Fund provides a grant for a wide-range of items and experiences, such as household items, respite care and travel costs to hospital visits. All applications for assistance are reviewed by a senior lead and grants awarded confidentially where deemed appropriate, based on the Association's guidelines. Trustees are eligible to apply for such grants and are dealt with in the same way as any other applicant.

**Statement on reserves and review of financial position as at 31st December 2023**

At the end of the year the TSA had total funds of £888,294 consisting of:

- Designated funds of £686,294 (further details as below) which are anticipated to be spent down in the coming years
- Non designated reserves of £202,000 representing 6 months of expenditure excluding any research commitments

**Designated Fund**

The Designated Fund largely arises from a bequest in 1993 by the late Mr H I Leech which does not form part of the TSA's normal reserves.

This Fund has been broadly treated as an "endowment" and invested with professional advisers to provide a resource which supports the TSA in delivering its charitable objectives. In particular, it enables the Trustees to:

- Fund or co-fund out of capital (and, if need be, at short notice) major medical research projects which are determined by the Trustees to be crucial for the treatment of TSC
- Help fund the charitable activities from investment income, thereby helping to secure the future of the charity and provide continuing support to future and current people affected by TSC

**Report of the Trustees  
for the year ended 31 December 2023**

In recent years, the balance on the Designated Fund has reduced significantly as a result of both additional research commitments and the provision of additional services, the cost of which have not been covered by the income of the Association.

The trustees are of the opinion that the Designated Funds should be retained to a minimum of £300,000. This allows the TSA to have at minimum sufficient funds equivalent to around 6 months of outgoings, as well as the means to instigate major medical research projects, co-funded by third parties, at short notice if necessary.

Result for the year

The Association's total income for the year was **£361,627** (2022 £284,640).

Our total investment gains were **£22,290** (2022 £87,971 loss).

Taking into account the investment gain/(loss), the overall surplus for the year was **£58,583** (2022 deficit £162,380).

Pre-investment surplus in 2023 was £36,293, compared to deficit of £74,409 in 2022. This improvement of £110,702 was primarily driven by increased income of £100k and a reduction in the costs of the organisation despite increased levels of support grants in the year. This reflects the continued efforts of the leadership team and their management of resources.

The Board of Trustees and Senior Management Team continue to make important steps towards the TSA being financially sustainable for the long-term. Achieving a surplus in 2023 has been a major milestone in this plan. The Board and senior team will ensure that this surplus is managed in the best and most sustainable way for the charity, investing in infrastructure and other opportunities as is sensible.

**Report of the Trustees  
for the year ended 31 December 2023**

**FUTURE PLANS  
Strategic objectives**

The 2024 Business Plan focuses on the following activities.

**Ensuring that the TSA is on solid ground across all teams, with a view to long-term stability**

- Recruit a new Head of Fundraising and establish a clear fundraising strategy across all income streams for the immediate and long-term
- Ensure that the TSA's internal practices and structures are up-to-date and easy to follow, including access to all banking and other procedures
- Recruit to the TSA Board of Trustees, ensuring more diversity in trustee skills and backgrounds

**Providing access to good quality, accessible and timely information**

- Expand on physical and digital support materials, in particular those within the TSA Welcome Pack
- Continue to build and improve TSA social media channels
- Undergo an in-depth audit of the TSA website, following recommendations as part of this by the Patient Information Forum following our recent accreditation

**Providing the opportunity for people with TSC to connect, support and learn together**

- Explore opportunities for an expanded TSA ambassador programme, where community members can connect with others in the community directly
- Deliver Big Day, our biggest annual face-to-face event, so people can connect face-to-face, with the focus being on networking and feeling like part of a community
- Deliver the face-to-face Outlook event, connecting adults mildly affected by TSC
- Continue to deliver ambitious calendar of virtual events, ensuring that geographical location is not a barrier to the TSA

**Capacity-build the knowledge and expertise of professionals working with people with TSC**

- Launch Continue to build and expand the NHS TSC Rare Disease Collaborative Network (RDCN) through a range of activities including:
  - NHS TSC Clinics Education Day (virtual)
  - NHS TSC Clinics Lead Meeting (2 virtual, 1 face-to-face)
  - NHS TSC Nurse Practitioner Meeting (virtual)
  - Virtual NHS TSC Multidisciplinary team meetings (x3, providing NHS staff the chance to discuss challenging TSC patient cases virtually)
  - NHS TSC Education Meeting (x1)
- Further solidify relationship with NHS TSC clinicians through regular communications focused on improving diagnosis, care and management of TSC
- Expand and improve upon the TSA's professional TSC training modules for social and education professionals

**Driving the research agenda with the aim of improving outcomes and quality of life for people living with TSC**

- Run a seed-corn funding grant round to support the preliminary work necessary to build competitive proposals for external funding that may lead to new research initiatives
- Carry out a refresh of the TSA Research Strategy
- Continue to Work with Epilepsy Research Institute UK on the successful application to the joint-funded 'Emerging Leader' award
- Support review of the UK clinical guidelines on identifying and managing TSC, so it is consistent with updated international guidelines and incorporates UK guidance on new treatments
- Continue to grow the TSA's research volunteer network to drive patient-centric research and increase investment in TSA research through patient and public involvement and engagement
- Continue to build relationships with potential partners and funders to identify new opportunities for joint working

**Report of the Trustees  
for the year ended 31 December 2023**

**Campaigning for better access to treatments and care**

- Disseminate our own and others' research findings internally, across TSC clinics and across TSC researchers, to drive improvements in TSC policy and practice
- Continue to work with pharmaceutical partners, fostering strong relationships in anticipation of pipeline product launches (i.e. topical sirolimus for facial angiofibromas; ganaxolone for TSC-related epilepsy; cannabidiol for TAND)
- Should NICE reject topical sirolimus funding application for TSC-related facial angiofibromas: Work with key stakeholders – including the TSC community – to appeal to NICE in order to get the decision that the TSC community deserve
- Should NICE accept topical sirolimus funding application for TSC-related facial angiofibromas: Work with key stakeholders – including the TSC community – to ensure timely access to the treatment
- Continue to efficiently work with stakeholders to ensure access to and raise awareness of new medicines, such as cannabidiol

Enablers

We will also invest time and energy in the strategic enablers that secure the long-term future of the charity including:

**High-quality, integrated financial management**

- TSA leadership to continue to develop financial management skills, improving confidence and capabilities that will benefit the charity Digital transformation and smart working to reach more people
- Work with our new IT provider to ensure smooth migration to new system(s)
- Continue our journey to working smarter, with more automation and streamlining across outputs
- Further encourage greater use of digital platforms across community, further reducing costs and resourcing

**An enterprising approach to income generation to drive more research**

- Continue to generate income by delivering patient and public involvement activities across both academic and industry research projects
- Continue to develop opportunities from alternative sources, including sponsorship by pharmaceutical companies
- Have a greater focus on trusts and foundations, opening new opportunities for income across small, medium and large applications
- Develop new approaches to supporting major donors and potential major donors, encouraging legacies and working with corporates to generate income
- Recruit an experienced and confident Head of Fundraising to lead in the development of a new fundraising strategy and income generation broadly

**Renew the TSA Board membership so we have a more diverse set of trustees with the right skills to deliver our strategic aims and a clear succession plan for senior trustee roles**

In review of the current TSA Board of Trustees, the Board agreed on the need to refresh its membership following loss and departures of several key individuals. A key focus is to re-introduce Board members with an in-depth professional background of income generation, fundraising and governance. This will help the Board to be re-invigorated and to welcome fresh knowledge and impetus into the organisation.

Our mission remains unchanged: to provide help for today and a cure for tomorrow.



**Report of the Trustees  
for the year ended 31 December 2023**

**STRUCTURE, GOVERNANCE AND MANAGEMENT**

**Structure, governance and management**

**Constitution**

The Association was incorporated under the Companies Act 1985 as a company limited by guarantee, registered in England, No 02900107, and is governed by its Memorandum and Articles of Association. It is also registered as a charity in England and Wales (No 1039549) and in Scotland (No SC042780).

**Recruitment and appointment of new trustees**

The Association considers the skill sets of existing trustees, and prospective trustees are considered for appointment, based on the additional skills they can bring to the Association. Candidates arise as a result of recruitment campaigns.

**Organisational structure**

A list of the Offices and other Trustees who served for all or part of the year, or who have been appointed before the date of this report, appears in 'Reference and administrative information' below.

At each Annual General Meeting, one-third of the Trustees retire by choice or rotation. 2023 saw the sad loss of TSA Lifetime President and Trustee, Tom Carter. Rajan Khullar stepped down from the Board. The Board and members elected and appointed Simon James as the new Treasurer, Frances Elmslie as the Chair and Sanjay Sethi as the Vice-Chair of the TSA.

**Risk management**

The Trustees meet as a Board four times each year.

The Trustee's policies ensure that strategic planning and risk management processes become part of the operating processes of the Association. The Trustees have identified the major risks to which the Association is exposed, determined the relevant significance of those risks, and regularly review the adequacy of the systems that have been established to mitigate those risks.

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

- Reviewing and approving a business plan and accompanying budget each year;
- Monitoring financial performance against the planned budget through quarterly 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 outlook for the charity;
- Overseeing the preparation of the statutory Annual Report and Accounts, ensuring compliance with accounting standards 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.

The Research Committee (Rescom) is an advisory committee to the Association's Board that is made up of a minimum of five and a maximum of 10 persons, including the Chair and a minimum of two professional and two lay members. Rescom meets to advise on strategic prioritisation of funding for research grant rounds. The TSA is a member of the Association of Medical Research Charities, and we are committed to following the principles and practices of effective grant management including the AMRC's five principles of peer review.

**REFERENCE AND ADMINISTRATIVE DETAILS**

**Registered Company number**

02900107 (England and Wales)

**Registered Charity number**

1039549

Report of the Trustees  
for the year ended 31 December 2023

**Registered office**

Nightingale House  
46-48 East Street  
Epsom  
Surrey  
KT17 1HQ

**Trustees**

T E Carter (resigned 25.11.23)  
Ms A Cotton  
Dr F V Elmslie  
R Khullar (resigned 25.11.23)  
Dr J C Kingswood  
J Rogers  
S Sethi  
Rev M P Short  
S J James (appointed 28.11.23)

**Company Secretaries**

Dr P Takhar  
L Langlands

**Investment managers**

Brewin Dolphin Limited, 12 Smithfield Street, London, EC1A 9BD

**Bankers**

CAF Bank Limited, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent, ME19 4JQ  
National Westminster Bank Plc, 67 High Street, Staines, TW18 4

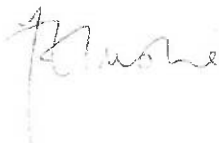
**Website**

[www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)

**Independent Examiner**

Tudor John Limited  
Nightingale House  
46-48 East Street  
Epsom  
Surrey  
KT17 1HQ

Approved by order of the board of trustees on ...8<sup>th</sup> August 2024..... and signed on its behalf by:



.....  
F Elmslie - Trustee

**Independent Examiner's Report to the Trustees of  
The Tuberous Sclerosis Association (Registered number: 02900107)**

**Independent examiner's report to the trustees of The Tuberous Sclerosis Association ('the Company')**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 December 2023.

**Responsibilities and basis of report**

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under Section 145(5) (b) of the 2011 Act.

**Independent examiner's statement**

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the **\*\*ERROR - relevant professional body must be completed\*\***, which is one of the listed bodies.

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:

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

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.



Hazel Day BSc FCA DChA

Tudor John Limited  
Nightingale House  
46-48 East Street  
Epsom  
Surrey  
KT17 1HQ

Date: 16 August 2024

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Statement of Financial Activities for the year ended 31 December 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies		250,553	90,547	341,100	241,232
<b>Charitable activities</b>					
Research		-	-	-	22,000
Other trading activities	2	2,225	-	2,225	3,668
Investment income	3	<u>18,302</u>	<u>-</u>	<u>18,302</u>	<u>17,740</u>
<b>Total</b>		<u>271,080</u>	<u>90,547</u>	<u>361,627</u>	<u>284,640</u>
 <b>EXPENDITURE ON</b>					
Raising funds	4	84,695	-	84,695	84,558
<b>Charitable activities</b>					
Family Care & Support		148,822	-	148,822	168,161
Research		<u>91,817</u>	<u>-</u>	<u>91,817</u>	<u>106,330</u>
<b>Total</b>		<u>325,334</u>	<u>-</u>	<u>325,334</u>	<u>359,049</u>
 Net gains/(losses) on investments		<u>22,290</u>	<u>-</u>	<u>22,290</u>	<u>(87,971)</u>
 <b>NET INCOME/(EXPENDITURE)</b>		(31,964)	90,547	58,583	(162,380)
 <b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		<u>829,711</u>	<u>-</u>	<u>829,711</u>	<u>992,091</u>
 <b>TOTAL FUNDS CARRIED FORWARD</b>		<u><u>797,747</u></u>	<u><u>90,547</u></u>	<u><u>888,294</u></u>	<u><u>829,711</u></u>

The notes form part of these financial statements

**THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)**

**Balance Sheet  
31 December 2023**

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
<b>FIXED ASSETS</b>					
Investments	12	660,307	-	660,307	642,707
<b>CURRENT ASSETS</b>					
Debtors	13	22,873	-	22,873	3,385
Cash at bank		<u>156,592</u>	<u>90,547</u>	<u>247,139</u>	<u>270,842</u>
		179,465	90,547	270,012	274,227
<b>CREDITORS</b>					
Amounts falling due within one year	14	(42,025)	-	(42,025)	(87,223)
<b>NET CURRENT ASSETS</b>		<u>137,440</u>	<u>90,547</u>	<u>227,987</u>	<u>187,004</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<u>797,747</u>	<u>90,547</u>	<u>888,294</u>	<u>829,711</u>
<b>NET ASSETS</b>		<u>797,747</u>	<u>90,547</u>	<u>888,294</u>	<u>829,711</u>
<b>FUNDS</b>	15				
Unrestricted funds				797,747	829,711
Restricted funds				<u>90,547</u>	<u>-</u>
<b>TOTAL FUNDS</b>				<u>888,294</u>	<u>829,711</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2023.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 December 2023 in accordance with Section 476 of the Companies Act 2006.

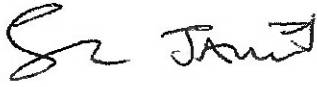
The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

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

The financial statements were approved by the Board of Trustees and authorised for issue on .....15 August 2024..... and were signed on its behalf by:

The notes form part of these financial statements



.....  
S James - Trustee

**THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)**

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- preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

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

The financial statements were approved by the Board of Trustees and authorised for issue on .....15 August 2024..... and were signed on its behalf by:



.....  
S James - Trustee

The notes form part of these financial statements

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements for the year ended 31 December 2023

### 1. ACCOUNTING POLICIES

#### **BASIS OF PREPARING THE FINANCIAL STATEMENTS**

The financial statements of the charitable company, which is a public benefit entity under FRS 102, 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)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention, with the exception of investments which are included at market value, as modified by the revaluation of certain assets.

#### **INCOME**

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

In the case of a donation, entitlement usually arises immediately on its receipt. However, some gifts may include terms or conditions which must be met before the Association is entitled to the resources.

In the case of a grant, evidence of entitlement will usually exist when the formal offer of funding is communicated in writing to the Association. However, some grants will contain terms or conditions which must be met before the Association has entitlement to the resources.

Entitlement to a legacy is recognised when it is probable that it will be received. Receipt is normally probably when there has been grant of probate; the executors have established that there are sufficient assets in the estate, after settling any liabilities, to pay the legacy; and any conditions attached to the legacy are either within the control of the charity or have been met.

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

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

#### **EXPENDITURE**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, 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 accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

#### **TANGIBLE FIXED ASSETS**

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Fixtures and fittings                      - 25% on reducing balance

#### **TAXATION**

The charity is exempt from corporation tax on its charitable activities.

#### **FUND ACCOUNTING**

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.



# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2023

### 1. ACCOUNTING POLICIES - continued

#### FUND ACCOUNTING

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

#### PENSION COSTS AND OTHER POST-RETIREMENT BENEFITS

The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

#### FINANCIAL INSTRUMENTS

The charity 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 the carrying value plus accrued interest less repayments. The financing charge to expenditure is at a constant rate calculated using the effective interest method.

#### Debtors

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

#### 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.

#### Creditors and Provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

### 2. OTHER TRADING ACTIVITIES

	2023	2022
	£	£
Christmas cards & other sales	<u>2,225</u>	<u>3,668</u>

### 3. INVESTMENT INCOME

	2023	2022
	£	£
Income from managed portfolio	<u>18,302</u>	<u>17,740</u>

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2023

### 4. RAISING FUNDS

#### INVESTMENT MANAGEMENT COSTS

	2023	2022
	£	£
Portfolio management charges	<u>4,592</u>	<u>4,767</u>

### 5. GRANTS PAYABLE

	2023	2022
	£	£
Research	<u>(2,109)</u>	<u>183</u>

The total grants paid to institutions during the year was as follows:

	2023	2022
	£	£
* University of Bristol NHS Foundation Trust - Randomised Controlled Trial of Acceptance and Commitment Therapy in the Tuberous Sclerosis Complex	-	183
*University College London - The TSC1 and TSC2 Variation Databases	(226)	-
*Institute of Medical Genetics, Cardiff	(1,370)	-
*Research Department of Genetics, University College London	<u>(513)</u>	<u>-</u>
	<u>(2,109)</u>	<u>183</u>

Research Grants are awarded on an annual basis and are only renewed after an annual review. In accordance with the SORP, only the first year of the grant is charged against the relevant fund up to the committed amount of the grant.

Negative balances represent the unclaimed elements of grants previously awarded, which have now expired.

### 6. SUPPORT COSTS

	Management	Other	Governance costs	Totals
	£	£	£	£
Family Care & Support	590	8,375	3,734	12,699
Research	<u>377</u>	<u>5,691</u>	<u>3,733</u>	<u>9,801</u>
	<u>967</u>	<u>14,066</u>	<u>7,467</u>	<u>22,500</u>

Support costs have been allocated between Raising donations and Legacies and the Activities of the Association by reviewing each cost type and identifying what drives the cost and splitting based on those cost drivers.

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2023

### 7. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2023 nor for the year ended 31 December 2022.

### TRUSTEES' EXPENSES

There were no trustees' expenses paid for the year ended 31 December 2023 nor for the year ended 31 December 2022.

The trustees are entitled to be paid expenses they incur in the governance of the Association. This may include travel, accommodation and similar expenses. No Trustees received payments for reimbursement of expenses during the year.

### 8. STAFF COSTS

	2023	2022
	£	£
Wages and salaries	216,096	204,113
Social security costs	16,718	16,360
Other pension costs	<u>10,688</u>	<u>11,013</u>
	<u>243,502</u>	<u>231,486</u>

The average monthly number of employees during the year was as follows:

	2023	2022
Fundraising	2	1
Family Support and Communications	4	4
Research	<u>2</u>	<u>2</u>
	<u>8</u>	<u>7</u>

No employees received emoluments in excess of £60,000.

### 9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	236,732	4,500	241,232
<b>Charitable activities</b>			
Research	22,000	-	22,000
Other trading activities	3,668	-	3,668
Investment income	<u>17,740</u>	<u>-</u>	<u>17,740</u>
<b>Total</b>	<u>280,140</u>	<u>4,500</u>	<u>284,640</u>
<b>EXPENDITURE ON</b>			
Raising funds	84,558	-	84,558
<b>Charitable activities</b>			
Family Care & Support	163,661	4,500	168,161
Research	<u>106,330</u>	<u>-</u>	<u>106,330</u>

**THE TUBEROUS SCLEROSIS ASSOCIATION**

**Notes to the Financial Statements - continued  
for the year ended 31 December 2023**

**9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued**

	Unrestricted funds £	Restricted funds £	Total funds £
<b>Total</b>	<u>354,549</u>	<u>4,500</u>	<u>359,049</u>
Net gains/(losses) on investments	<u>(87,971)</u>	<u>-</u>	<u>(87,971)</u>
<b>NET INCOME/(EXPENDITURE)</b>	<b>(162,380)</b>	<b>-</b>	<b>(162,380)</b>
<b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	<u>992,091</u>	<u>-</u>	<u>992,091</u>
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u><b>829,711</b></u>	<u><b>-</b></u>	<u><b>829,711</b></u>

**10. INTANGIBLE FIXED ASSETS**

	Database costs £
<b>COST</b>	
At 1 January 2023 and 31 December 2023	<u>19,624</u>
<b>AMORTISATION</b>	
At 1 January 2023 and 31 December 2023	<u>19,624</u>
<b>NET BOOK VALUE</b>	
At 31 December 2023	<u>-</u>
At 31 December 2022	<u>-</u>

**11. TANGIBLE FIXED ASSETS**

	Fixtures and fittings £
<b>COST</b>	
At 1 January 2023 and 31 December 2023	<u>1,135</u>
<b>DEPRECIATION</b>	
At 1 January 2023 and 31 December 2023	<u>1,135</u>
<b>NET BOOK VALUE</b>	
At 31 December 2023	<u>-</u>
At 31 December 2022	<u>-</u>

**THE TUBEROUS SCLEROSIS ASSOCIATION**

**Notes to the Financial Statements - continued  
for the year ended 31 December 2023**

**12. FIXED ASSET INVESTMENTS**

	2023	2022
	£	£
Shares	651,203	628,541
Brewin Dolphin capital account	<u>9,104</u>	<u>14,166</u>
	<u>660,307</u>	<u>642,707</u>

Additional information as follows:

	Listed investments £
<b>MARKET VALUE</b>	
At 1 January 2023	628,541
Additions	165,929
Disposals	(165,557)
Revaluations	<u>22,290</u>
At 31 December 2023	<u>651,203</u>
<b>NET BOOK VALUE</b>	
At 31 December 2023	<u>651,203</u>
At 31 December 2022	<u>628,541</u>

All investments were managed through UK investment managers.

The historical cost of the investments at the year end is £609,599 (2022 £597,504).

Investments (neither listed nor unlisted) were as follows:

	2023	2022
	£	£
Brewin Dolphin capital account	<u>9,104</u>	<u>14,166</u>

**13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	2023	2022
	£	£
Other debtors	5,471	1,502
Prepayments	<u>17,402</u>	<u>1,883</u>
	<u>22,873</u>	<u>3,385</u>

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2023

### 14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023	2022
	£	£
Trade creditors	8,238	36,776
Social security and other taxes	5,263	5,241
Other creditors	1,482	383
Accrued expenses	<u>27,042</u>	<u>44,823</u>
	<u>42,025</u>	<u>87,223</u>

The provision for grants awarded is for the full amount of future expenditure up to the committed amount of each grant. The following table shows the research institution, a breakdown of the unexpended commitment brought forward, the amount paid, the commitments arising during the year (and hence recognised in the Statement of Financial Activities (SOFA) and the unexpended commitment carried forward at the end of the year in respect of each grant. Further detail in respect of each grant is given in note 5.

	At 1.1.23	SOFA	Paid	At 31.12.23
	£	£	£	£
* Institute of Medical Genetics, Cardiff	1,371	(1,371)	-	-
* Cardiff University	618	-	618	-
* Research Department of Genetics, University College, London	513	(513)	-	-
* University of Manchester, Faculty of Life Sciences	226	-	-	226
* Erasmus MC, Department of Clinical Genetics	180	-	180	-
* University College London - The TSC1 and TSC2 Variation Databases	228	(228)	-	-
* Whitehead Institute - Towards specific Motor Inhibitors capable of rescuing Tuberous Sclerosis Complex loss-of-function	185	-	-	185
* Cardiff University - Targeting the Ref1/STAT3 axis to treat Tuberous Sclerosis Complex	5,169	-	4,544	625
* Cardiff University - Characterising the roles of exosomes in Tuberous Sclerosis Complex	620	-	-	620
* University of Bristol NHS Foundation Trust - Randomised Controlled Trial of Acceptance and Commitment Therapy in Tuberous Sclerosis Complex	37,022	-	32,793	4,229
* Institute of Psychiatry Psychology and Neuroscience - Neurocognitive predictors of neurodevelopmental impairment in infants and toddlers with TSC	67	-	-	67
* Cardiff University - An innovative model system to cell invasion in TSC/LAM to uncover new drug targets and therapies	65	-	-	65
*TANDem Consortium - to fund a number of small seed projects linked to the TANDem project to help build research capacity in TAND.	<u>30,000</u>	<u>-</u>	<u>7,517</u>	<u>22,483</u>
	<u>76,264</u>	<u>(2,112)</u>	<u>23,621</u>	<u>28,497</u>

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2023

### 15. MOVEMENT IN FUNDS

	At 1.1.23 £	Net movement in funds £	At 31.12.23 £
<b>Unrestricted funds</b>			
General fund	300,000	(70,073)	229,927
Designated Endowment Fund	<u>529,711</u>	<u>38,109</u>	<u>567,820</u>
	829,711	(31,964)	797,747
<b>Restricted funds</b>			
Research	-	46,047	46,047
Sponsored events	<u>-</u>	<u>44,500</u>	<u>44,500</u>
	<u>-</u>	<u>90,547</u>	<u>90,547</u>
<b>TOTAL FUNDS</b>	<u>829,711</u>	<u>58,583</u>	<u>888,294</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
<b>Unrestricted funds</b>				
General fund	252,778	(322,851)	-	(70,073)
Designated Endowment Fund	<u>18,302</u>	<u>(2,483)</u>	<u>22,290</u>	<u>38,109</u>
	271,080	(325,334)	22,290	(31,964)
<b>Restricted funds</b>				
Research	46,047	-	-	46,047
Sponsored events	<u>44,500</u>	<u>-</u>	<u>-</u>	<u>44,500</u>
	<u>90,547</u>	<u>-</u>	<u>-</u>	<u>90,547</u>
<b>TOTAL FUNDS</b>	<u>361,627</u>	<u>(325,334)</u>	<u>22,290</u>	<u>58,583</u>

### Comparatives for movement in funds

	At 1.1.22 £	Net movement in funds £	Transfers between funds £	At 31.12.22 £
<b>Unrestricted funds</b>				
General fund	108,969	(85,922)	276,953	300,000
Designated Endowment Fund	<u>883,122</u>	<u>(76,458)</u>	<u>(276,953)</u>	<u>529,711</u>
	992,091	(162,380)	-	829,711
<b>TOTAL FUNDS</b>	<u>992,091</u>	<u>(162,380)</u>	<u>-</u>	<u>829,711</u>

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2023

### 15. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
<b>Unrestricted funds</b>				
General fund	262,399	(348,321)	-	(85,922)
Designated Endowment Fund	<u>17,741</u>	<u>(6,228)</u>	<u>(87,971)</u>	<u>(76,458)</u>
	280,140	(354,549)	(87,971)	(162,380)
<b>Restricted funds</b>				
Education	2,500	(2,500)	-	-
Glasgow TSC Clinic	<u>2,000</u>	<u>(2,000)</u>	-	-
	<u>4,500</u>	<u>(4,500)</u>	-	-
<b>TOTAL FUNDS</b>	<u>284,640</u>	<u>(359,049)</u>	<u>(87,971)</u>	<u>(162,380)</u>

### 16. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 December 2023.