THE TUBEROUS SCLEROSIS ASSOCIATION

England & Wales · Charity number 1039549

Details

Other names	TSA
Status	Registered
Legal form	Charitable company
Company number	02900107
Registered	1994-09-14
Register	View on the Charity Commission register

Contact

Address	The TSA Courtenay House Pynes Hill Exeter EX2 5AZ
Phone	0300 222 5737
Email	admin@tuberous-sclerosis.org
Website	www.tuberous-sclerosis.org

Activities

Objects: TO PROMOTE THE CARE WELFARE TREATMENT INTEREST EDUCATION AND ADVANCEMENT OF PERSONS SUFFERING FROM TUBEROUS SCLEROSIS AND RESEARCH INTO ITS CAUSE AND CURE INCLUDING THE DISSEMINATION OF THE USEFUL RESULTS OF SUCH RESEARCH

Activities: The TSA:-supports individuals affected by Tuberous Sclerosis Complex(TSC), together with their families and carers;-encourages and supports research into the causes and management of TSC; and-provides education, publicity and information to promote awareness of the problems caused by TSC.

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Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Human Resources, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities

Geography

- **Area of benefit:** NOT DEFINED (IN PRACTICE GREAT BRITAIN AND NORTHERN IRELAND)
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£656,551	£468,469	£1,299,561	9
2023-12-31	£361,627	£325,334	-	-
2022-12-31	£284,640	£359,049	-	-
2021-12-31	£443,454	£476,367	-	-
2020-12-31	£418,746	£614,314	-	-

Trustees

Name	Role	Appointed
Dr Frances Elmslie	Chair	2019-06-08
Annemarie Cotton		2019-06-08
DR CHRIS KINGSWOOD		
Jane Rogers		2019-06-08
Sanjay Sethi		2018-11-10
Simon John James		2023-11-28
Stacey Louise Rose		2024-11-18

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THE TUBEROUS SCLEROSIS ASSOCIATION

England & Wales - Charity number 1039549

Accounts

Tuberous Sclerosis Association
Annual Report

“Providing help for today and a cure for tomorrow”

Annual report and financial statements for the year ended 31 December 2024

Registered charity 1039549 (England & Wales). Registered charity SC042780 (Scotland)
Company registration number 02900107

Trustees' and Directors' report

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

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

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

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

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

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

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

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

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

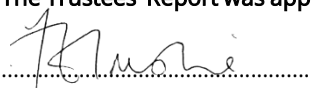
In accordance with the company's articles, a resolution proposing who be reappointed as auditor of the company will be put at a General Meeting.

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

Public benefit

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

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



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

Statement of Trustees' responsibilities

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

The law applicable to charities in England & Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the Trustees are required to:

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

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

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

Disclosure of information to auditors

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

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

Auditors

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

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Trustees

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

Secretaries: Luke Langlands, Dr Pooja Takhar

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

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

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

HALLIE'S STORY

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

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

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

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

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

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

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

ABOUT THE TSA

Our goals, values and public benefit

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

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

We have three main charitable objectives:

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

We do this through:

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

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

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

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

A MESSAGE FROM OUR CHAIR AND CHIEF EXECUTIVES

Dear reader,

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

Highlights of what we've recently accomplished include:

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

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

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

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

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

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

Dr Frances Elmslie
Chair, TSA Board of Trustees

Dr Pooja Takhar and Luke Langlands
TSA Joint Chief Executives

MEET YOUR TSA TEAM

Current TSA Board of Trustees

Dr Frances Elmslie (Chair)

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

Dr Frances Elmslie

Annemarie Cotton (Vice Chair, appointed November 2024)

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

Annemarie Cotton

Simon James (Treasurer)

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

Simon James

Our other highly valued Trustees are:

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

Company secretaries: Luke Langlands and Dr Pooja Takhar.

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

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

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

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

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

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

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

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

TSA leadership

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

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

Dr Pooja Takhar

The wider and vital TSA team

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

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

Luke Langlands

Some of the TSA team during lunch at Big Day 2024

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

Volunteers and ambassadors

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

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

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

TSA ANNUAL GENERAL MEETING 2025

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

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

Agenda items are:

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

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

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

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

A NEW STRATEGIC PERIOD FOR 2025 - 2027

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

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

Our 2025 – 2027 strategy has four key priorities:

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

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

WHAT WE ACHIEVED IN 2024

The end of our previous strategy: A major success

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

1. Reach more people

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

2. Drive more research

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

3. Continue to balance the TSA's finances

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

Support and information

TSA Support Line

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

> **"You couldn't have possibly helped any more than what you did"**
> - TSA Support Line user

> **"The service that you provide is amazing"**
> - TSA Support Line user

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

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

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

TSA Welcome Packs

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

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

TSA Support Fund

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

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

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

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

Keeping you updated

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

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

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

TSA community events

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

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

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

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

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

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

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

> **"It was very informative and engaging, it was good to talk about TSC with others"**
>
> - TSA event attendee

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

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

Working with TSC professionals

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

TSC Rare Disease Collaborative Network

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

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

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

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

Valued experts

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

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

Accredited TSC courses for professionals

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

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

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

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

100%

professionals agree that TSA training courses met their learning objectives

> **"Thank you for this great course and your efforts, much appreciated!"**
>
> - Teacher who completed TSA training course

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

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

Research and advocacy

Funding TSC research

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

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

Our live grants for 2024

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

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

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

TSC Research Volunteer Network

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

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

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

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

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

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

Campaigning and advocacy

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

Access to new and vital treatments

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

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

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

Dr Amanda Almacellas Barbanoj (TSC researcher)

Dr Elaine Dunlop (TSC researcher)

Influencing national rare disease policy

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

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

Ensuring a TSC-focus at professional gatherings

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

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

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

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

Fundraising and income generation

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

London Marathon 2024

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

Big Give 2024

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

In memory giving

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

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

Corporate giving

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

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

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

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

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

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NOT ALL SUPERHEROES WEAR CAPES

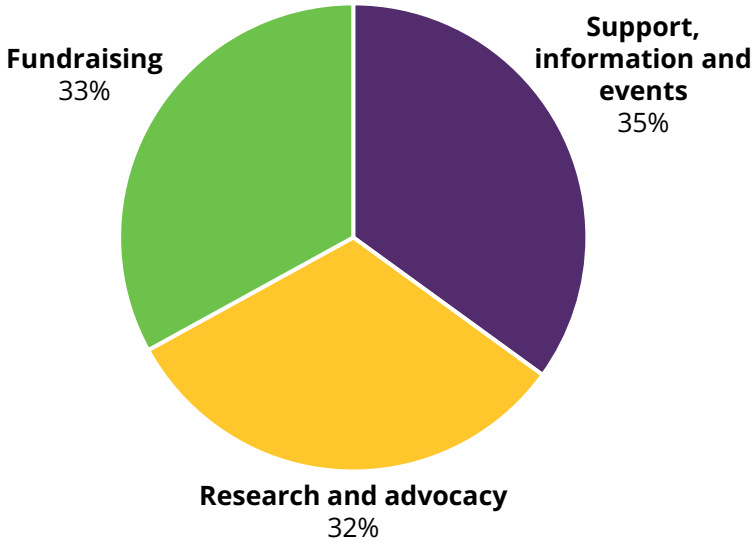
MONEY MATTERS

Where we spent funds in 2024

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

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

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



Financial overview at the end of 2024

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

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

More information on each fund is provided in our financial statements, starting on page **37**.

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

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

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

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

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

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

Read about this plan on page 30.

Non-designated reserves and reserves policy

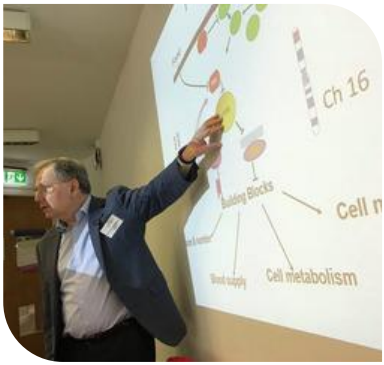
The TSA Board of Trustees has agreed to hold up to the equivalent of six months of running costs as free reserves. This is around **£222,000** and allows the charity to cover operating deficits and unexpected drops in income, while ensuring liquidity for ongoing costs. We also hold designated funds in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

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

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

> **The event was fabulous and very informative.**
> - Teacher who completed TSA training course

> **The process was so easy from start to finish the conversation was so easy and I was treated like part of a big family**
> - TSA Support Line user



Investment policy

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

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

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

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

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

OUR FINANCIAL PLANS FOR THIS STRATEGIC PERIOD

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

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

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

Designated funds explained

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

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

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

'Endowment-like' funds for ongoing activities explained

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

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

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

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

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

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

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

GOVERNANCE AND OPERATIONS

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

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

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

Risk management

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

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

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

Risk register

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

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

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

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

Declarations of interest

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

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

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

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

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

Going concern

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

Monitoring our success and impact

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

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

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

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

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

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

FINANCIAL REPORT 2024

Independent auditor's report

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

In our opinion, the financial statements:

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

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

We have nothing to report in this regard.

Opinion on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

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

Responsibilities of Trustees

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

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

Auditors' responsibilities for the audit of the financial statements

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

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

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

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

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

Other matters

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

Use of our report

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

Laura Waycott FCA (Senior Statutory auditor). For and on behalf of Griffin Accountancy
Courtenay House
Pynes Hill
Exeter
EX2 5AZ
Date: 26 September 2025

Statement of Financial Activities including income and expenditure account
For the year ended 31 December 2024

	Notes	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds As restated 2023 £	Restricted funds 2023 £	Total As restated 2023 £
Income from:							
Donations and legacies	3	614,432	7,350	621,782	392,577	90,547	483,124
Charitable activities	4	2,105	-	2,105	2,666	-	2,666
Investments	5	32,664	-	32,664	25,559	-	25,559
Total income		649,201	7,350	656,551	420,802	90,547	511,349
Expenditure on:							
Raising funds	6	153,957	-	153,957	84,073	-	84,073
Charitable activities	7	229,575	84,937	314,512	218,779	-	218,779
Total expenditure		383,532	84,937	468,469	302,852	-	302,852
Net gains/(losses) on investments	13	50,981	-	50,981	22,290	-	22,290
Net income/(expenditure) and movement in funds		316,650	(77,587)	239,063	140,240	90,547	230,787
Reconciliation of funds:							
Fund balances at 1January 2024		969,951	90,547	1,060,498	829,711	-	829,711
Fund balances at 31 December 2024		1,286,601	12,960	1,299,561	969,951	90,547	1,060,498

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

Balance sheet
As at 31 December 2024

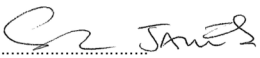
	Notes	2024 £	2024 £	2023 As restated £	2023 As restated £
Fixed assets					
Tangible assets	**15**		2,708		-
Investments	**16**		706,437		660,307
			709,145		660,307
Current assets					
Debtors	**17**	24,766		169,873	
Cash at bank and in hand		594,532		249,860	
		619,298		419,733	
Creditors: amounts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

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

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

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

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



Simon James (Treasurer, Tuberous Sclerosis Association)

Statement of cash flows
For the year ended 31 December 2024

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

Notes to the financial statements
For the year ended 31 December 2024

1 Accounting policies

Charity information

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

1.1 Accounting convention

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

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

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

1.2 Going concern

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

1.3 Charitable funds

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

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

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

1.4 Income

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

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

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

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

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

1 Accounting policies **(Continued)**

1.5 Expenditure

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

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

Database costs	Over estimated useful life

1.6 Tangible fixed assets

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

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

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

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

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

1.7 Fixed asset investments

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

1.8 Impairment of fixed assets

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

1.9 Cash and cash equivalents

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

1 Accounting policies **(Continued)**

1.10 Financial instruments

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

Basic financial assets

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

Basic financial liabilities

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

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

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

Derecognition of financial liabilities

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

1.11 Employee benefits

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

1.12 Retirement benefits

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

2 Critical accounting estimates and judgements

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

3 Income from donations and legacies

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

4 Income from charitable activities

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

5 Income from investments

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

6 Expenditure on raising funds

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

7 Expenditure on charitable activities

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

8 Grants payable

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

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

9 Support costs allocated to activities

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

10 Net movement in funds

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

11 Trustees

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

12 Employees

The average monthly number of employees during the year was:

	2024	2023
Fundraising	5	2
Family Support and Communications	2	4
Research	2	2
Total	9	8

Notes to the financial statements (continued)
For the year ended 31 December 2024

12 Employees **(Continued)**

Employment costs

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

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

Remuneration of key management personnel
The remuneration of key management personnel was as follows:

	2024 £	2023 £
Aggregate compensation	116,600	105,000

13 Gains and losses on investments

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

14 Taxation

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

15 Intangible fixed assets

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

16 Tangible fixed assets

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

17 Fixed asset investments

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

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

18 Debtors

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

19 Creditors: amounts falling due within one year

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

20 Retirement benefit schemes

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

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

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

21 Restricted funds

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

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

Previous year:	At 1 January 2023	Incoming resources	Resources expended	At 31 December 2023
	£	£	£	£
Research	-	46,047	-	46,047
Sponsored events	-	44,500	-	44,500
	-	90,547	-	90,547

Notes to the financial statements (continued)
For the year ended 31 December 2024

21 Restricted funds **(Continued)**

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

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

22 Unrestricted funds

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

	At 1 January 2024	Incoming resources	Resources expended	Gains and losses	At 31 December 2024
	£	£	£	£	£
Designated Endowment Fund	567,820	-	-	-	567,820
General funds	402,131	649,201	(383,532)	50,981	718,781
	969,951	649,201	(383,532)	50,981	1,286,601

Previous year:	At 1 January 2023	Incoming resources	Resources expended	Gains and losses	At 31 December 2023
		As restated	As restated		As restated
	£	£	£	£	£
Designated Endowment Fund	529,711	18,302	(2,483)	22,290	567,820
General funds	300,000	402,500	(300,369)	-	402,131
	829,711	420,802	(302,852)	22,290	969,951

23 Analysis of net assets between funds

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

23 Analysis of net assets between funds (Continued)

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

24 Related party transactions

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

25 Cash generated from/(absorbed by) operations

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

26 Analysis of changes in net funds

The Charity had no material debt during the year.

27 Prior year adjustment

The following prior year adjustments have been made:
- An accrual for £147,000 of legacy income
- A reversal of an accrued grant dispersal of £22,483
- A £2,721 adjustment to agree the year-end cash at bank figure

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

Notes to the financial statements (continued)
For the year ended 31 December 2024

28 Prior period adjustment **(Continued)**

Changes to the balance sheet **At December 2023**

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

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

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

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

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

tuberous-sclerosis.org/donate

Switchboard:
0300 222 5737
admin@tuberous-sclerosis.org

TSA Support Line:
0808 801 0700
support@tuberous-sclerosis.org
Webchat (tuberous-sclerosis.org)

Tuberous Sclerosis Association is a registered charity in England and Wales (1039549) and Scotland (SC042780), and is a company limited by guarantee registered in England and Wales (no. 2900107).

tsa
tuberous sclerosis association

THE TUBEROUS SCLEROSIS ASSOCIATION

England & Wales - Charity number 1039549

Accounts

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

THE TUBEROUS SCLEROSIS ASSOCIATION

Unaudited Financial Statements for the Year Ended 31 December 2023

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

THE TUBEROUS SCLEROSIS ASSOCIATION

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Report of the Trustees
for the year ended 31 December 2023

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 December 2023. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Report of the Trustees
for the year ended 31 December 2023

OBJECTIVES AND ACTIVITIES

Objectives and aims, including public benefit

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

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

TSC in numbers:

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

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

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

SUMMARY OF ANNUAL PERFORMANCE: 2023

The TSA has continued to deliver on its strategic priorities:

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

OBJECTIVES AND ACTIVITIES

Purpose and Strategy

The TSA has 3 main charitable objectives:

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

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

During this strategy we plan to:

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

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

Our strategic aims are to:

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

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

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

Our strategic enablers that make it possible are:

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

2023 Business Plan

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

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

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

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

Providing access to good quality, accessible and timely information

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

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

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

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

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

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

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

Campaigning for better access to treatments and care

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

Strategic enablers

We will focus on:

High-quality, integrated financial management

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

Digital transformation and smart working to reach more people

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

An enterprising approach to income generation to drive more research

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

STRATEGIC REPORT

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

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

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

Reaching more people

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

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

Driving more research

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

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

Balancing the books

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

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

OBJECTIVES AND ACTIVITIES

PERFORMANCE:

Support and information, events and communications

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

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

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

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

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

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

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

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

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

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

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

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

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

Research and advocacy

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

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

Live grants table 2023

Reference	Investigator	Institution	Title and purpose of grant	Co-funder
2018-S02 Dunlop	Dr Elaine Dunlop	Cardiff University	**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.	
2018-S04 Tee	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.	

2019-F01 Tye	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.	
2019-P01 Dunlop	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 'lymphangioleiomyomatosis') 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 Amin	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

TSC Research Volunteer Network

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

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

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

New treatments for TSC

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

Advocacy

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

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

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

Income Generation

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Investment policy

The Trustees have appointed investment managers to manage the Association's investment portfolio under a discretionary investment mandate. Our investment objective is to maximise total returns over the longer term and to provide a stable level of income to be generated with a medium level of risk. The level of risk applies to the portfolio as a whole rather than to individual stocks.

In the year ended 31 December 2023, the total return on the portfolio was 6.55% . Over the longer term, our investment managers have consistently outperformed the benchmark. Their performance continues to be kept under review and Trustees have an annual review meeting with them. The Trustees have agreed a formal investment policy reflecting the investment objective stated above.

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

FINANCIAL REVIEW

Financial position

Grant making policy

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

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

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

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

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

Designated Fund

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

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

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

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

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

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

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

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

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

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

FUTURE PLANS
Strategic objectives

The 2024 Business Plan focuses on the following activities.

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

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

Providing access to good quality, accessible and timely information

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

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

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

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

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

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

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

Campaigning for better access to treatments and care

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

Enablers

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

High-quality, integrated financial management

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

An enterprising approach to income generation to drive more research

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

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

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

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

STRUCTURE, GOVERNANCE AND MANAGEMENT

Structure, governance and management

Constitution

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

Recruitment and appointment of new trustees

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

Organisational structure

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

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

Risk management

The Trustees meet as a Board four times each year.

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

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

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

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

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

02900107 (England and Wales)

Registered Charity number

1039549

Report of the Trustees
for the year ended 31 December 2023

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

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

Company Secretaries
Dr P Takhar
L Langlands

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

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

Website
www.tuberous-sclerosis.org

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

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

.....
F Elmslie - Trustee

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

Independent examiner's report to the trustees of The Tuberous Sclerosis Association ('the Company')
I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 December 2023.

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

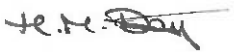
Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('the 2011 Act').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

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

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

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

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



Hazel Day BSc FCA DChA

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

Date: 16 August 2024

THE TUBEROUS SCLEROSIS ASSOCIATION

Statement of Financial Activities
for the year ended 31 December 2023

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

The notes form part of these financial statements

Balance Sheet
31 December 2023

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

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

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

The trustees acknowledge their responsibilities for

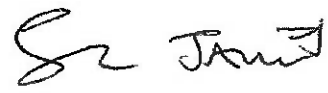
(a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and

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

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

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

The notes form part of these financial statements



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S James - Trustee

The notes form part of these financial statements

Balance Sheet
31 December 2023

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.....
S James - Trustee

The notes form part of these financial statements

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

1. ACCOUNTING POLICIES

BASIS OF PREPARING THE FINANCIAL STATEMENTS

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention, with the exception of investments which are included at market value, as modified by the revaluation of certain assets.

INCOME

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

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

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

Entitlement to a legacy is recognised when it is probable that it will be received. Receipt is normally probably when there has been grant of probate; the executors have established that there are sufficient areas 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.

continued...

1. ACCOUNTING POLICIES - continued

FUND ACCOUNTING

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

PENSION COSTS AND OTHER POST-RETIREMENT BENEFITS

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

FINANCIAL INSTRUMENTS

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at the carrying value plus accrued interest less repayments. The financing charge to expenditure is at a constant rate calculated using the effective interest method.

Debtors

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

Cash at bank and in hand

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

Creditors and Provisions

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

2. OTHER TRADING ACTIVITIES

	2023	2022
	£	£
Christmas cards & other sales	2,225	3,668

3. INVESTMENT INCOME

	2023	2022
	£	£
Income from managed portfolio	18,302	17,740

continued...

4. RAISING FUNDS

INVESTMENT MANAGEMENT COSTS

	2023	2022
	£	£
Portfolio management charges	4,592	4,767

5. GRANTS PAYABLE

	2023	2022
	£	£
Research	(2,109)	183

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

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

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

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

6. SUPPORT COSTS

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

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

continued...

7. TRUSTEES' REMUNERATION AND BENEFITS

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

TRUSTEES' EXPENSES

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

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

8. STAFF COSTS

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

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

	2023	2022
Fundraising	2	1
Family Support and Communications	4	4
Research	2	2
	8	7

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	236,732	4,500	241,232
Charitable activities			
Research	22,000	-	22,000
Other trading activities	3,668	-	3,668
Investment income	17,740	-	17,740
Total	280,140	4,500	284,640
EXPENDITURE ON			
Raising funds	84,558	-	84,558
Charitable activities			
Family Care & Support	163,661	4,500	168,161
Research	106,330	-	106,330

continued...

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

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

10. INTANGIBLE FIXED ASSETS

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

11. TANGIBLE FIXED ASSETS

	Fixtures and fittings £
COST	
At 1 January 2023 and 31 December 2023	1,135
DEPRECIATION	
At 1 January 2023 and 31 December 2023	1,135
NET BOOK VALUE	
At 31 December 2023	-
At 31 December 2022	-

continued...

12. FIXED ASSET INVESTMENTS

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

Additional information as follows:

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

All investments were managed through UK investment managers.

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

Investments (neither listed nor unlisted) were as follows:

	2023	2022
	£	£
Brewin Dolphin capital account	9,104	14,166

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

continued...

14. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

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

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

continued...

15. MOVEMENT IN FUNDS

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

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	252,778	(322,851)	-	(70,073)
Designated Endowment Fund	18,302	(2,483)	22,290	38,109
	271,080	(325,334)	22,290	(31,964)
Restricted funds				
Research	46,047	-	-	46,047
Sponsored events	44,500	-	-	44,500
	90,547	-	-	90,547
TOTAL FUNDS	361,627	(325,334)	22,290	58,583

Comparatives for 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	883,122	(76,458)	(276,953)	529,711
	992,091	(162,380)	-	829,711
TOTAL FUNDS	992,091	(162,380)	-	829,711

continued...

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	262,399	(348,321)	-	(85,922)
Designated Endowment Fund	17,741	(6,228)	(87,971)	(76,458)
	280,140	(354,549)	(87,971)	(162,380)
Restricted funds				
Education	2,500	(2,500)	-	-
Glasgow TSC Clinic	2,000	(2,000)	-	-
	4,500	(4,500)	-	-
TOTAL FUNDS	284,640	(359,049)	(87,971)	(162,380)

16. RELATED PARTY DISCLOSURES

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

THE TUBEROUS SCLEROSIS ASSOCIATION

England & Wales - Charity number 1039549

Accounts

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

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

THE TUBEROUS SCLEROSIS ASSOCIATION

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for the year ended 31 December 2022

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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).

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

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

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.

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.

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.

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.

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.	

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 'lymphangioleiomyomatosis') 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.	

OBJECTIVES AND ACTIVITIES

Dr Liesl Schlebusch	University of Cape Town	**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.	
Dr Stacey Bissell	University of Birmingham	**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.	

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.

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 devasting 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 Mootoosamy 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 Tuberous 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 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 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 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

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 Epilyolex (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

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.

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 than 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(l)(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 ofmy 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 undetiake the examination because I am a registered member ofICAEW 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.

H.M Day

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

Date: ..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	17,740	-	17,740	14,959
Total		280,140	4,500	284,640	443,454
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		106,330	-	106,330	186,889
Total		354,549	-	359,049	476,367
Net gains/(losses) on investments		(87,971)	-	(87,971)	52,835
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		829,711	-	829,711	992,091

The notes form part of these financial statements

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		270,842	-	270,842	202,171
		274,227	-	274,227	292,911
CREDITORS					
Amounts falling due within one year	14	(87,223)	-	(87,223)	(207,543)
NET CURRENT ASSETS		187,004	-	187,004	85,368
TOTAL ASSETS LESS CURRENT LIABILITIES		829,711	-	829,711	992,091
NET ASSETS		829,711	-	829,711	992,091
FUNDS	15				
Unrestricted funds				829,711	992,091
TOTAL FUNDS				829,711	992,091

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

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 areas 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.

continued...

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	3,668	6,290

3. INVESTMENT INCOME

	2022	2021
	£	£
Income from managed portfolio	17,740	14,959

continued...

4. RAISING FUNDS

INVESTMENT MANAGEMENT COSTS

	2022	2021
	£	£
Portfolio management charges	4,767	8,307

5. GRANTS PAYABLE

	2022	2021
	£	£
Research	183	27,848

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	-	(24,607)
	183	27,848

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	9,505	5,527	15,032
	23,604	11,054	34,658

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

continued...

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	11,013	17,053
	231,486	280,315

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

	2022	2021
Fundraising	1	3
Family Support and Communications	4	4
Research	2	3
	7	10

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	14,959	-	14,959
Total	443,454	-	443,454
EXPENDITURE ON			
Raising funds	127,006	-	127,006
Charitable activities			
Family Care & Support	162,472	-	162,472
Research	186,889	-	186,889

continued...

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted funds £	Restricted funds £	Total funds £
Total	476,367	-	476,367
Net gains on investments	52,835	-	52,835
NET INCOME	19,922	-	19,922
RECONCILIATION OF FUNDS			
Total funds brought forward	972,169	-	972,169
TOTAL FUNDS CARRIED FORWARD	992,091	-	992,091

10. INTANGIBLE FIXED ASSETS

	Database costs £
COST	
At 1 January 2022 and 31 December 2022	19,624
AMORTISATION	
At 1 January 2022 and 31 December 2022	19,624
NET BOOK VALUE	
At 31 December 2022	-
At 31 December 2021	-

11. TANGIBLE FIXED ASSETS

	Fixtures and fittings £
COST	
At 1 January 2022 and 31 December 2022	1,135
DEPRECIATION	
At 1 January 2022 and 31 December 2022	1,135
NET BOOK VALUE	
At 31 December 2022	-
At 31 December 2021	-

continued...

12. FIXED ASSET INVESTMENTS

	2022	2021
	£	£
Shares	628,541	562,003
Brewin Dolphin capital account	14,166	344,720
	642,707	906,723

Additional information as follows:

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

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	14,166	344,720

13. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022	2021
	£	£
Other debtors	1,502	15,133
Prepayments	1,883	75,607
	3,385	90,740

continued...

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	44,824	38,002
	87,223	207,543

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 Refl/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.	26,289	-	26,289	-
	141,618	-	95,537	46,264

continued...

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	883,122	(76,458)	(276,953)	529,711
	992,091	(162,380)	-	829,711
TOTAL FUNDS	992,091	(162,380)	-	829,711

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	17,740	(6,228)	(94,495)	(82,983)
	284,639	(360,327)	(94,495)	(170,183)
TOTAL FUNDS	284,639	(360,327)	(94,495)	(170,183)

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	851,483	31,639	883,122
	972,169	19,922	992,091
TOTAL FUNDS	972,169	19,922	992,091

continued...

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	14,959	(36,155)	52,835	31,639
	443,454	(476,367)	52,835	19,922
TOTAL FUNDS	443,454	(476,367)	52,835	19,922

16. RELATED PARTY DISCLOSURES

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

THE TUBEROUS SCLEROSIS ASSOCIATION

England & Wales - Charity number 1039549

Accounts

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

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

THE TUBEROUS SCLEROSIS ASSOCIATION

Unaudited Financial Statements for the Year Ended 31 December 2021

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THE TUBEROUS SCLEROSIS ASSOCIATION

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for the year ended 31 December 2021

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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).

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

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

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.

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 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.

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.

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.	

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 'lymphangioleiomyomatosis') 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

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.	

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.

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.

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.

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.

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.

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.

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.

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 and 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		443,454	-	443,454	418,746
EXPENDITURE ON					
Raising funds	4	127,006	-	127,006	110,927
Charitable activities					
Family Care & Support		162,472	-	162,472	246,864
Research		186,889	-	186,889	256,523
Total		476,367	-	476,367	614,314
Net gains/(losses) on investments		52,835	-	52,835	(50,959)
NET INCOME/(EXPENDITURE)		19,922	-	19,922	(246,527)
RECONCILIATION OF FUNDS					
Total funds brought forward		972,169	-	972,169	1,218,696
TOTAL FUNDS CARRIED FORWARD		992,091	-	992,091	972,169

The notes form part of these financial statements

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		202,171	-	202,171	251,433
		292,911	-	292,911	333,604
CREDITORS					
Amounts falling due within one year	15	(207,543)	-	(207,543)	(322,029)
NET CURRENT ASSETS		85,368	-	85,368	11,575
TOTAL ASSETS LESS CURRENT LIABILITIES		992,091	-	992,091	972,169
NET ASSETS		992,091	-	992,091	972,169
FUNDS	16				
Unrestricted funds				992,091	972,169
TOTAL FUNDS				992,091	972,169

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.

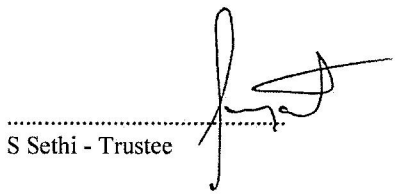
The notes form part of these financial statements

continued...

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 ..28.. September 2022.. and were signed on its behalf by:



S Sethi - Trustee

The notes form part of these financial statements

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 probably when there has been grant of probate; the executors have established that there are sufficient areas 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.

continued...

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	6,290	2,884

3. INVESTMENT INCOME

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

continued...

4. RAISING FUNDS

INVESTMENT MANAGEMENT COSTS

	2021	2020
	£	£
Portfolio management charges	8,307	8,496

5. GRANTS PAYABLE

	2021	2020
	£	£
Research	27,848	147,224

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 Psysiology, University of Edinburgh	(335)	-
*University of Birmingham	(3,499)	-
*Institute of Psychiatry, Kings College London	(24,607)	-
	27,848	147,224

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.

continued...

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
	675	1,157	21,585	15,062	38,479

Support costs have been allocated between Raising donations and Legacies and the Actitivities 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	17,053	16,743
	280,315	342,421

continued...

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	3	3
	10	13

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	51,496	-	51,496
Total	392,746	26,000	418,746
EXPENDITURE ON			
Raising funds	110,927	-	110,927
Charitable activities			
Family Care & Support	246,864	-	246,864
Research	225,823	30,700	256,523
Total	583,614	30,700	614,314
Net gains/(losses) on investments	(50,959)	-	(50,959)
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	972,169	-	972,169

continued...

11. INTANGIBLE FIXED ASSETS

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

12. TANGIBLE FIXED ASSETS

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

13. FIXED ASSET INVESTMENTS

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

continued...

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	52,835
At 31 December 2021	545,214
NET BOOK VALUE	
At 31 December 2021	545,214
At 31 December 2020	570,319

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	361,509	390,275

14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

continued...

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	38,002	6,403
	207,543	322,029

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 Refl/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

continued...

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.	-	26,289		26,289
	293,515	27,848	179,745	141,618

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	851,483	31,639	883,122
	972,169	19,922	992,091
TOTAL FUNDS	972,169	19,922	992,091

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	14,959	(36,155)	52,835	31,639
	443,454	(476,367)	52,835	19,922
TOTAL FUNDS	443,454	(476,367)	52,835	19,922

continued...

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	1,023,996	(172,513)	851,483
	1,213,996	(241,827)	972,169
Restricted funds			
Research	4,700	(4,700)	-
TOTAL FUNDS	1,218,696	(246,527)	972,169

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	34,166	(155,720)	(50,959)	(172,513)
	392,746	(583,614)	(50,959)	(241,827)
Restricted funds				
Research	22,000	(26,700)	-	(4,700)
Scotland	4,000	(4,000)	-	-
	26,000	(30,700)	-	(4,700)
TOTAL FUNDS	418,746	(614,314)	(50,959)	(246,527)

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	74,527	3,000
	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	14,959	34,167
	14,959	34,308
Charitable activities		
Conference	77,969	-
Other income		
Government grants - CJRS	-	51,496
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	-	88
	115,576	100,051

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	27,848	147,224
	310,882	452,782
Support costs		
Management		
Chief executive expenses	-	154
Recruitment costs	675	50
	675	204
Finance		
Postage and stationery	1,157	358
Bank charges	-	716
Fixtures and fittings	-	763
	1,157	1,837
Other		
IT & GDPR Services	11,047	15,113
Carried forward	11,047	15,113

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	-	(75)
	21,585	32,389
Governance costs		
Accountancy and legal fees	9,623	10,634
Annual report	5,439	5,541
	15,062	16,175
Total resources expended	476,367	614,314
Net expenditure	(32,913)	(195,568)

THE TUBEROUS SCLEROSIS ASSOCIATION

England & Wales - Charity number 1039549

Accounts

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

THE TUBEROUS SCLEROSIS ASSOCIATION

Unaudited Financial Statements for the Year Ended 31 December 2020

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

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Report of the Trustees
for the year ended 31 December 2020

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 2020. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Report of the Trustees
for the year ended 31 December 2020

OBJECTIVES AND ACTIVITIES

Objectives and aims, including public benefit

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

Tuberous Sclerosis Complex (TSC) is a rare genetic condition. Every month around 10 babies are born with TSC in the UK. TSC 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
- Five out of every 10 people with TSC have learning disabilities. Around three 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: 2020

Despite an extraordinary year, the TSA proactively responded to the upheaval caused by the coronavirus pandemic and managed to deliver on its strategic priorities:

- Supporting the TSC community
- Being at the forefront of the the research agenda
- Reducing its operating deficit

OBJECTIVES AND ACTIVITIES

The TSA has three main goals:

- 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 five-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. We plan to:

- REACH more people - significantly increase the number of people being supported by the TSA by 2023
- Drive more REseArCH - stimulate at least the same amount of investment in TSC research during 2019-2023 as was invested by the TSA over the last five years
- 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

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

2020 Business Plan

The Business Plan for 2020 (approved in November 2019) reflected the second year of implementing our strategy to reach more people, drive more research and balance expenditure with income by prioritising the following actions:

Providing access to good quality, accessible and timely information
- Launch new free and confidential Support Line in January 2020 and make sure it meets people's needs for emotional and practical support
- Continue building high-quality website and social media channels to reach more people with online information

Providing the opportunity for people with TSC to connect, support and learn together
- Refresh Ambassadors role to welcome those with a new diagnosis to the TSA
- Introduce more regular Family Fun Days so people living with TSC and families can get together
- Hold a TSC Community Education Afternoon so that people living with TSC and their families see the latest research from international experts on TSC

Building the knowledge and expertise of professionals working with people with TSC
- Develop a new approach to working with NHS TSC clinics and publish online resources to help those living with TSC to prepare for clinic visits
- Introduce a training programme for health, social care and education professionals to help them provide the best possible care when working with people living with TSC and their families

Driving the research agenda with the aim of improving outcomes and quality of life for people living with TSC
- Implement new approach to driving investment in TSC research through joint working with partners and funders rather than using the TSA's Designated Endowment Fund
- Host the 2020 International TSC Research Conference in London

Campaigning for better access to treatments and care
- Contribute views of people living with TSC and their families to NICE and SMC decision-making on, for example, Epidiolex® (cannabidiol) for TSC-related epilepsy amongst other treatments.
- Support an NHS England Clinical Reference Group review of TSC service delivery

During 2020 we planned to continue reducing expenditure and increasing income with an ambitious goal of balancing the TSA's budget by 2021

Revisions to 2020 Business Plan as a result of Covid-19

An urgent review was performed in April 2020 after the coronavirus pandemic caused extraordinary changes in the external environment.

The Trustees were concerned about the impact of the pandemic on our community (some of whom were already isolated and living in difficult circumstances) and wanted to ensure that the TSA could meet their needs now and in the future.

The TSA paused delivery on planned strategic objectives and agreed a revised plan that focused on:

Supporting people living with TSC and their families during this difficult time by:

- Sharing high quality, timely and accurate information about coronavirus and TSC developed by the TSA on our website, newsletter emails and social media channels as well as content developed by larger charities when relevant and helpful for the community
- Providing emotional support and tailored information for individuals and families who need help primarily through the new Support Line and those that contact us via social media and other means
- Developing regular, innovative ways for the TSC community to keep in touch with one-another through digital channels, including bringing people together virtually to reassure them that they are not alone while socially-isolating or shielding
- Developing regular and innovative ways for the TSA and TSC community to keep in touch through the post with individuals and families who are not active online while they are isolating or shielding

Ensuring the survival of the charity by:

It was recognised that our determination to balance the TSA's finances by 2021 was unlikely to be achieved due to the impact of coronavirus on the charity's ability to raise funds in the short term. Trustees took the difficult decisions needed to manage our finances proactively with actions that included:
- Asking senior staff to work reduced hours to save cost
- Furloughing six members of staff through the Government's Coronavirus Job Retention Scheme to safeguard future employment
- Pausing planned activities
- Launched emergency coronavirus fundraising appeal
- Providing dedicated supporters opportunities to continue to fundraise for the TSA through indoor activities and challenges that can still take place during the pandemic
- Rebuilding our trusts and foundations fundraising which is less likely to be affected even if the mechanisms for decision-making may cause some delays during this period

We moved the 2020 International Research Conference and the parallel TSC Community Education Afternoon to July 2021 and changed the format from an in-person to online event to minimise the likely impact of the pandemic on delegate numbers, delegate income and sponsorship.

In addition to reducing headcount and non-pay expenditure as set out on page 24, Trustees approved additional withdrawals from the Designated Fund (see page 28) during 2020 to top up income and meet our existing research funding obligations.

STRATEGIC REPORT

Despite the pandemic, the TSA's Trustees and staff remained ambitious about what we wanted to achieve for the TSC community. We remain determined to ensure that Coronavirus would not stop us being here for individuals living with TSC and their families.

Our mission remains unchanged: 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 new five year strategy.

Reaching more people

We believe there are between 3,700 and 11,000 people living with TSC in the UK and we aim to significantly increase the number of people being supported by the TSA by 2023.

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 2020 the TSA had increased this number by 19 per cent with 4,187 people in contact with the charity.

The launch of our new Support Line in 2020 meant we were well positioned to provide advice by telephone and email to people living with TSC across the UK while they were self-isolating or shielding. 384 people contacted our Support Line for support in 2020, and 20,639 users visited our website for information.

Driving more research

The three-day International TSC Research Conference was moved from November 2020 to July 2021 to minimise the likely impact of the pandemic on the event.

In November 2020 we delivered a three-hour virtual 2020 International Research Symposium in place of an in-person event, bringing together 129 clinicians and researchers from across the globe. This event focused on emerging research around TSC and Covid-19 and was hosted jointly with the US TS Alliance and US LAM Foundation. We remained determined to strengthen links across the global scientific community and drive more research which brings hope for the future to individuals and families living with TSC.

Balancing the books

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

After considering significantly reduced income due to Covid-19, the Trustees made the difficult decision in June 2020 to make staffing cuts of 30% and to ask remaining staff to work reduced hours until 2022 to enable us to run sustainably at a projected much-reduced income level.

It was decided that the Designated Endowment Fund would be used to fund the already sunk costs of hosting the postponed International TSC Research Conference and cover the cost of our ongoing research grants programme in 2020-21.

The Trustees' goal is to retain our reserves at a sensible level to give us the best possible opportunity to grow the charity when a more normal life resumes and deliver the goals set out in the five-year strategy 2019-2023.

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.

The TSA joined the Helplines Partnership to access high quality advice and training and ensure the development of a service that is informed by best practice across the health and care charity sector.

We recruited two experienced helpline advisers in January 2020 as part of a Support Line formally launching in April 2020 that enables people across the UK to contact our small team of professional and friendly advisers confidentially by telephone, email and post (9am to 5pm on Monday to Friday each week).

We were contacted by around 43 people each month asking for help and support, and around 25% of the enquiries that we received related to the coronavirus. We supported the TSC community by responding to a variety of questions about issues including when people living with TSC needed to shield, how to support children living with TSC when schools were closed, and how to keep in touch with loved ones living in residential care for long periods without visits from family and friends. Some callers wanted practical advice and information, others needed a listening ear and emotional support. We also provided proactive information and resources through our website (www.tuberous-sclerosis.org/news-coronavirus-tsc).

We worked with expert clinicians in the NHS TSC clinics to answer the questions that were being asked most by those contacting our Support Line (for example, are people with TSC more at risk from coronavirus? Should I stop taking immunosuppressive drugs to treat symptoms of my TSC?) and shared their responses on the TSC website, social media channels and at virtual events which were also recorded and shared online.

A Coronavirus and TSC insert was added to our Spring 2020 Scan magazine to ensure access for members of our community (some of whom who may be less comfortable with online communications). We also sent targeted postcards to the 200 members of the community who we only reach by post to remind them of our Support Line and encourage them to get in touch.

While we were able to deliver one community event before the pandemic (a day for children with TSC and their families at the Blue Reef Aquarium in Portsmouth), other events moved online as we found innovative ways for the TSC community to come together and reassure them that they were not alone.

We held two virtual Outlook events to bring together adults who are mildly affected by TSC and organised at least one virtual event every month focused on the concerns that people were expressing on the Support Line. These events were recorded and shared online so they were accessible for families with caring responsibilities. Events included:

- Managing aggressive and violent behaviours in TSC (expert speaker from the US with 103 people registered attendees and 369 views after the event).
- A virtual Welsh Get Together jointly with the Cardiff NHS TSC Clinic (28 people registered)
- Scottish Get Together with the Glasgow Clinic (7 people registered)
- and Northern Ireland Get Together jointly with the Belfast Clinic (8 people registered).

At the Welsh Get Together, both clinicians and members of the TSC community raised concerns about the sustainability of the Cardiff TSC Clinic and the lack of funding for Vortibia® (everolimus) for TSC-related epilepsy in Wales. In response the TSA wrote to the Welsh Health Minister and Chairs of relevant health committees to raise these concerns on behalf of the TSC community. We also developed template letters for members of the TSC community in Wales to use to directly raise their concerns with their elected representatives.

Christmas 2020 was a difficult time for everyone as festive gatherings were cancelled at short notice for many families. The TSA worked hard to bring the community together virtually with:

- A lovely online reading of 'The Night Before Christmas' by Sir David Suchet CBE who continued to support the charity throughout the year
- A Christmas Sing-a-Long led by families and individuals living with TSC

OBJECTIVES AND ACTIVITIES

- A virtual Outlook festive quiz bringing mildly affected people living with TSC together

During 2020 we awarded £3,329 in grants from the TSA Support Fund to 14 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.

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 2020 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.

Research

Our research team remain 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 of £147,224.

The charity's Trustees are determined to honour the research grant commitments that we made in 2018 and 2019, and Trustees decided that the Designated Endowment Fund would be used to cover the cost of our ongoing research grants programme over 2020-21.

The TSA's research portfolio of previously committed grants in 2020 consists of 12 live grants (three of which are jointly funded). Our portfolio of ongoing projects is worth £1,227,576, and we expect all of our previously committed research projects to be completed by 2023 at the latest.

Investigator	Institution	Title and purpose of grant	Co-Funder
Professor Patrick Bolton and Dr Charlotte Tye	Kings College London	**Autism Spectrum and Attention Deficit Hyperactivity Disorder in the Tuberous Sclerosis 2000 Cohort Study**The research is exploring links between the gene mutated (TSC1 or TSC2), the extent of brain abnormality (number of tubers), the severity of epilepsy in the early and later years and the neurodevelopmental outcome (Intellectual disability, Autism Spectrum Disorder, ADHD).	
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.	

OBJECTIVES AND ACTIVITIES

Dr Martin Baron	University of Manchester	**Exploiting Notch regulation to probe alternative mechanisms of TSC signalling** The research team is using the fruit fly model to uncover new mechanisms of action of TSC genes in the cell, which involve the control of the transport of key regulatory signalling components such, as the Notch receptor, around the cell to different locations where they are turned off or activated. By defining the components and links involved in this new pathway, they hope to identify candidates that will offer new targets to develop as TSC therapies that would augment Tor inhibitor strategies.
Dr Mark Nellist	Erasmus MC	**Functional and structural characterisation of the TSC complex; improved function assessment of TSC1 and TSC2 variants associated with tuberous sclerosis complex** The aim of this project is to assess the effects of TSC1 and TSC2 variants on TSC protein complex function using new, more sensitive assays. Comparing the biochemical effects of specific changes in TSC1 and TSC2 could help explain why some individuals have more or less severe TSC disease.
Dr Rosemary Ekong and Dr Mark Thomas	University College London	**The TSC1 and TSC2 variation databases** The two databases (www.LOVD.nl/TSC1 and www.LOVD.nl/TSC2) list as far as possible all known changes in the TSC1 and TSC2 genes, together with evidence for which of them can cause Tuberous sclerosis Complex (TSC).
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
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.
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.

OBJECTIVES AND ACTIVITIES

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 'lymphangioleiomyomatosis') 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 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

The research portfolio continues to yield results and 2020 saw ten live grants submit data. Of these ten, three were published in six different academic journals while five reported seven 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.

The International TSC Research Symposium took place in November 2020 and was jointly hosted by TSA-UK with TS Alliance-US and the LAM Foundation-US. Over 140 people registered to attend with 129 delegates signing in on the day. Attendees were able to access recordings from the event a month after it took place, and feedback was sought to help us learn about the best approach to developing and delivering virtual research events. We charged a small fee for delegates to attend and raised just under £2,000 from ticket sales which was a welcome contribution to the charity's funds. The Symposium was also sponsored by GW Pharmaceuticals and Plusultra Pharma who each paid £2,000 to sponsor the event.

We continue to benefit from membership of the Association of Medical Research Charities (AMRC) and the UK Child Health Collaboration. The AMRC will audit our research grants programme in 2021 and we look forward to this opportunity to learn from their feedback and continually improve our work in this area.

We continue to build our relationship with NHS TSC clinics through our annual TSC Clinics Day which is organised by the TSA's research team. This year's TSC Clinics Day was held in March 2020 and brought together clinic leads (usually senior clinicians) and clinic coordinators (usually nurses) 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:

OBJECTIVES AND ACTIVITIES

- 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

Income generation

We noted that our ambition to balance the TSA's finances by 2021 was unlikely to be possible given the impact of coronavirus on the charity's ability to raise funds. The Trustees took the difficult decisions needed to manage our finances with a view to **balancing the books** by 2022 or 2023.

The coronavirus pandemic made for a daunting fundraising environment in 2020 and many of the activities we would traditionally use to raise income from our community were cancelled due to social distancing restrictions, such as:
- Tea and SCones for TSC coffee mornings (which raised £4,655 in 2019)
- the London Marathon (£15,473 in 2019)
- Great North Run (£10,133 in 2019)
- Ride100 (£10,583 in 2019).

This unprecedented 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 which included:
- the Government's Coronavirus Job Retention Scheme which we used to furlough six out of thirteen members of staff on 80% of their usual salaries in an effort to safeguard as many jobs at the charity as possible in the longer term, resulting in furlough income of £51,000 during 2020.
- A £10,000 grant from the Coronavirus Community Support Fund (distributed by The National Lottery Community Fund) which helped us through the pandemic
- A coronavirus-related grant of £2,000 from the London Borough of Tower Hamlets where the TSA's office is based

We sent out a direct mail Coronavirus Emergency Appeal to the TSC community to ask them to make one-off donations or sign up to give a regular direct debit to make sure that the charity continues to be here for everyone who needs us. We received an unprecedented response with 224 individuals contributing a total of £21,695 in response to the appeal.

We sent Coronavirus Emergency Appeal requests to seven pharmaceutical companies with an interest in TSC or epilepsy and received pledges of unrestricted grants from GW Pharmaceuticals and Plusultra Pharma which will be received by the charity early in 2021.

We developed ideas for coronavirus-proof fundraising which were shared with our community. This included encouraging more digital fundraising through online platforms such as Facebook and introducing the TSA Gaming Champion so that people could fundraise through a gaming challenge while staying at home. We encouraged our supporters to join the virtual 2.6 Challenge which was developed by the team who run the London Marathon and raised a welcome £3,800 for the charity.

Private equity firm Equistone had selected the TSA as their Charity of the Year for 2020 before the pandemic struck. The lockdown and restrictions on people meeting meant that some of their planned activities were unable to go ahead, and Equistone's UK team had to be creative to replace the events that would have taken place. They decided to climb the equivalent of Mount Everest's elevation (8,846 metres) on their stairs at home in fancy dress. They also held online events such as quizzes. Over the course of that extraordinary year, Equistone raised £45,000 which is testimony to their determination, imagination and desire to support the TSA through a most challenging year.

Other companies kindly supporting the charity during 2020 included Pearson who donated space at their head office and a facilitator for our senior management team away day, and Moo Creative who donated their time and expertise to deliver the design of our publications.

We received several amazing individual gifts and legacies from supporters of the TSA during 2020, which would be greatly appreciated at any time but were particularly timely given the challenging year facing the TSA.

OBJECTIVES AND ACTIVITIES

We received an incredible gift of £35,000 from a member of the TSC community who had been left the money by a relative to donate to a charity of her choice. We also received a generous legacy of £40,000 and two generous legacies of £5,000 each which made a substantial difference to the charity during this difficult year. We would like to formally record a huge thank you to everyone who supported us in this way.

We received a grant of £5,000 from The Adint Charitable Trust, plus an additional grant of £5,000 to help charities that they support to survive the covid-19 outbreak. The Bank of Scotland Foundation awarded us £2,000 to help support virtual events and support line tasks focused on Scotland-based community members.

We also received support from: Charles & Elsie Sykes Charitable Trust, Esher House Charitable Trust, The Michael and Anna Wix Charitable Trust, Anglo American Foundation and the Dunn Family Trust. We invested in Trusts and Foundations support to draft additional bids for support which were sent to trusts and foundations during a challenging period for charities.

We are profoundly grateful to all the trusts and foundations who helped us in 2020.

Organisation development and people

We noted that our ambition to balance the TSA's finances by 2021 was unlikely to be met given the impact of coronavirus on the charity's ability to raise funds. The Trustees took the steps needed to manage our finances with a view to balancing the books by 2022 or 2023.

In June 2020, the Trustees made the difficult decision to right size the charity and approve a proposal for restructuring. Following a two-week period of formal consultation, the Board reviewed and approved four redundancies: Head of Support and Information Services, Information Officer, Trusts and Foundations Manager, and Communications and Events Assistant. We would like to thank the staff who worked in these posts for their hard work and commitment during their time with the TSA, and wish them the very best for the future.

These staff cuts were the second round of redundancies that have needed to be made in order to make the charity the right size for the future.

In addition we asked all four members of the senior management team at the charity to voluntarily reduce their salaries to 80% of their usual hours and pay to support the charity during 2020. We are grateful for this much-needed support.

A new structure for the Support Line team was implemented. The Head of Communications and Support is responsible for leading the team, alongside two Support Line Managers. This team continued working hours and pay at 100% due to a business need for the Support Line to be available from 9am to 5pm from Monday to Friday.

We recruited a part time Joint Chief Executive for a twelve-month period to support the charity alongside our long-standing Chief Executive (who temporarily reduced her working hours to manage home-schooling and work) whilst the Head of Income Generation was on maternity leave. The Joint Chief Executive brought expertise in finance and fundraising to upskill colleagues and provide 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.

OBJECTIVES AND ACTIVITIES

In the year ended 31 December 2020, the total return on the portfolio was -1.4% as against the benchmark of 3.5%. Over the longer term, our investment managers have consistently out-performed 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. Part of the reason for the underperformance of the portfolio is that in 2020 £391k was held in cash which was generated in late September 2020 to ensure the charity held the cash it needed in 2020 and 2021. This prudent decision was taken in an uncertain market, but taken ahead of the significant recovery of markets in Q4 it resulted in the underperformance of the portfolio against the benchmark over the year.

FINANCIAL REVIEW

Financial position

Grant making policy

Research grants are given for purposes directly concerned with furthering an understanding of Tuberous Sclerosis Complex and its treatment. The Association is a member of the Association of Medical Research Charities 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

At the end of the year the Association has total funds of **£972,169**. This included designated funds of **£851,483**, further details of which are given below. The designated funds are anticipated to reduce to approximately £300,000 by the end of 2022.

The reserves of the Association amounted to **£120,686** at 31 December 2020, 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 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 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) are such that the trustees expect the Designated Fund to reduce to approximately £300,000 by the end of 2022. The trustees are of the opinion that this £300,000 designated fund should be retained so that the TSA 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 **£418,746** (2019 £303,000).

Our total investment gains/(losses) were **(£50,959)** (2019 £208,000). 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.

Taking into account the investment gain/(loss), the overall deficit for the year was **£247,000** (2019 £489,000).

FUTURE PLANS

Strategic objectives

The first two years of our 2019-2023 strategy has seen the TSA significantly reduce expenditure (from £974,646 in 2018 to £614,314 in 2020) and headcount (from 18 posts in 2018 to nine posts by the end of 2020) to address the charity's structural deficit, while simultaneously improving the quality of our services and increasing our reach into the TSC community.

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

We will focus on:

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 and regular supervision for advisers) and introduce the new web chat function to drive better access for family carers and young people with TSC.

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

- Make sure that no-one with TSC feels alone as the pandemic continues 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.

Capacity 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.
- Host a Community Education Afternoon to share this research with the TSC community, again keeping the option of this being a virtual event under review.

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

- Work with our external finance provider to move the TSA onto the Xero accounting system which will reduce the senior capacity needed to run parallel management accounts.

Digital transformation and smart working to reach more people

- Maximise the impact of our information by continuing our journey to regular and timely 'digital first' communications across the website and social media.
- Move our 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

- Develop new approaches to supporting major donors and potential major donors, encouraging legacies and working with corporates to generate income
- Develop general cases for support to generate unrestricted donations from trusts and foundations (for example, drafting separate cases of support targeting trusts who fund projects for young people, mental health, learning disabilities and elderly carers)
- Increase the number of individuals on the database, segment them, and develop bespoke stewardship journeys with the aim of making them into regular donors to the TSA

- Maximise income generation from every touch point (for example, using the Impact Report and AGM mailing to steward donors and funders)
- Maximise income from delegates and sponsors at International TSC Research Conference
- Identify opportunities to bring in funding for Scan and virtual events

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 will put our accounting and audit services out to tender and move from an annual audit to an independent examination. We will close our small office and switch to being an entirely home-based organisation, sadly resulting in a decision by Trustees to make the post of Office Manager redundant when the office closes in October 2021.

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 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 2020, these are Chris Kingswood, Martin Short, Lisa Suchet and Rob Vaughan. Chris Kingswood, Martin Short and Lisa Suchet offer themselves for re-election; after an appraisal process, the Board recommends their re-election. Rob Vaughan who has served as both Trustee and Treasurer will retire by choice at the 2021 AGM, and the Board is most grateful to him for all of his work and commitment to the TSA. Martin Short will remain as a trustee but relinquish his role as Vice Chair after holding the role for two years. From the 2021 AGM Rajan Khullar will take on the role of Treasurer and Robert Woodthorpe Browne will take on the role of Vice Chair.

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 Rescom 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.

Risk management

The Trustees meet as a Board four times each year.

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

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

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

Report of the Trustees
for the year ended 31 December 2020

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number
02900107 (England and Wales)

Registered Charity number
1039549

Registered office
Unit 56
Emma Street
Tower Hamlets
London
E2 9FP

Trustees
P F Bolton Doctor
T E Carter Company Director
Ms A Cotton Iass Adviser
Dr F V Elmslie Doctor
R Khullar Chartered Management Accountant (appointed 26.11.20)
Dr J C Kingswood Hospital Physician
J Rogers Nurse
S Sethi Fund 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
Ms L Fish

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

Approved by order of the board of trustees on .....28/09/2021..... 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 2020.

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

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

Independent examiner's statement
Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a 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; 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.

H. M. Day

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

Date: 29th September 2021

Statement of Financial Activities
for the year ended 31 December 2020

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		304,058	26,000	330,058	234,374
Charitable activities					
Family Care & Support		-	-	-	1,510
Other trading activities	2	2,884	-	2,884	1,756
Investment income	3	34,308	-	34,308	65,176
Other income		51,496	-	51,496	-
Total		392,746	26,000	418,746	302,816
EXPENDITURE ON					
Raising funds	4	110,927	-	110,927	157,232
Charitable activities					
Family Care & Support		246,864	-	246,864	457,658
Research		225,823	30,700	256,523	385,571
Total		583,614	30,700	614,314	1,000,461
Net gains/(losses) on investments		(50,959)	-	(50,959)	208,190
NET INCOME/(EXPENDITURE)		(241,827)	(4,700)	(246,527)	(489,455)
RECONCILIATION OF FUNDS					
Total funds brought forward		1,213,996	4,700	1,218,696	1,708,151
TOTAL FUNDS CARRIED FORWARD		972,169	-	972,169	1,218,696

The notes form part of these financial statements

Balance Sheet
31 December 2020

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
FIXED ASSETS					
Tangible assets	12	-	-	-	851
Investments	13	960,594	-	960,594	1,268,946
		960,594	-	960,594	1,269,797
CURRENT ASSETS					
Debtors	14	82,171	-	82,171	98,608
Cash at bank		251,432	-	251,432	264,938
		333,603	-	333,603	363,546
CREDITORS					
Amounts falling due within one year	15	(322,028)	-	(322,028)	(414,647)
NET CURRENT ASSETS		11,575	-	11,575	(51,101)
TOTAL ASSETS LESS CURRENT LIABILITIES		972,169	-	972,169	1,218,696
NET ASSETS		972,169	-	972,169	1,218,696
FUNDS	16				
Unrestricted funds				972,169	1,213,996
Restricted funds				-	4,700
TOTAL FUNDS				972,169	1,218,696

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2020.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 December 2020 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

continued...

Balance Sheet - continued
31 December 2020

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 .....28/09/2021..... and were signed on its behalf by:

.....
S Sethi - Trustee

The notes form part of these financial statements

Notes to the Financial Statements
for the year ended 31 December 2020

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 areas 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.

continued...

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

	2020	2019
	£	£
Christmas cards & other sales	2,884	1,756

3. INVESTMENT INCOME

	2020	2019
	£	£
Deposit account interest	141	201
Income from managed portfolio	34,167	64,975
	34,308	65,176

continued...

4. RAISING FUNDS

INVESTMENT MANAGEMENT COSTS

	2020	2019
	£	£
Portfolio management charges	8,496	11,795

5. GRANTS PAYABLE

	2020	2019
	£	£
Family Care & Support	-	(13,053)
Research	147,224	265,618
	147,224	252,565

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

	2020	2019
	£	£
* Addenbrookes Hospital - TSC Psychology	-	(13,053)
* Brighton TS Registry	-	(101)
* Whitehead Institute - Towards Specific Mtor Inhibitors Capable of Rescuing Tuberous Sclerosis Complex Loss-of-function	51,000	51,000
* Cardiff University - Targeting the Ref1/STAT3 axis to treat Tuberous Sclerosis Complex	32,719	61,744
* Cardiff University - Characterising the Role of Exosomes in Tuberous Sclerosis	32,712	32,537
* Cardiff University - An innovative model system of cell invasion in TSC/LAM to uncover new drug targets and therapies	30,793	-
* Institute of Psychiatry Psychology and Neuroscience - Neurocognitive predictors of neurodevelopmental impairment in infants and toddlers with TSC	-	16,740
* University of Cape Town - Empowering Families through Technology: a mobile-health project to reduce the TAND identification and treatment gap	-	41,697
* University of Bristol NHS Foundation Trust - Randomised Controlled Trial of Acceptance and Commitment Therapy in the Tuberous Sclerosis Complex	-	62,000
	147,224	252,564

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.

continued...

6. SUPPORT COSTS

	Management	Finance	Other	Governance costs	Totals
	£	£	£	£	£
Family Care & Support	127	1,004	22,796	8,088	32,015
Research	77	833	9,593	8,087	18,590
	204	1,837	32,389	16,175	50,605

Support costs have been allocated between Raising donations and Legacies and the Actitivities 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):

	2020	2019
	£	£
Auditors' remuneration	-	6,357
Depreciation - owned assets	851	284
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 2020 nor for the year ended 31 December 2019.

TRUSTEES' EXPENSES

	2020	2019
	£	£
Trustees' expenses	-	3,036

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 (2019 - 5) Trustees received payments for reimbursement of expenses during the year.

9. STAFF COSTS

	2020	2019
	£	£
Wages and salaries	298,750	397,223
Social security costs	26,928	35,294
Other pension costs	16,743	21,705
	342,421	454,222

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

	2020	2019
Fundraising	2	3
Family Support and Communications	8	10
Research	3	3
	13	16

continued...

9. STAFF COSTS - continued

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	229,674	4,700	234,374
Charitable activities			
Family Care & Support	1,510	-	1,510
Other trading activities	1,756	-	1,756
Investment income	65,176	-	65,176
Total	298,116	4,700	302,816
EXPENDITURE ON			
Raising funds	157,232	-	157,232
Charitable activities			
Family Care & Support	452,237	5,421	457,658
Research	385,571	-	385,571
Total	995,040	5,421	1,000,461
Net gains on investments	208,190	-	208,190
NET INCOME/(EXPENDITURE)	(488,734)	(721)	(489,455)
RECONCILIATION OF FUNDS			
Total funds brought forward	1,702,730	5,421	1,708,151
TOTAL FUNDS CARRIED FORWARD	1,213,996	4,700	1,218,696

11. INTANGIBLE FIXED ASSETS

	Database costs £
COST	
At 1 January 2020 and 31 December 2020	19,624
AMORTISATION	
At 1 January 2020 and 31 December 2020	19,624
NET BOOK VALUE	
At 31 December 2020	-
At 31 December 2019	-

continued...

12. TANGIBLE FIXED ASSETS

	Fixtures and fittings £
COST	
At 1 January 2020 and 31 December 2020	1,135
DEPRECIATION	
At 1 January 2020	284
Charge for year	851
At 31 December 2020	1,135
NET BOOK VALUE	
At 31 December 2020	-
At 31 December 2019	851

13. FIXED ASSET INVESTMENTS

	2020 £	2019 £
Shares	570,319	1,259,896
Brewin Dolphin capital account	390,275	9,050
	960,594	1,268,946

Additional information as follows:

	Listed investments £
MARKET VALUE	
At 1 January 2020	1,259,896
Additions	36,726
Disposals	(675,344)
Revaluations	(50,959)
At 31 December 2020	570,319
NET BOOK VALUE	
At 31 December 2020	570,319
At 31 December 2019	1,259,896

There were no investment assets outside the UK.

Investments (neither listed nor unlisted) were as follows:

	2020 £	2019 £
Brewin Dolphin capital account	390,275	9,050

The historical cost of the investments at the year end is £324,612 (2019 £721,783).

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14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020	2019
	£	£
Other debtors	82,171	98,608

15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020	2019
	£	£
Trade creditors	13,354	36,410
Social security and other taxes	5,413	8,892
Other creditors	296,858	358,888
Accrued expenses	6,403	10,457
	322,028	414,647

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 1.1.20	SOFA	Paid	At 31.12.20
	£	£	£	£
* 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	24,679	-	(8,981)	15,698
* Erasmus MC, Department of Clinical Genetics	180	-	-	180
* University College London - The TSC1 and TSC2 Variation Databases	29,945	-	(21,064)	8,881
* Whitehead Institute - Towards specific Motor Inhibitors capable of rescuing Tuberous Sclerosis Complex loss-of-function	35,321	51,000	(61,985)	24,336
* Cardiff University - Targeting the Ref1/STAT3 axis to treat Tuberous Sclerosis Complex	36,659	32,719	(31,954)	37,424
* Cardiff University - Characterising the roles of exosomes in Tuberous Sclerosis Complex	36,273	32,712	(27,634)	41,351
* University of Bristol NHS Foundation Trust - Randomised Controlled Trial of Acceptance and Commitment Therapy in Tuberous Sclerosis Complex	62,000	-	-	62,000

continued...

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	16,740	-	(5,191)	11,549
* University of Cape Town - Empowering Families through technology: a mobilehealth project to reduce the TAND identification and treatment gap	41,697	-	(41,697)	-
* Cardiff University - An innovative model system to cell invasion in TSC/LAM to uncover new drug targets and therapies	28,353	30,793	(12,146)	47,000
	356,942	147,224	(210,652)	293,515

16. 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	1,023,996	(172,513)	851,483
	1,213,996	(241,827)	972,169
Restricted funds			
Research	4,700	(4,700)	-
TOTAL FUNDS	1,218,696	(246,527)	972,169

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	34,166	(155,720)	(50,959)	(172,513)
	392,746	(583,614)	(50,959)	(241,827)
Restricted funds				
Research	22,000	(26,700)	-	(4,700)
Scotland	4,000	(4,000)	-	-
	26,000	(30,700)	-	(4,700)
TOTAL FUNDS	418,746	(614,314)	(50,959)	(246,527)

continued...

16. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.1.19 £	Net movement in funds £	Transfers between funds £	At 31.12.19 £
Unrestricted funds				
General fund	-	(496,057)	686,057	190,000
Designated Endowment Fund	1,473,818	236,235	(686,057)	1,023,996
Kilmain Family Research Fellowship	228,912	(228,912)	-	-
	1,702,730	(488,734)	-	1,213,996
Restricted funds				
Research	-	4,700	-	4,700
Education	5,421	(5,421)	-	-
	5,421	(721)	-	4,700
TOTAL FUNDS	1,708,151	(489,455)	-	1,218,696

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	233,141	(729,198)	-	(496,057)
Designated Endowment Fund	64,975	(36,930)	208,190	236,235
Kilmain Family Research Fellowship	-	(228,912)	-	(228,912)
	298,116	(995,040)	208,190	(488,734)
Restricted funds				
Research	4,700	-	-	4,700
Education	-	(5,421)	-	(5,421)
	4,700	(5,421)	-	(721)
TOTAL FUNDS	302,816	(1,000,461)	208,190	(489,455)

17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 December 2020.

Detailed Statement of Financial Activities for the year ended 31 December 2020

	2020 £	2019 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations and subscription	327,058	230,180
Grants	3,000	4,194
	330,058	234,374
Other trading activities		
Christmas cards & other sales	2,884	1,756
Investment income		
Deposit account interest	141	201
Income from managed portfolio	34,167	64,975
	34,308	65,176
Charitable activities		
Family days and weekends	-	1,510
Other income		
Government grants - CJRS	51,496	-
Total incoming resources	418,746	302,816
EXPENDITURE		
Raising donations and legacies		
Wages	68,133	82,081
Social security	4,521	7,310
Pensions	2,769	4,611
Events fees	280	11,823
Sundries	2,391	26,514
Travel & Communications	1,884	7,458
Bid writing	2,800	-
Staff training	-	3,325
Marketing & Media	2,622	-
Insurance	1,337	-
Office costs	4,452	-
Professional fees	687	-
Accountancy & legal fees	5,317	-
AGM, Big Day and Annual Report costs	2,770	-
Fixtures and fittings	88	-
	100,051	143,122
Other trading activities		
Christmas card sales	2,380	2,315
Investment management costs		
Portfolio management charges	8,496	11,795

Detailed Statement of Financial Activities for the year ended 31 December 2020

	2020 £	2019 £
Charitable activities		
Wages	230,617	271,142
Social security	22,407	22,955
Pensions	13,974	14,454
Sundries	1	-
Staff training	3,714	-
No description	-	22,577
Accommodation and room hire	4,532	-
Publications	7,409	18,704
Travel & Communications	4,750	-
Benevolent grants	3,070	5,700
Family days and weekends	314	1,175
Subscriptions	2,041	-
Postage and Stationery	2,751	-
Sundries	5,054	2,237
Insurance	758	-
IT and GDPR services	540	-
Marketing & Media	2,610	-
Professional fees	1,016	-
Grants to institutions	147,224	252,565
	452,782	611,509
Support costs (see page 24 no. 6)		
Management		
Chief executive salary	-	44,000
Social security	-	5,029
Pensions	-	2,640
Chief executive expenses	154	1,375
Recruitment costs	50	1,028
	204	54,072
Finance		
Postage and stationery	358	3,386
Bank charges	716	2,173
Amortisation of intangible fixed assets	-	333
Depreciation of tangible fixed assets	763	250
	1,837	6,142
Other		
Trustees' expenses	-	3,036
IT & GDPR Services	15,113	15,375
Insurance	2,674	3,551
Office costs	10,386	11,564
Sundries	723	4,677
Professional fees	3,441	7,053
Marketing	-	24,420
Travel	127	608
Carried forward	32,464	70,284

Detailed Statement of Financial Activities for the year ended 31 December 2020

	2020 £	2019 £
Other		
Brought forward	32,464	70,284
Loss on sale of tangible fixed assets	(75)	-
Redundancy costs	-	52,333
	32,389	122,617
Governance costs		
Auditors' remuneration	-	6,357
Sundries	-	13,926
Accountancy and legal fees	10,634	10,264
AGM expenditure	5,541	18,342
	16,175	48,889
Total resources expended	614,314	1,000,461
Net expenditure	(195,568)	(697,645)