

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

THE TUBEROUS SCLEROSIS ASSOCIATION

Unaudited Financial Statements for the Year Ended 31 December 2022

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THE TUBEROUS SCLEROSIS ASSOCIATION

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for the year ended 31 December 2022**

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THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

**Report of the Trustees
for the year ended 31 December 2022**

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 2022. 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).

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

**Report of the Trustees
for the year ended 31 December 2022**

OBJECTIVES AND ACTIVITIES

Objectives and aims, including public benefit

BACKGROUND

The Tuberous Sclerosis Association (TSA) was launched in 1977 with a membership of 50 families and funds of just £25 and has 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 associated neuropsychiatric disorders which can include autism spectrum disorders, attention deficit hyperactivity disorders, aggression, depression, anxiety and sleep disorders which have a serious impact on family life

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: 2022

The TSA has continued to deliver on its strategic priorities:

- Supporting the TSC community
- Being at the forefront of the research agenda

OBJECTIVES AND ACTIVITIES

The TSA has 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 problems caused by TSC

The TSA is in the 4th year of a 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. This overall strategy has been disrupted by Covid. We plan to:

- REACH more people - significantly increase the number of people the TSA supports by 2023
- Drive more REseArCH - stimulate the same amount of investment in TSC research during 2019-2023 as was invested by the TSA over the previous 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 2022**

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

**Report of the Trustees
for the year ended 31 December 2022**

2022 Business Plan

The first three 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 into the TSC community.

However, due to cost-of-living impact and working with a smaller team than originally envisaged in 2022 and beyond, we focussed our resource on a smaller number of strategic objectives in 2022 to help the TSA community and the professionals who work with them. These were:

Providing access to good quality, accessible and timely information

- Develop an integrated package of support for individuals living with TSC and their families on TSC-Associated Neuropsychiatric Disorders (TAND) which can be delivered across our support line, website, social media, and regular monthly webinars
- 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.

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

- Deliver a slimmed-down Big Day so people can connect face-to-face, as well as virtually across other events, with fewer formal sessions and more time for networking.
- Carry out a 'TSC Census' to better understand who the TSA is supporting, where there are gaps in the people we reach, and how we can reach them.

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

- Develop and launch virtual training for residential and home support workers which will help them to provide better support for individuals living with TSC and their families.
- Develop and launch virtual training for SEND leads, teachers and teaching assistants which is ready for launch in September 2022, helping those who have a child with TSC joining their new class to understand how best to support them over the coming year.
- Support the NHS TSC Clinics Network through a range of activities including a virtual annual NHS TSC clinics day and a revival of the role of medical advisers.

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

- Continue to support the TSA's current portfolio of funded grants, as some projects will continue into 2022 due to delays in data gathering caused by the pandemic.
- Repurpose the money ring-fenced for a TANDem workshop to open a TAND-focused flexi-grant round, open to researchers across the globe.
- Develop and deliver the UK Natural history of epilepsy and standards of care in TSC, working closely with the Chief Investigator and Co-Investigators.
- Support review of the UK clinical guideline on identifying and managing TSC, so it is consistent with updated international guidelines and incorporates UK guidance on new treatments.

Campaigning for better access to treatments and care

- Share the views of people living with TSC and their families on newly licensed treatments for TSC-related epilepsy (Epidyolex, cannabidiol) with UK decision-makers.
- Make sure people living with TSC and their families are involved in research by manufacturers relating to topical sirolimus treatments for facial angiofibromas.
- 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.

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

**Report of the Trustees
for the year ended 31 December 2022**

Strategic enablers

We will focus on:

High-quality, integrated financial management

- Senior Management continue to upskill and utilise accounting software to make informed decisions faster with support of our accountants.

Digital transformation and smart working to reach more people

- Continue our journey to regular and timely 'digital first' communications across the website and social media.
- 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.
- Review the TSA's IT assets such as laptops and scanners which are rapidly depreciating, and identify funding for a rolling programme of replacements.
- Invest in the development of our website so we have the technical capability to support ambitious online fundraising campaigns by other charities that we would like to emulate.

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.
- Define a 'medium gifts' programme of donations up to £3k per annum and develop a new strategy to identify a pool of donors and potential donors who will support us.
- Review whether we can generate most income by developing a new community fundraising campaign to replace Tea and Scones or by identifying and piggybacking on an external community fundraising campaign such as the Big Give.

STRATEGIC REPORT

The TSA's Trustees and staff continue to be ambitious about what we want to achieve for individuals living with TSC and their families.

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

In 2022, 5,253 people made up of those living with TSC, their families, carers and friends contacted the Charity. This was 55 per higher than the start of the strategy (2018: 3,394 people)

The TSA Support Line continues to provide vital support by telephone and email to people living with TSC across the UK with 413 people in contact in 2022 (2021: 408 people). The website was visited by 26,598 users in 2022 which was 13% higher than last year (2021: 23,458 users) reflecting the increasing importance of a digital footprint.

**Report of the Trustees
for the year ended 31 December 2022**

Driving more research

The TSA continued to drive the research agenda by running the 2022 TANDem Seed Grant Funding Round jointly with TAND Consortium. The purpose of the grant round was to offer small 'seed' grants to international researchers that will address priority research areas identified in a recent scoping review of all TAND research to date. In order to ensure the most direct benefit to people with TSC and their families, the grant call specifically encouraged small projects that would be complementary to the TANDem project (a project already co-funded by the TSA and the King Baudouin Foundation) and/or that could 'bolt on' to the TANDem project. Following the review process, the TAND review panel awarded funding to Dr Liezl Schlebusch (University of Cape Town), Ms Shoba Srivastava (University of Cape Town) and Dr Stacey Bissell (University of Birmingham).

2022 also saw the TSA join forces with Epilepsy Research UK to jointly fund a research fellowship with a focus on TSC-related epilepsy. The selected researcher will highlight an area of epilepsy research that will benefit not only epilepsy as a whole, but also TSC-related epilepsy. 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 is a central pillar of the TSA purpose. However, the Trustees have made the difficult but ultimately responsible decision that further research commitments will only be made from operating surpluses to ensure that the charity is able to continue to deliver its mission from a position of financial stability. All existing research commitments continue to be met, and the charity continues to drive TSC research more broadly.

2022 was a year of transition for the TSA team with key individuals leaving the charity which impacted overall income generation. The new leadership team is committed to the 5-year strategy including the plan to balance income and expenditure to ensure the charity is sustainable in the long term.

**Report of the Trustees
for the year ended 31 December 2022**

OBJECTIVES AND ACTIVITIES

PERFORMANCE:

Support services 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, which enables people across the UK to contact our small team of professional advisers confidentially by telephone, email, webchat and post (9am to 5pm on Monday to Friday). We were contacted by around 32 people each month in 2022 asking for help and support. Some callers wanted practical information, others needed a listening ear and emotional support.

We also provided proactive information and resources through our website (www.tuberous-sclerosis.org) and signpost to them through our popular social media channels (we use Facebook for people living with TSC and their families, Twitter for researchers, clinicians, and opinion formers in the media and Parliament, and LinkedIn for other professionals).

The TSA has been always proud to offer support and information to everyone in the TSC community, including the training of professionals focused on the condition. To further improve our capabilities and impact of training professionals, in 2022 we developed online training packages for social and education professionals. The modules cover vital areas of TSC, to allow these professionals to offer the best support possible to people with TSC. The modules, which will be eligible for Continual Professional Development points (CPD, ongoing education that many professionals must do every year) are expected to launch in 2023.

During 2022 we continued to host our popular virtual events, giving the TSC community the opportunity to virtually come together in order to network, receive support and information, and learn more about TSC as a condition.

We organised regular virtual events focused on the concerns that people were expressing on the TSA Support Line. These events were recorded and shared online so they were accessible for families with caring responsibilities. Virtual events in 2022 included:

- Talks on the physical and medical impact of TSC, such as an overview of TSC and its relationship to the lung condition lymphangioleiomyomatosis (LAM), the kidneys, and women's health
- Meetings with specific NHS TSC clinics, allowing people to better understand their role and how to access such clinics
- Virtual get-togethers, such as our festive event in December 2022 for Outlook – our group for adults mildly affected by TSC

In 2022, we returned to hosting face-to-face events for the first time since the covid-19 pandemic. In April 2022, we welcomed adults mildly affected by TSC to the longstanding Outlook meeting. Hosted in Durham, the event gathered 21 attendees. The TSA had planned to re-introduce Big Day, our annual face-to-face meeting for everyone in the TSC community, in 2022. However, Big Day needed to be postponed to 2023 due to rail strikes.

During 2022 we awarded £4,500 across 19 grants from the TSA Support Fund to individuals and families. The TSA Support Fund provides small discretionary grants confidentially to our community, offering a lifeline to individuals and families when the financial implications of TSC overwhelm them. We prioritise community members in receipt of benefits or on low incomes who are unlikely to have savings.

The TSA worked hard with all decision-makers across the UK in discussions regarding access to cannabidiol (brand name Epidyolex) for TSC-related epilepsy. Following a hard series of campaigning, the TSA was delighted to secure funding agreements in Scotland and Wales for cannabidiol in 2022, with Northern Ireland also following. Indication from England decision-makers that they were likely to reject funding of the medicine led to the TSA spearheading an in-depth campaign to change their mind – this subsequently led to a 'Yes' for England, in early 2023.

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OBJECTIVES AND ACTIVITIES

We continue to build new and solidify existing relationships with TSC clinicians and NHS TSC clinics throughout the UK. Regular contact with TSC clinicians helps to:

- Act as a trusted partner to the clinics supporting people with TSC and their loved ones
- Provide support and information to the TSC community outside of clinics, including practical information as well as a listening and empathetic ear
- Act a central pillar between clinicians, other professionals and the TSC community
- Ensure that as many people as possible are registered with an NHS TSC clinic

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 2022, we continued to work closely with colleagues from the Specialised Healthcare Commissioning Alliance (SHCA) and Genetic Alliance to raise awareness of the need to the views of patients and families when making decisions about treatments for rare diseases. We continued our membership 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.

Two issues of the TSA's popular community magazine, Scan, were published in 2022. 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 2022.

Research

Our research team are 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 2022 of £473,073.51. 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 over 2020-22.

The TSA's research portfolio of previously committed grants in 2022 consists of 9 live grants (6 of which are jointly funded). Our portfolio of ongoing projects is worth £473,073.51.

Investigator	Institution	Title and purpose of grant	Co-funder
Dr Elaine Dunlop	Cardiff University	Characterising the role of exosomes in TSC 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.	
Professor Andrew Tee	Cardiff University	Understanding the limits of everolimus and rapamycin 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.	

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OBJECTIVES AND ACTIVITIES

Dr Charlotte Tye	Kings College London	Designing a protocol to measure the developmental trajectory of infants with Tuberous Sclerosis 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.	
Dr Elaine Dunlop	Cardiff University	A model of cell invasion in TSC-LAM 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.	US Ministry of Defence
Dr Sam Amin and Dr Ingram Wright	University of Bristol	Better understanding the accessibility of mental health services for children and young people with TSC 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.	Anonymous major donor
Professor Petrus deVries and Professor Anna Jansen	University of Cape Town and 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 (such as anxiety, depression and aggressive behaviour). The two-part project will first focus on the development of a self-report TAND checklist and identification smartphone app, to measure how people are affected by TAND. The second part of the study will investigate the best ways to treat TAND, including agreement on suitable clinical guidelines for TAND. Following work in identifying and treating TAND, the TANDem Project will prepare a global team of TAND researchers to raise awareness and lead future research into TAND.	King Baudouin Foundation
Ms Shoba Srivastava	University of Cape Town	TAND in India The PhD project will ask families who live with TSC and clinicians who support families what they know about TAND, what their TAND needs are and what their priorities would be for actions in India. It will then examine how useful the self-complete quantified version of the TAND checklist (TAND-SQ) and the TAND Toolkit (draft) App are for Indian families. Finally, it will run a short caregiver wellbeing programme to see how useful and relevant it may be to TSC families in India.	

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

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OBJECTIVES AND ACTIVITIES

Dr Liesl Schlebusch	University of Cape Town	<p>Well-Beans for Caregivers Programme This project proposes a pilot study to investigate the feasibility, acceptability, and potential impact of a Caregiver Skills Training programme (developed by The World Health Organization which includes a 3-session module that focuses on improving caregivers' well-being, based on Acceptance and Commitment Therapy (ACT)) when delivered online to a group of caregivers of children with TSC living in South Africa and the United Kingdom.</p>	
Dr Stacey Bissell	University of Birmingham	<p>Exploring Sleep experiences in people with tuberous sclerosis complex (e-Slept) Sleep difficulties are outlined within TAND as an area of clinical concern (e.g. night waking, daytime sleepiness), but lived experiences of sleep management concerns and access to support. With a view towards targeted assessment and treatment from the perspective of families and caregivers, the e-Slept project aims to document caregiver experiences of managing sleep difficulties in the individual they care for with TSC in the UK.</p>	

The research portfolio continues to yield results and 2022 saw 4 live grants submit data. 3 projects reported 9 publications in preparation in 9 academic journals, while 2 projects reported 2 other forms of engagement (for example, oral and poster presentations at academic conferences or professional meetings).

TSC Research Volunteer Network

In 2022, 11 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 29 volunteers, including individuals with TSC, parents and siblings.

Throughout 2022, the TSA offered a range of opportunities to volunteers, including:

- Attending a conference organised by Epilepsy Research UK at the Frances Crick Institute in London. The event covered a range of research topics, with network attendees also raising awareness of TSC.
- Helping TSC researchers apply for funding from major funders. This was done by reading summaries of the researcher’s work, to ensure that the work was impactful and meaningful to people who are affected by TSC on a daily basis.
- Giving feedback on draft information leaflets written by a pharmaceutical companies conducting a trials 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.
- Participating in workshops focused on NHS Genomics Programme. The Newborn Genomes Programme is a plan to create an NHS pilot study to offer whole genome sequencing (WGS) to all new-borns. It is hoped that WGS of new-borns in NHS England will make it quicker and easier to identify and also treat rare conditions like TSC.

New treatments for TSC

In early 2022, Scottish Medicines Consortium approved Epidyolex (generic name ‘cannabidiol’) to treat TSC-related epilepsy. The news means that the TSC community in Scotland have been able to access this important new medicine from May 2022. The drug was approved by the All Wales Medicines Strategy Group in winter 2021. 2022 also saw decision makers in England start the appraisal process for Epidyolex and topical sirolimus cream for TSC-associated facial angiofibromas with final outcomes to be announced in 2023.

**Report of the Trustees
for the year ended 31 December 2022**

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 2022 would be a year of replenishment and returning to normality following the devastating consequences of covid-19. However, in reality the long-term financial impact of the covid-19 pandemic continued to devastate the TSA in 2022. This was further exacerbated in fresh challenges through rapidly rising inflation and a major cost of living crisis. The result of this three-pronged challenge for income generation in 2022 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 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 felt these financial challenges even harder than most charities in 2022. The TSA's small and dedicated team has 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 2022: The Zedra Trust (£3,000), The Thomas Sivewright Catto Charitable Trust (£750), The Hiscox Foundation (£3,320), The Adint Trust (£5,000), The Charities Trust (£1,000), The Street Foundation (£3,000) and the Dunn Family Charitable Foundation (£3,000).

In addition, we received unrestricted grants from Jazz Pharmaceuticals (£12,000) and Plusultra Pharma (£10,000) which was a welcome boost for the charity.

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, The Harry Krish Mootosamy Foundation (£2,000) for giving us the opportunity to deliver virtual music therapy sessions and The Reed Foundation (£1,500) who generously contributed funding to assist with discretionary grants through The TSA Support Fund. The Care Tech Charitable Foundation (£5,000) and the Peter Sowerby Foundation (£10,500) both kindly enabled us to establish a Social Care education training programme for professionals to enhance their knowledge and understanding of Tuberos Sclerosis Complex and the impact it has on individuals and families.

The generosity of grant-making trusts and foundations who supported us in 2022 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. Hiscox Market Operations Team (London) fundraised during 2021/22 and their efforts were kindly match funded by the Hiscox Foundation, bringing the total raised by the group to £6,640. We are also hugely grateful to Blinkhorns Accountancy (London) for their generous donation of £27,696.

The TSA would like to thank the amazing people who took part in the October 2022 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 £10,300. In addition, a 'virtual runner' completed the 26.2-mile distance on his own and raised a further £1,165.

Sir David Suchet CBE continued to generously support the TSA throughout 2022 through a range of means including a West End matinee performance of 'Poirot and More, A Retrospective' that he dedicated to the TSA community. In addition, as a part of the 750-year celebrations of the Fishmongers Company, Sir David kindly signed copies of his latest book, raising a fantastic £2,100 to support research into TSC.

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 £13,091 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 2022, this income stream raised over £6,000 for the TSA.

In December 2022, 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 this target to raise £4,000 for the TSA Support Fund through the Big Give Christmas Challenge in seven hours. This was then doubled by the Big Give and the Reed Foundation to £8,000.

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

Report of the Trustees for the year ended 31 December 2022

The response to our 2022 Christmas cards was fantastic, raising £3,642 for the TSA. The winner of our Christmas card competition was talented illustrator Annaliese Howard (who is mildly affected by TSC) with her 'Snowman and turkey' card.

Despite the challenges so many people faced throughout 2022, 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 2023 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. To measure the performance of the investment portfolio the Association has, in common with other charities, adopted the WM Total Charity benchmark.

In the year ended 31 December 2022, the total return on the portfolio was -8.8%, against the benchmark of -6.31%. 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.

FINANCIAL REVIEW

Financial position

Grant making policy

Research grants are given 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 2022

At the end of the year the TSA had total funds of £829,711 consisting of:

- Designated funds of £529,711 (further details as below) which are anticipated to be spent down in the coming years
- Non designated reserves of £300,000 representing ten 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

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 TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

Report of the Trustees for the year ended 31 December 2022

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 10 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 £284,639 (2021 £443,454).

Total investment loss was £87,971 (2021 £52,835 gain). To fund deficits and payments relating to research commitments entered into during the year, some investments needed to be sold to provide the Association with additional working capital.

Adjusting for the investment loss, the overall deficit for the year was £162,380. This represents a significant decline on the surplus of £19,922 in 2021. Pre-investment deficit in 2022 was £75,688, compared to £32,913 in 2021. This decline of £42,775 was primarily driven by the net and non-recurring benefit of hosting the International TSC Research Conference in 2021, which resulted in additional income of £73,399. Excluding the international conference, pre-investment net expenditure for 2021 is £106,312 which provides a better view of underlying performance and allows a more meaningful comparison with other years including 2022. On this basis, the 2022 pre-investment deficit of £75,688 is £30,624 better than the adjusted 2021 pre-investment deficit of £106,312. This reflects the continued efforts of the leadership team and their management of resources.

Political and macro-economic uncertainty in 2022 contributed to higher inflation and interest rates which in turn had an adverse effect on equity and bond markets. This resulted in a reported loss of on investments of £94,495 in 2022 which was £147,330 worse than 2021 which saw a gain of £52,835.

After adjusting for the investment loss, the overall deficit for the 2022 was £170,183, which is £190,105 lower than the £19,922 surplus in 2021.

The Board of Trustees and Senior Management Team continue to make important steps towards the TSA being financially sustainable for the long-term.

Political and macro-economic uncertainty in 2022 contributed to higher inflation and interest rates which in turn had an adverse effect on equity and bond markets. This resulted in a reported loss of on investments of £94,495 in 2022 which was £147,330 worse than 2021 which saw a gain of £52,835.

FUTURE PLANS

Strategic objectives

The 2022 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 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 audit of TSC website, updating and removing content as needed to better represent the digital-first TSA and TSC community

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

Report of the Trustees for the year ended 31 December 2022

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 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-recognised 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 clinical 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 (ie, 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

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

- 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 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
- 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 CRM

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

Report of the Trustees for the year ended 31 December 2022

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 departures of several key individuals. A key focus is to re-introduce Board members with an in-depth professional background of income generation and fundraising. 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.

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. In 2022, Lisa Suchet and Prof Patrick Bolton stepped down from the Board. Sanjay Sethi, Annemarie Cotton, Jane Rogers, and Frances Elmslie offer themselves for re-election; after an appraisal process, the Board recommends their re-election. Following untimely demise of TSA Vice-Chair, Robert Woodthorpe Browne, Sanjay Sethi continued as the Chair of the TSA, with Dr Frances Elmslie appointed to the role of Vice Chair.

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 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 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.

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.

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

**Report of the Trustees
for the year ended 31 December 2022**

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number
02900107 (England and Wales)

Registered Charity number
1039549

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

Trustees

T E Carter Company Director
Ms A Cotton Iass Adviser
Dr F V Elmslie Doctor
R Khullar Chartered Management Accountant
Dr J C Kingswood Hospital Physician
J Rogers Nurse
S Sethi Investment Manager
Rev M P Short Clerk In Holy Orders
R Woodthorpe Browne Company Director

Chief Executives

Luke Langlands
Dr Pooja Takhar
Louise Fish (January-June 2022)
John Shepherd (June-October 2022)

Company Secretaries

Luke Langlands and Dr Pooja Takhar

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

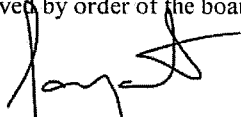
Website

www.tuberous-sclerosis.org

Independent Examiner

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

Approved by order of the board of trustees on and signed on its behalf by:



.....
S Sethi - 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 2022.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act') and the terms of the Charities and Trustee Investment (Scotland) Act 2005. The Charity's trustees consider that an audit is not required for this year (under Section 144(2) of the Charities Act 2011 (the 2011 Act)) and that the requirement of Regulation 10(I)(a) to (c) of the 2006 Accounts Regulations does not apply and that an independent examination is required. It is my responsibility to examine the accounts as required under Section (44(J)(c) of the Act and to state whether particular matters have come to my attention.

I report in respect of my examination of the Trust's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act and in accordance with Regulation 11 of the 2006 Accounts (Scotland) Regulations.

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 registered member of ICAEW which is one of the listed bodies.

I have completed my examination. I confirm that no material 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 Trust as required by section 130 of the Act and Section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations (Scotland); 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.



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

Date: ~~25~~ 25 September 2023

THE TUBEROUS SCLEROSIS ASSOCIATION

**Statement of Financial Activities
for the year ended 31 December 2022**

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		236,732	4,500	241,232	344,236
Charitable activities					
Research		22,000	-	22,000	77,969
Other trading activities	2	3,668	-	3,668	6,290
Investment income	3	<u>17,740</u>	<u>-</u>	<u>17,740</u>	<u>14,959</u>
Total		<u>280,140</u>	<u>4,500</u>	<u>284,640</u>	<u>443,454</u>
EXPENDITURE ON					
Raising funds	4	84,558	-	84,558	127,006
Charitable activities					
Family Care & Support		163,661	4,500	168,161	162,472
Research		<u>106,330</u>	<u>-</u>	<u>106,330</u>	<u>186,889</u>
Total		<u>354,549</u>	<u>-</u>	<u>359,049</u>	<u>476,367</u>
Net gains/(losses) on investments		<u>(87,971)</u>	<u>-</u>	<u>(87,971)</u>	<u>52,835</u>
NET INCOME/(EXPENDITURE)		(162,380)	-	(162,380)	19,922
RECONCILIATION OF FUNDS					
Total funds brought forward		992,091	-	992,091	972,169
TOTAL FUNDS CARRIED FORWARD		<u>829,711</u>	<u>-</u>	<u>829,711</u>	<u>992,091</u>

The notes form part of these financial statements

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

**Balance Sheet
31 December 2022**

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
FIXED ASSETS					
Investments	12	642,707	-	642,707	906,723
CURRENT ASSETS					
Debtors	13	3,385	-	3,385	90,740
Cash at bank		<u>270,842</u>	<u>-</u>	<u>270,842</u>	<u>202,171</u>
		274,227	-	274,227	292,911
CREDITORS					
Amounts falling due within one year	14	(87,223)	-	(87,223)	(207,543)
NET CURRENT ASSETS		<u>187,004</u>	<u>-</u>	<u>187,004</u>	<u>85,368</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>829,711</u>	<u>-</u>	<u>829,711</u>	<u>992,091</u>
NET ASSETS		<u>829,711</u>	<u>-</u>	<u>829,711</u>	<u>992,091</u>
FUNDS	15				
Unrestricted funds				<u>829,711</u>	<u>992,091</u>
TOTAL FUNDS				<u>829,711</u>	<u>992,091</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2022.

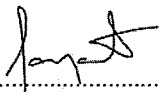
The members have not required the company to obtain an audit of its financial statements for the year ended 31 December 2022 in accordance with Section 476 of the Companies Act 2006.

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
and were signed on its behalf by:


.....
S Sethi - Trustee

The notes form part of these financial statements

THE TUBEROUS SCLEROSIS ASSOCIATION

Notes to the Financial Statements for the year ended 31 December 2022

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 2022

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

	2022	2021
	£	£
Christmas cards & other sales	<u>3,668</u>	<u>6,290</u>

3. INVESTMENT INCOME

	2022	2021
	£	£
Income from managed portfolio	<u>17,740</u>	<u>14,959</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**Notes to the Financial Statements - continued
for the year ended 31 December 2022**

4. RAISING FUNDS

INVESTMENT MANAGEMENT COSTS

	2022	2021
	£	£
Portfolio management charges	<u>4,767</u>	<u>8,307</u>

5. GRANTS PAYABLE

	2022	2021
	£	£
Research	<u>183</u>	<u>27,848</u>

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

	2022	2021
	£	£
* University of Bristol NHS Foundation Trust - Randomised Controlled Trial of Acceptance and Commitment Therapy in the Tuberous Sclerosis Complex	183	30,000
*TANDEM Consortium	-	26,289
*Centre for Integrative Psysiology, University of Edinburgh	-	(335)
*University of Birmingham	-	(3,499)
*Institute of Psychiatry, Kings College London	<u>-</u>	<u>(24,607)</u>
	<u>183</u>	<u>27,848</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

	Other	Governance costs	Totals
	£	£	£
Family Care & Support	14,099	5,527	19,626
Research	<u>9,505</u>	<u>5,527</u>	<u>15,032</u>
	<u>23,604</u>	<u>11,054</u>	<u>34,658</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 2022**

7. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2022 nor for the year ended 31 December 2021.

TRUSTEES' EXPENSES

There were no trustees' expenses paid for the year ended 31 December 2022 nor for the year ended 31 December 2021.

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

	2022	2021
	£	£
Wages and salaries	204,113	246,355
Social security costs	16,360	16,907
Other pension costs	<u>11,013</u>	<u>17,053</u>
	<u><u>231,486</u></u>	<u><u>280,315</u></u>

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

	2022	2021
Fundraising	1	3
Family Support and Communications	4	4
Research	<u>2</u>	<u>3</u>
	<u><u>7</u></u>	<u><u>10</u></u>

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

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	344,236	-	344,236
Charitable activities			
Research	77,969	-	77,969
Other trading activities	6,290	-	6,290
Investment income	<u>14,959</u>	<u>-</u>	<u>14,959</u>
Total	<u><u>443,454</u></u>	<u><u>-</u></u>	<u><u>443,454</u></u>
EXPENDITURE ON			
Raising funds	127,006	-	127,006
Charitable activities			
Family Care & Support	162,472	-	162,472
Research	186,889	-	186,889

THE TUBEROUS SCLEROSIS ASSOCIATION

**Notes to the Financial Statements - continued
for the year ended 31 December 2022**

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued	Unrestricted funds £	Restricted funds £	Total funds £
Total	<u>476,367</u>	-	<u>476,367</u>
Net gains on investments	<u>52,835</u>	-	<u>52,835</u>
NET INCOME	19,922	-	19,922
RECONCILIATION OF FUNDS			
Total funds brought forward	<u>972,169</u>	-	<u>972,169</u>
TOTAL FUNDS CARRIED FORWARD	<u><u>992,091</u></u>	<u>-</u>	<u><u>992,091</u></u>
10. INTANGIBLE FIXED ASSETS			Database costs £
COST			
At 1 January 2022 and 31 December 2022			<u>19,624</u>
AMORTISATION			
At 1 January 2022 and 31 December 2022			<u>19,624</u>
NET BOOK VALUE			
At 31 December 2022			<u>-</u>
At 31 December 2021			<u>-</u>
11. TANGIBLE FIXED ASSETS			Fixtures and fittings £
COST			
At 1 January 2022 and 31 December 2022			<u>1,135</u>
DEPRECIATION			
At 1 January 2022 and 31 December 2022			<u>1,135</u>
NET BOOK VALUE			
At 31 December 2022			<u>-</u>
At 31 December 2021			<u>-</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**Notes to the Financial Statements - continued
for the year ended 31 December 2022**

12. FIXED ASSET INVESTMENTS	2022 £	2021 £
Shares	628,541	562,003
Brewin Dolphin capital account	<u>14,166</u>	<u>344,720</u>
	<u>642,707</u>	<u>906,723</u>

Additional information as follows:

	Listed investments £
MARKET VALUE	
At 1 January 2022	562,003
Additions	346,517
Disposals	(192,008)
Revaluations	<u>(87,971)</u>
At 31 December 2022	<u>628,541</u>
NET BOOK VALUE	
At 31 December 2022	<u>628,541</u>
At 31 December 2021	<u>562,003</u>

There were no investment assets outside the UK.

The historical cost of the investments at the year end is £597,504 (2021 £367,751).

Investments (neither listed nor unlisted) were as follows:

	2022 £	2021 £
Brewin Dolphin capital account	<u>14,166</u>	<u>344,720</u>

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR	2022 £	2021 £
Other debtors	1,502	15,133
Prepayments	<u>1,883</u>	<u>75,607</u>
	<u>3,385</u>	<u>90,740</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**Notes to the Financial Statements - continued
for the year ended 31 December 2022**

14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022	2021
	£	£
Trade creditors	36,775	162,912
Social security and other taxes	5,241	5,003
Other creditors	383	1,626
Accrued expenses	<u>44,824</u>	<u>38,002</u>
	<u>87,223</u>	<u>207,543</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 1.1.22	SOFA	Paid	At 31.12.22
	£	£	£	£
* 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	14,931	-	9,762	5,169
* Cardiff University - Characterising the roles of exosomes in Tuberous Sclerosis Complex	10,030	-	9,410	620
* University of Bristol NHS Foundation Trust - Randomised Controlled Trial of Acceptance and Commitment Therapy in Tuberous Sclerosis Complex	63,095	183	26,256	37,022
* Institute of Psychiatry Psychology and Neuroscience - Neurocognitive predictors of neurodevelopmental impairment in infants and toddlers with TSC	2,517	-	2,450	67
* Cardiff University - An innovative model system to cell invasion in TSC/LAM to uncover new drug targets and therapies	21,435	-	21,370	65
*TANDEM Consortium - to fund a number of small seed projects linked to the TANDEM project to help build research capacity in TAND.	<u>26,289</u>	<u>-</u>	<u>26,289</u>	<u>-</u>
	<u>141,618</u>	<u>-</u>	<u>95,537</u>	<u>46,264</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**Notes to the Financial Statements - continued
for the year ended 31 December 2022**

14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR - continued

15. MOVEMENT IN FUNDS

	At 1.1.22	Net movement in funds	Transfers between funds	At 31.12.22
	£	£	£	£
Unrestricted funds				
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>
	<u>992,091</u>	<u>(162,380)</u>	-	<u>829,711</u>
TOTAL FUNDS	<u>992,091</u>	<u>(162,380)</u>	-	<u>829,711</u>

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

	Incoming resources	Resources expended	Gains and losses	Movement in funds
	£	£	£	£
Unrestricted funds				
General fund	266,899	(354,099)	-	(87,200)
Designated Endowment Fund	<u>17,740</u>	<u>(6,228)</u>	<u>(94,495)</u>	<u>(82,983)</u>
	<u>284,639</u>	<u>(360,327)</u>	<u>(94,495)</u>	<u>(170,183)</u>
TOTAL FUNDS	<u>284,639</u>	<u>(360,327)</u>	<u>(94,495)</u>	<u>(170,183)</u>

Comparatives for movement in funds

	At 1.1.21	Net movement in funds	At 31.12.21
	£	£	£
Unrestricted funds			
General fund	120,686	(11,717)	108,969
Designated Endowment Fund	<u>851,483</u>	<u>31,639</u>	<u>883,122</u>
	<u>972,169</u>	<u>19,922</u>	<u>992,091</u>
TOTAL FUNDS	<u>972,169</u>	<u>19,922</u>	<u>992,091</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**Notes to the Financial Statements - continued
for the year ended 31 December 2022**

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 £
Unrestricted funds				
General fund	428,495	(440,212)	-	(11,717)
Designated Endowment Fund	<u>14,959</u>	<u>(36,155)</u>	<u>52,835</u>	<u>31,639</u>
	<u>443,454</u>	<u>(476,367)</u>	<u>52,835</u>	<u>19,922</u>
TOTAL FUNDS	<u>443,454</u>	<u>(476,367)</u>	<u>52,835</u>	<u>19,922</u>

16. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 December 2022.