

REGISTERED COMPANY NUMBER: 02900107 (England and Wales)
REGISTERED CHARITY NUMBER: 1039549, SCO42780

THE TUBEROUS SCLEROSIS ASSOCIATION

Unaudited Financial Statements for the Year Ended 31 December 2021

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

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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 2021**

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 2021. 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 2021

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: 2021

The TSA has continued to deliver on its strategic priorities:

- Supporting the TSC community
- Being at the forefront of the research agenda
- Reducing its 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 midway through its 5 year strategy (2019-23) which sets out a clear vision for the charity's mission to provide help for today and a cure for tomorrow. We plan to:

- REACH more people - significantly increase the number of people being supported by the TSA 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
- Balance the TSA's finances by 2021 - having invested in research in recent years, we need to rein in expenditure and grow our income so that the charity is sustainable in the long-term

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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 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

2021 Business Plan

The first 2 years of our 2019-2023 strategy saw the TSA significantly reduce expenditure to address the charity's structural deficit while simultaneously maintaining the quality of our services and increasing our reach into the TSC community.

However, as a result of the pandemic and working with less resources than originally envisaged in 2021 and beyond, we agreed to concentrate resource on a smaller number of strategic objectives in 2021 to help the TSA community and the professionals who work with them. These were:

Providing access to good quality, accessible and timely information

- Embed the new Support Line including introducing LanguageLine for users with English as a second language, the new web chat function to drive better access for family carers and young people with TSC, and regular supervision for our Support Line advisers

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

- Make sure that no-one with TSC feels alone by bringing together individuals living with TSC, families and professionals at regular virtual events that focus on the topics that matter most to our community

Building the knowledge of professionals supporting people living with TSC

- Develop an income-generating training offer for generalist healthcare professionals, social workers and teachers combining online training modules and webinars to improve their understanding of TSC, ready for launch in 2022

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

- Host the 2021 International TSC Research Conference in June, keeping the option of moving to a virtual event under review as the pandemic continues

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Campaigning for better access to treatments and care

- Work with pharmaceutical companies developing new treatments for TSC related epilepsy and facial angiofibromas to ensure that they understand the impact of TSC on individuals living with the condition and their families and the most important outcomes of their work for patients and carers

Strategic enablers

We will focus on:

- **High-quality, integrated financial management:** working with our new finance provider to move the TSA onto the Xero accounting system reducing the senior capacity needed to run parallel management accounts
- **Digital transformation and smart working to reach more people:** introducing a regular monthly e-newsletter and reducing our postal mailings to two Scan magazines each year (Spring, Summer) and a refreshed Impact Report/Annual General Meeting mailing (Autumn)
- **An enterprising approach to income generation to drive more research:** maximising income from delegates and sponsors at the International TSC Research Conference and continuing to deliver incremental improvements across our support for major donors and potential major donors, encouraging legacies, working with corporates, trusts and foundations, and individual givers

Trustees are keen to ensure that the TSA operates as efficiently as possible, so we can invest more of our income in driving improvements in services and research for our beneficiaries. In 2021 we reviewed our overhead costs resulting in the following changes:

- We tendered our accounting and audit services and moving to a new and more cost-effective finance provider;
- We moved from an annual audit to an independent examination;
- We closed our small office and switched to being an entirely home-based organisation.
- We reduced headcount to eight members of staff, following the closure of the TSA's office
- We asked the majority of staff to voluntarily work at 90% of contracted hours, reducing salaries in 2021

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 2018 there were 3,394 people in contact with the charity including people living with TSC, their families, carers and friends. By the end of 2021 the TSA had increased this number by 47 per cent with 5,009 people in contact with the charity.

Our Support Line continued to provide vital support and advice by telephone and email to people living with TSC across the UK. 406 people contacted our Support Line for support in 2021 (2020: 384 people), and 23,458 users (2020: 20,639 users) visited our website for information.

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Driving more research

The TSA hosted the International TSC Research Conference from Thursday 17 to Saturday 19 June 2021 to encourage and support research into the causes and management of TSC. The event, which was planned to take place face-to-face in 2020 and postponed due to the pandemic, was delivered virtually in 2021 through the Royal College of Physicians online event platform

Around 250 TSC professional delegates joined the research conference from 22 countries, all of whom are dedicating their lives to improving the lives of people affected by TSC.

The theme of the research conference was 'A Vision for the Future' exploring how academics, researchers and clinicians from across the globe are ambitiously driving new opportunities in TSC to advance their understanding, deliver innovation in clinical practice, and transform the lives of people living with TSC and their families.

Balancing the books

The Trustees are clear that for the charity to be sustainable we need to be raising sufficient funds to ensure that the charity is making a surplus before any further research commitments are made.

During 2021 the Trustees took a number of steps to address the deficit:

- Moving to a new and more cost-effective finance provider
- Closing down the TSA head office and reducing the head count
- Working in partnership with other organisations and capitalising on the exceptional opportunity to raise funds through delegate fees, sponsorship and exhibition fees by hosting the 2021 international TSC research conference.

The Trustees' goal is to retain our reserves at a sensible level to give us the best possible opportunity to grow the charity from 2022 and deliver the ambitions set out in the five-year strategy 2019-2023.

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 a Support Line that enables people across the UK to contact our small team of professional advisers confidentially by telephone, email and post (9am to 5pm on Monday to Friday each week). We were contacted by around 34 people each month in 2021 asking for help and support. Some callers want practical advice and information, others need 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 opinion formers in the media and Parliament, and LinkedIn for health, social care and education professionals).

The TSA is a proud member of the Helplines Partnership, a national body that represents and supports organisations that manage help and support lines. In 2021 we were delighted that the TSA Support Line achieved accreditation by Helplines Partnership, demonstrating the level of quality and service that the TSA's small, friendly and professional support team offers those who we support.

We're proud to offer a service of a high quality and continue to work hard to make it even better. During 2021 we introduced LanguageLine to make it easier for users with English as a second language to speak to our Support Line advisers, and launched a new web chat function to drive better access for family carers and young people with TSC. We also introduced regular supervision for our Support Line advisers as part of our procedures to proactively manage the risk of vicarious trauma which can harm helpline workers and have negative implications for service users.

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During 2021 we hosted regular virtual events to provide innovative ways for the TSC community to come together and reassure them that they were not alone as the pandemic continued.

We organised thirteen virtual events focused on the concerns that people were expressing on the Support Line, and 283 people attended live – an average of 20 people per session. These events were recorded and shared online so they were accessible for families with caring responsibilities, and the event recordings were viewed 3,674 times. Virtual events in 2021 included:

- Events focused on practical aspects of TSC such as better sleep for children with the condition
- Events led by specialist clinicians focused on particular aspects of TSC such as growths on the skin and lungs
- A Welsh Get Together jointly with the Cardiff NHS TSC Clinic
- Scottish Get Together with the Glasgow Clinic
- and Northern Ireland Get Together jointly with the Belfast Clinic.

We also held a virtual Outlook event to bring together adults who are mildly affected by TSC, together with an Outlook Festive Special in the run-up to Christmas 2021.

During 2021 we awarded £3,379 in grants from the TSA Support Fund to individuals and families. The 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.

In October 2021 everolimus was finally approved for use in TSC-related epilepsy in Wales after ongoing campaigning by the TSA and the Cardiff NHS TSC Clinic. In December 2021 the Welsh Government approved a recommendation from the All-Wales Medicines Strategy Group (AWMSG) that cannabidiol (brand name Epidyolex®) should be funded within Wales for managing TSC-related epilepsy that is ‘refractory’ (not well managed using other medicines). This means that people living with TSC in Wales can access this new medicine from early 2022. Decision-makers in Wales noted the “real difference” that the input of the TSA and the TSC community had on the approval process.

The TSA continues to work hard with decision-makers across the other UK nations to ensure that they hear the voices of people living with TSC and their families when making decisions about funding cannabidiol for TSC-related refractory epilepsy in the other UK nations. A decision is expected in Scotland in early 2022 and in England in late 2022.

We continue to build our relationship with NHS TSC clinics through our annual TSC Clinics Day. In 2021 the TSC Clinics Day was held virtually in partnership with St George’s University Hospitals NHS Foundation Trust and the Evelina Children’s Hospital. The day brought together clinic leads (usually senior clinicians), clinic coordinators (usually nurses) and specialist colleagues from the 15 clinics in England and one clinic each in Scotland, Wales and Northern Ireland. Regular contact with the staff leading and managing the clinics helps to facilitate:

- Working in partnership with the clinics supporting patients and their families
- Providing support and information to the clinics in relation to education, social care and welfare
- Flagging patients with wider support needs to external agencies in social care, education and welfare
- Signposting to and facilitating engagement with TSA support services and information.

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 2021 we continued to work closely with colleagues from Genetic Alliance UK and the Specialised Healthcare Commissioning Alliance (SHCA) 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.

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Research

Our research team is committed to driving more research to give people living with TSC and their families hope for the future.

The International TSC Research Conference 2021 was originally planned to be face-to-face, and we were forced to postpone the meeting. The TSA and the international TSC research committee were determined to drive research forward despite covid-19, and we agreed to host the event virtually through an RCP platform Thursday 17 – Saturday 19 June 2021.

Around 250 TSC professional delegates joined the research conference from 22 countries. Attendees included healthcare professionals, academics, clinical and lab researchers, early career researchers, including PhD students and post-doctoral fellows, and TSC-focused organisations including TS Alliance (USA) and e-TSC (Europe-wide).

We received 70 written overviews from attendees about significant TSC research that they are undertaking and watched presentations from 12 keynote speakers and 42 presenters. The conference also included a virtual exhibition area for TSC-focused groups and industry bodies, a networking area for delegates, and two industry-sponsored events for healthcare professionals and prescribers to attend. Delegates were able to access recordings from the event through the online platform for one month afterwards so that they could maximise their learning from the conference.

We charged a fee for delegates to attend the research conference and raised £29,159 from ticket sales which was a welcome contribution to the charity's funds. The research conference was sponsored by GW Pharmaceuticals and Plusultra Pharma, and the Early Career Researcher Awards were sponsored by Noema Pharma. Novartis purchased a virtual exhibition stand at the event. In total £44,240 was generated through sponsorship and exhibition services at the conference.

The TSA is the only UK charity dedicated to supporting TSC research with a forward commitment / liability of research funding at 1 January 21 of £268,981 with an in-year research grant commitment in 2021 of £130,290. The TSA's research portfolio of committed grants at 31 December 2021 consists of 8 live grants (three of which are jointly funded). Our portfolio of ongoing projects has a combined funding commitment of £138,691.

The charity's Trustees remain determined to honour the research grant commitments that we have made despite the pandemic and decided that the Designated Endowment Fund would be used to cover the cost of our ongoing research grants programme through 2022.

Live grants table 2021

Reference	Investigator	Institution	Title and purpose of grant	Co-funder
2016-P01	Dr Martin Baron	University of Manchester	Exploiting Notch regulation to probe alternative mechanisms of TSC signalling	
2018-F01	Dr Kacper Rogala	Whitehead Institute – MIT	Identifying and creating more specific medicines for TSC This project focuses on research into the structural biology of TSC and how this can help to identify and create new and more specific drugs to treat it. It is hoped that the research can contribute towards developing a treatment that would provide all the benefits of rapamycin, but without its unwanted long-term side-effects.	
2018-S02	Dr Elaine Dunlop	Cardiff University Hospital	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.	

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2018-S04	Professor Andrew Tee	Cardiff University Hospital	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.	
2019-P01	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 'lymphangiomyomatosis') 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
2019-P02	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
2019-P03	Professor Petrus de Vries and Professor Anna Janssen	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

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2019-F01	Dr Charlotte Tye	King's 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.	
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The research portfolio continues to yield results and 2021 saw 11 grants submit data. Of these 11, 9 grants reported 10 publications while 8 reported 36 other forms of engagement (for example, oral and poster presentations at academic conferences or professional meetings).

These figures are lower than previous years as the pandemic meant that some researchers were unable to carry out lab work which impacted on data generation and delayed publication and presentation of the data.

We continue to benefit from various memberships of the Association of Medical Research Charities (AMRC) and the UK Child Health Collaboration, and Charities Research Involvement Group – part of the Shared Learning Group on Involvement.

The AMRC audited our research grants programme in 2021 and we are grateful for the opportunity to learn from their feedback and continually improve our work in this area. Every five years, the AMRC holds an audit of each member, to ensure that members are upholding processes of the highest quality. Not only did we successfully pass our audit, but the AMRC also commented that the TSA's processes are "a great example of how a smaller charity can still meet the requirements." The audit helps us to make sure that every pound the TSA invests in research is spent on high quality research that is peer reviewed to world-class standards.

Income Generation

The coronavirus pandemic continued to make for a daunting fundraising environment in 2021, and we worked hard to maximise our income from every opportunity.

We welcomed the return of mass participation challenge events; in September our six strong team raised £3,013 at the rescheduled 40th Anniversary Great North Run and in October five runners took on the London Marathon and raised an incredible £20,500 for the charity.

In addition, in April we launched our own virtual event the 'TSC Clinics Virtual Challenge', which saw our community covering an equivalent distance to travelling between two chosen NHS TSC clinics in their local area. In total we had eight individuals take part raised £3,806.

The ongoing challenging environment encouraged us to seek innovative ways to generate income for the TSA. We assessed and utilised opportunities available from national and local government to support charities through the pandemic, and successfully applied for a grant of £74,527 from the UK Government COVID medical research charity support fund. This grant reimbursed the TSA for the research grant payments that the TSA paid out in 2021 for work delivered by eligible early career researchers.

We received unrestricted grants from GW Pharmaceuticals (£10,000) in response to our Coronavirus Emergency Appeal which was a welcome boost for the charity.

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Sir David Suchet CBE continued to generously support the TSA throughout 2021 through a range of means including donating profits from his books and signing books and photographs. He also gave his time to the charity for 'In Conversation with Sir David Suchet CBE', a virtual evening event where Sir David discussed his incredible career across stage, television and film, as well as his passions and interests away from performing. Sir David raised an incredible £16,667 for the TSA during 2021.

Corporate support plays an increasingly important role in the work of the TSA, with organisations choosing to help us in lots of different ways. We would like to thank Hiscox London Market Operations team and Softcat PLC for their support in 2021. Other companies kindly supporting the charity during 2021 included Moo Creative who continue to donate a proportion of their time and expertise when delivering the design of our publications.

We received over £16,000 from supporters who chose to give to the TSA in memory of someone special during 2021. Honouring someone's life through a TSA donation is an incredibly kind offer and one that we do not take lightly. We would like to thank everyone who chose to celebrate the life of their loved one in this way.

We received generous grants for the TSA's Support Line from the Ian Fleming Charitable Trust (£1,000), St James Place Charitable Foundation (£1,000) and Ardwick Trust (£500), together with grants from the Bailey Thomas Charitable Foundation (£2,000), PF Charitable Trust (£4,000) and Swann-Morton Foundation (£1,000) to fund the introduction of Web Chat.

The Meikle Foundation awarded the TSA £2,000 to help support virtual events and support line tasks focused on Scotland-based community members.

The Leach Fourteenth Trust (£1,000) and Hospital Saturday Fund (£2,000) awarded grants to our vital research project on better understanding the accessibility of mental health services for children and young people with TSC.

The Gosling Foundation awarded us a grant (£5,200) toward the creation of a training program for Social Care professionals on TSC.

We also received support from:

- A J & K M Barnett Charitable Trust (£3,000)
- Arnold Clark Community Fund (£1,000)
- Beechwood Trust (£500)
- Dunn Charitable Trust (£3,000)
- Esher House Charitable Trust (£2,500)
- Hamilton Wallace Charitable Trust (£2,000)
- Jeans for Genes (£3,417)
- Joseph Strong Frazer Trust (£2,000)
- Marsh Charitable Trust (£350)
- R S Brownless Charitable Trust (£200)
- Rainford Trust (£2,000)
- Sir James Roll Charitable Trust (£1,000)
- Swann-Morton Foundation (£1,000)
- The Bartlett Taylor Charitable Trust (£750)
- The Michael and Anna Wix Charitable Trust (£1,000)
- The Rest-Harrow Trust (£1,500)

We are profoundly grateful to all the trusts and foundations who helped us in 2021.

In December 2021 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 smashed our target to raise £3,000 for the TSA Support Fund through the Big Give Christmas Challenge in seven hours – which was be doubled by the Big Give to £6,000 providing us with funding for the TSA Support Fund for the whole of 2022! Our generous supporters continued to give after the target was reached donating a total of £4,650 to the 2021 TSA's Big Give Challenge, and including gift aid a total of £8,674 was raised for the charity.

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Finally, the response to our 2021 Festive season was fantastic raising £5,475 for the TSA. The Christmas cards sold this year included a lovely 'robins in the snow' design from our festive card competition winner 10-year-old Jasmine Ferguson whose 7-year-old brother Leo lives with TSC. Not only was it a bumper year for card sales, but the TSA also received fantastic support through additional donations such as swapping Christmas card giving to provide a gift to the TSA.

Organisation Development and People

In 2020 we noted that our ambition to balance the TSA's finances by 2021 was unlikely given the impact of coronavirus on the charity's ability to raise funds. In fact, in 2021 the charity ended the year in surplus for the first time since the start of the five-year strategy 2019-2023. We are delighted to have reached this milestone due to the Trustees' focus on reducing the charity's expenditure and increasing and diversifying our sources of income.

In 2021 the Trustees continued to take the difficult decisions needed to manage our finances with a view to giving us the best possible opportunity to grow the charity from 2022 and deliver the ambitions set out in the five-year strategy 2019-2023.

Throughout 2021 most staff at the charity continued to voluntarily reduce their salaries to 90% of their usual hours and pay to support the charity. Trustees are grateful for this much-needed support, and glad that we have been able to keep our firm commitment that all staff at the TSA can return to their usual hours and pay from 1 January 2022.

In October 2021 the TSA closed our small office and switched to being an entirely home-based organisation which resulted in significant savings. The charity's registered address and postal address have moved to our new external finance provider. Sadly, the closure of our office resulted in the post of Office Manager at the charity being made redundant in October 2021.

During 2021 we tendered our accounting and audit services and moved to a new and more cost-effective finance provider, Tudor John. We moved from an annual audit to an independent examination to ensure we can spend more of the TSA's income on supporting our beneficiaries.

We continued to benefit from the expertise of a part-time Joint Chief Executive from January to August 2021 to support the charity alongside our long-standing Chief Executive (who temporarily reduced her working hours to manage home-schooling and work). The Joint Chief Executive brought expertise in finance and fundraising to upskill colleagues and additional capacity for the charity during the pandemic.

Investment policy

The Trustees have appointed investment managers to manage the TSA'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 ARC steady growth benchmark.

In the year ended 31 December 2021, the total return on the portfolio was 6.71% as against the benchmark of 13.77%. Over the longer term, our investment managers have consistently outperformed the benchmark. Their performance continues to be kept under review and the Trustees have an annual review meeting with them. The Trustees have agreed a formal investment policy reflecting the investment objective stated above. In 2021 £344,720 was held in cash due to continuing economic uncertainty because of the pandemic. The effect of this cash drag in rising markets resulted in the underperformance of the portfolio against the benchmark over the year.

In Q1 2022 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.

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FINANCIAL REVIEW

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 are given to families to purchase necessary medical or household equipment, or to provide parents, carers, and families with much-needed breaks. All applications for assistance are reviewed by the Chief Executive or the Head of Support Services and Communications and grants awarded where deemed appropriate on a basis of confidentiality, 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 2021

At the end of the year the Association has total funds of £992,091. This included designated funds of £883,122, further details of which are given below.

The reserves of the Association amounted to £108,969 at 31 December 2021, representing three months of expenditure excluding any research commitments entered into.

Designated Fund

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

This Fund has been broadly treated as an "endowment" and invested with professional advisers to provide a resource which supports the Association 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 sufferers of TSC

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

The policy in place for 2022 onwards is that the Designated Fund can be drawn upon to help fund commitments that the Association intends to make in the forthcoming years, including Research that has already commenced and is renewed on an annual basis, subject to a satisfactory review. However, there needs to be strong emphasis on securing new funding for future research with the aim of keeping the Designated Fund balance above £300,000 so that the Association has sufficient funds 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 £443,454 (2020 £418,746).

Total investment gain was £52,835 (2020 -£50,959 loss). To fund 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 surplus for the year was £19,922. This represents a significant improvement on the deficit of (£246,527) in 2020.

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

**Report of the Trustees
for the year ended 31 December 2021**

**FUTURE PLANS
Strategic objectives**

The 2022 Business Plan focuses on the following activities.

Providing access to good quality, accessible and timely information.

- Developing 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
- Building and improving 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.

- Carrying 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.
- Delivering a face-to-face Big Day for people living with TSC and their families to come together for the first time since the pandemic, as well as continuing to bring people together through our monthly virtual events.

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

- Supporting 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.
- Developing and launching virtual training for residential and home support workers which will help them to provide better support for individuals living with TSC and their families.
- Developing and launching virtual training for special educational need (SEND) leads, teachers, and teaching assistants ready for launch in September 2022, helping those with a child who has TSC joining their new class to understand how to support them over the coming year.

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

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

Campaigning for better access to treatments and care.

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

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

Report of the Trustees for the year ended 31 December 2021

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:** working with our new finance provider to build the skills and confidence of senior managers using the Xero accounting system
- **Digital transformation and smart working to reach more people:** tendering our IT provider in a more competitive market due to the increase in home-workers following covid; reviewing our IT assets such as laptops and scanners which are rapidly depreciating and identifying funding for a rolling programme of replacements; invest in our website so we have the technical capability to support online fundraising.
- **An enterprising approach to income generation:** generating income by delivering patient and public involvement activities across both academic and industry research projects; developing a 'medium gifts' programme of donations up to £3k per annum; reviewing the relative merits of our own community fundraising campaigns (such as Tea and SCones) compared to external community fundraising campaigns (such as the Big Give).

The Board has discussed the 2019-2023 Strategy and the need to refresh it in view of the coronavirus pandemic's impact on the charity's operating environment, income and staffing levels. The Trustees agreed that we should discuss what we can achieve as a smaller charity and how we will fund it, with a focus on the fast-changing world of genomics; the potential for a UK TSC registry or database; and the need to improve the support provided for families affected by TSC through social care.

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

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 2021, these are Sanjay Sethi, Robert Woodthorpe Browne, Patrick Bolton, Annemarie Cotton, Jane Rogers, and Frances Elmslie. Sanjay Sethi, Robert Woodthorpe Brown, Patrick Bolton, Annemarie Cotton, Jane Rogers, and Frances Elmslie offer themselves for re-election; after an appraisal process, the Board recommends their re-election.

From the 2022 AGM Robert Woodthorpe Browne will take on the role of Chair at the TSA, with Sanjay Sethi moving to the role of Vice Chair.

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

**Report of the Trustees
for the year ended 31 December 2021**

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 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 2021**

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
P F Bolton Doctor
T E Carter Textiles Manger
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
Ms L A C P Suchet Company Director
D R Vaughan Chartered Accountant
R Woodthorpe Browne Company Director

Company Secretary
Mr J Shepherd

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

Approved by order of the board of trustees on 28 October 2022 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 2021.

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'), 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(1)(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(1)(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.

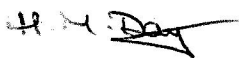
Independent examiner's statement

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

Date: 25 October 2022

THE TUBEROUS SCLEROSIS ASSOCIATION

**Statement of Financial Activities
for the year ended 31 December 2021**

	Notes	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		344,236	-	344,236	330,058
Charitable activities					
Research		77,969	-	77,969	-
Other trading activities	2	6,290	-	6,290	2,884
Investment income	3	14,959	-	14,959	34,308
Other income		-	-	-	51,496
Total		<u>443,454</u>	<u>-</u>	<u>443,454</u>	<u>418,746</u>
EXPENDITURE ON					
Raising funds	4	127,006	-	127,006	110,927
Charitable activities					
Family Care & Support		162,472	-	162,472	246,864
Research		<u>186,889</u>	<u>-</u>	<u>186,889</u>	<u>256,523</u>
Total		<u>476,367</u>	<u>-</u>	<u>476,367</u>	<u>614,314</u>
Net gains/(losses) on investments		<u>52,835</u>	<u>-</u>	<u>52,835</u>	<u>(50,959)</u>
NET INCOME/(EXPENDITURE)		19,922	-	19,922	(246,527)
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>972,169</u>	<u>-</u>	<u>972,169</u>	<u>1,218,696</u>
TOTAL FUNDS CARRIED FORWARD		<u><u>992,091</u></u>	<u><u>-</u></u>	<u><u>992,091</u></u>	<u><u>972,169</u></u>

The notes form part of these financial statements

THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

**Balance Sheet
31 December 2021**

	Notes	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
FIXED ASSETS					
Investments	13	906,723	-	906,723	960,594
CURRENT ASSETS					
Debtors	14	90,740	-	90,740	82,171
Cash at bank		<u>202,171</u>	<u>-</u>	<u>202,171</u>	<u>251,433</u>
		292,911	-	292,911	333,604
CREDITORS					
Amounts falling due within one year	15	(207,543)	-	(207,543)	(322,029)
NET CURRENT ASSETS		<u>85,368</u>	<u>-</u>	<u>85,368</u>	<u>11,575</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>992,091</u>	<u>-</u>	<u>992,091</u>	<u>972,169</u>
NET ASSETS		<u>992,091</u>	<u>-</u>	<u>992,091</u>	<u>972,169</u>
FUNDS	16				
Unrestricted funds				<u>992,091</u>	<u>972,169</u>
TOTAL FUNDS				<u>992,091</u>	<u>972,169</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2021.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 December 2021 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.

The notes form part of these financial statements

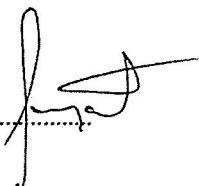
THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)

**Balance Sheet - continued
31 December 2021**

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 ~~25 October 2022~~ and were signed on its behalf by:

.....
S Sethi - Trustee

A handwritten signature in black ink, appearing to be 'S Sethi', written over a dotted line.

The notes form part of these financial statements

THE TUBEROUS SCLEROSIS ASSOCIATION

Notes to the Financial Statements for the year ended 31 December 2021

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 probable 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.

THE TUBEROUS SCLEROSIS ASSOCIATION

Notes to the Financial Statements - continued for the year ended 31 December 2021

1. ACCOUNTING POLICIES - continued

FUND ACCOUNTING

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.

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

	2021	2020
	£	£
Christmas cards & other sales	<u>6,290</u>	<u>2,884</u>

3. INVESTMENT INCOME

	2021	2020
	£	£
Deposit account interest	-	141
Income from managed portfolio	<u>14,959</u>	<u>34,167</u>
	<u>14,959</u>	<u>34,308</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

Notes to the Financial Statements - continued for the year ended 31 December 2021

4. RAISING FUNDS

INVESTMENT MANAGEMENT COSTS

	2021	2020
	£	£
Portfolio management charges	<u>8,307</u>	<u>8,496</u>

5. GRANTS PAYABLE

	2021	2020
	£	£
Research	<u>27,848</u>	<u>147,224</u>

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

	2021	2020
	£	£
* Whitehead Institute - Towards Specific Mtor Inhibitors Capable of Rescuing Tuberous Sclerosis Complex Loss-of-function	-	51,000
* Cardiff University - Targeting the Ref1/STAT3 axis to treat Tuberous Sclerosis Complex	-	32,719
* Cardiff University - Characterising the Role of Exosomes in Tuberous Sclerosis	-	32,712
* Cardiff University - An innovative model system of cell invasion in TSC/LAM to uncover new drug targets and therapies	-	30,793
* University of Bristol NHS Foundation Trust - Randomised Controlled Trial of Acceptance and Commitment Therapy in the Tuberous Sclerosis Complex	30,000	-
*TANDEM Consortium	26,289	-
*Centre for Integrative Physiology, University of Edinburgh	(335)	-
*University of Birmingham	(3,499)	-
*Institute of Psychiatry, Kings College London	<u>(24,607)</u>	<u>-</u>
	<u>27,848</u>	<u>147,224</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.

THE TUBEROUS SCLEROSIS ASSOCIATION

Notes to the Financial Statements - continued for the year ended 31 December 2021

6. SUPPORT COSTS

	Management	Finance	Other	Governance costs	Totals
	£	£	£	£	£
Family Care & Support	675	712	12,996	7,531	21,914
Research	-	445	8,589	7,531	16,565
	<u>675</u>	<u>1,157</u>	<u>21,585</u>	<u>15,062</u>	<u>38,479</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.

7. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2021	2020
	£	£
Depreciation - owned assets	-	851
Surplus on disposal of fixed assets	-	(75)

8. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2021 nor for the year ended 31 December 2020.

TRUSTEES' EXPENSES

There were no trustees' expenses paid for the year ended 31 December 2021 nor for the year ended 31 December 2020.

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.

9. STAFF COSTS

	2021	2020
	£	£
Wages and salaries	246,355	298,750
Social security costs	16,907	26,928
Other pension costs	<u>17,053</u>	<u>16,743</u>
	<u>280,315</u>	<u>342,421</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**Notes to the Financial Statements - continued
for the year ended 31 December 2021**

9. STAFF COSTS - continued

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

	2021	2020
Fundraising	3	2
Family Support and Communications	4	8
Research	<u>3</u>	<u>3</u>
	<u>10</u>	<u>13</u>

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

10. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	304,058	26,000	330,058
Other trading activities	2,884	-	2,884
Investment income	34,308	-	34,308
Other income	<u>51,496</u>	<u>-</u>	<u>51,496</u>
Total	<u>392,746</u>	<u>26,000</u>	<u>418,746</u>
EXPENDITURE ON			
Raising funds	110,927	-	110,927
Charitable activities			
Family Care & Support	246,864	-	246,864
Research	<u>225,823</u>	<u>30,700</u>	<u>256,523</u>
Total	<u>583,614</u>	<u>30,700</u>	<u>614,314</u>
Net gains/(losses) on investments	<u>(50,959)</u>	<u>-</u>	<u>(50,959)</u>
NET INCOME/(EXPENDITURE)	(241,827)	(4,700)	(246,527)
RECONCILIATION OF FUNDS			
Total funds brought forward	1,213,996	4,700	1,218,696
TOTAL FUNDS CARRIED FORWARD	<u>972,169</u>	<u>-</u>	<u>972,169</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**Notes to the Financial Statements - continued
for the year ended 31 December 2021**

11. INTANGIBLE FIXED ASSETS

	Database costs £
COST	
At 1 January 2021 and 31 December 2021	<u>19,624</u>
AMORTISATION	
At 1 January 2021 and 31 December 2021	<u>19,624</u>
NET BOOK VALUE	
At 31 December 2021	<u><u>-</u></u>
At 31 December 2020	<u><u>-</u></u>

12. TANGIBLE FIXED ASSETS

	Fixtures and fittings £
COST	
At 1 January 2021 and 31 December 2021	<u>1,135</u>
DEPRECIATION	
At 1 January 2021 and 31 December 2021	<u>1,135</u>
NET BOOK VALUE	
At 31 December 2021	<u><u>-</u></u>
At 31 December 2020	<u><u>-</u></u>

13. FIXED ASSET INVESTMENTS

	2021	2020
	£	£
Shares	545,214	570,319
Brewin Dolphin capital account	<u>361,509</u>	<u>390,275</u>
	<u><u>906,723</u></u>	<u><u>960,594</u></u>

THE TUBEROUS SCLEROSIS ASSOCIATION

**Notes to the Financial Statements - continued
for the year ended 31 December 2021**

13. FIXED ASSET INVESTMENTS - continued

Additional information as follows:

	Listed investments £
MARKET VALUE	
At 1 January 2021	570,319
Additions	121,814
Disposals	(199,754)
Revaluations	<u>52,835</u>
At 31 December 2021	<u>545,214</u>
NET BOOK VALUE	
At 31 December 2021	<u>545,214</u>
At 31 December 2020	<u>570,319</u>

There were no investment assets outside the UK.

The historical cost of the investments at the year end is £367,751 (2020 £324,612).

Investments (neither listed nor unlisted) were as follows:

	2021 £	2020 £
Brewin Dolphin capital account	<u>361,509</u>	<u>390,275</u>

14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 £	2020 £
Other debtors	15,133	82,171
Prepayments	<u>75,607</u>	<u>-</u>
	<u>90,740</u>	<u>82,171</u>

THE TUBEROUS SCLEROSIS ASSOCIATION

Notes to the Financial Statements - continued for the year ended 31 December 2021

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021	2020
	£	£
Trade creditors	162,912	13,355
Social security and other taxes	5,003	5,413
Other creditors	1,626	296,858
Accrued expenses	<u>38,002</u>	<u>6,403</u>
	<u>207,543</u>	<u>322,029</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 1.1.21	SOFA	Paid	At 31.12.21
	£	£	£	£
* University of Birmingham	3,499	(3,499)	-	-
* Institute of Psychiatry, Kings College London - Designing a Protocol to Measure the Development Trajectory of Infants with Tuberous Sclerosis	24,607	(24,607)	-	-
* Institute of Medical Genetics, Cardiff	1,371	-	-	1,371
* Centre for Integrative Physiology, University of Edinburgh	335	(335)	-	-
* Institute of Psychiatry, Kings College London	14,153	-	14,153	-
* Cardiff University	618	-	-	618
* Research Department of Genetics, University College, London	513	-	-	513
* University of Manchester, Faculty of Life Sciences	15,698	-	15,472	226
* Erasmus MC, Department of Clinical Genetics	180	-	-	180
* University College London - The TSC1 and TSC2 Variation Databases	8,881	-	8,653	228
* Whitehead Institute - Towards specific Motor Inhibitors capable of rescuing Tuberous Sclerosis Complex loss-of-function	24,336	-	24,151	185
* Cardiff University - Targeting the Ref1/STAT3 axis to treat Tuberous Sclerosis Complex	37,424	-	22,493	14,931
* Cardiff University - Characterising the roles of exosomes in Tuberous Sclerosis Complex	41,351	-	31,321	10,030
* University of Bristol NHS Foundation Trust - Randomised Controlled Trial of Acceptance and Commitment Therapy in Tuberous Sclerosis Complex	62,000	30,000	28,905	63,095

THE TUBEROUS SCLEROSIS ASSOCIATION

**Notes to the Financial Statements - continued
for the year ended 31 December 2021**

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

* Institute of Psychiatry Psychology and Neuroscience - Neurocognitive predictors of neurodevelopmental impairment in infants and toddlers with TSC	11,549	-	9,032	2,517
* Cardiff University - An innovative model system to cell invasion in TSC/LAM to uncover new drug targets and therapies	47,000	-	25,565	21,435
*TANDEM Consortium - to fund a number of small seed projects linked to the TANDEM project to help build research capacity in TAND.	<u>-</u>			<u>26,289</u>
	<u>293,515</u>		<u>179,745</u>	<u>141,618</u>
		<u>26,289</u>		<u>26,289</u>
		<u>27,848</u>		<u>141,618</u>

16. 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>

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>

THE TUBEROUS SCLEROSIS ASSOCIATION

**Notes to the Financial Statements - continued
for the year ended 31 December 2021**

16. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.1.20 £	Net movement in funds £	At 31.12.20 £
Unrestricted funds			
General fund	190,000	(69,314)	120,686
Designated Endowment Fund	<u>1,023,996</u>	<u>(172,513)</u>	<u>851,483</u>
	1,213,996	(241,827)	972,169
Restricted funds			
Research	<u>4,700</u>	<u>(4,700)</u>	<u>-</u>
TOTAL FUNDS	<u><u>1,218,696</u></u>	<u><u>(246,527)</u></u>	<u><u>972,169</u></u>

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	358,580	(427,894)	-	(69,314)
Designated Endowment Fund	<u>34,166</u>	<u>(155,720)</u>	<u>(50,959)</u>	<u>(172,513)</u>
	392,746	(583,614)	(50,959)	(241,827)
Restricted funds				
Research	22,000	(26,700)	-	(4,700)
Scotland	<u>4,000</u>	<u>(4,000)</u>	<u>-</u>	<u>-</u>
	<u>26,000</u>	<u>(30,700)</u>	<u>-</u>	<u>(4,700)</u>
TOTAL FUNDS	<u><u>418,746</u></u>	<u><u>(614,314)</u></u>	<u><u>(50,959)</u></u>	<u><u>(246,527)</u></u>

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 December 2021.

THE TUBEROUS SCLEROSIS ASSOCIATION

**Detailed Statement of Financial Activities
for the year ended 31 December 2021**

	2021 £	2020 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations and subscription	269,709	327,058
Grants	<u>74,527</u>	<u>3,000</u>
	344,236	330,058
Other trading activities		
Christmas cards & other sales	6,290	2,884
Investment income		
Deposit account interest	-	141
Income from managed portfolio	<u>14,959</u>	<u>34,167</u>
	14,959	34,308
Charitable activities		
Conference	77,969	-
Other income		
Government grants - CJRS	<u>-</u>	<u>51,496</u>
Total incoming resources	443,454	418,746
EXPENDITURE		
Raising donations and legacies		
Wages	75,855	68,133
Social security	5,078	4,521
Pensions	5,309	2,769
Events fees	1,368	280
Sundries	3,727	2,391
Travel & Communications	1,803	1,884
Bid writing	2,400	2,800
Staff training	676	-
Marketing & Media	1,783	2,622
Insurance	1,327	1,337
Office costs	7,828	4,452
Professional fees	591	687
Accountancy & legal fees	4,812	5,317
AGM, Big Day and Annual Report costs	2,719	2,770
Subscriptions	300	-
Fixtures and fittings	<u>-</u>	<u>88</u>
	115,576	100,051

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THE TUBEROUS SCLEROSIS ASSOCIATION

**Detailed Statement of Financial Activities
for the year ended 31 December 2021**

	2021 £	2020 £
Raising donations and legacies		
Other trading activities		
Christmas card sales	3,123	2,380
Investment management costs		
Portfolio management charges	8,307	8,496
Charitable activities		
Wages	170,500	230,617
Social security	11,829	22,407
Pensions	11,744	13,974
Sundries	-	1
Staff training	1,710	3,714
Accommodation and room hire	-	4,532
Publications	178	7,409
Travel & Communications	234	4,750
Benevolent grants	3,379	3,070
Family days and weekends	-	314
Subscriptions	2,494	2,041
Postage and Stationery	594	2,751
Sundries	2,158	5,054
Insurance	1,680	758
IT and GDPR services	13,853	540
Marketing & Media	978	2,610
Professional fees	-	1,016
Conference	52,467	-
Scan	9,236	-
Grants to institutions	<u>27,848</u>	<u>147,224</u>
	310,882	452,782
Support costs		
Management		
Chief executive expenses	-	154
Recruitment costs	<u>675</u>	<u>50</u>
	675	204
Finance		
Postage and stationery	1,157	358
Bank charges	-	716
Fixtures and fittings	<u>-</u>	<u>763</u>
	1,157	1,837
Other		
IT & GDPR Services	11,047	15,113
Carried forward	11,047	15,113

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THE TUBEROUS SCLEROSIS ASSOCIATION

**Detailed Statement of Financial Activities
for the year ended 31 December 2021**

	2021 £	2020 £
Other		
Brought forward	11,047	15,113
Insurance	2,654	2,674
Office costs	5,042	10,386
Sundries	734	723
Professional fees	1,281	3,441
Travel	827	127
Loss on sale of tangible fixed assets	<u>-</u>	<u>(75)</u>
	21,585	32,389
Governance costs		
Accountancy and legal fees	9,623	10,634
Annual report	<u>5,439</u>	<u>5,541</u>
	<u>15,062</u>	<u>16,175</u>
Total resources expended	<u>476,367</u>	<u>614,314</u>
Net expenditure	<u><u>(32,913)</u></u>	<u><u>(195,568)</u></u>

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