

**REGISTERED COMPANY NUMBER: 02900107 (England and Wales)**  
**REGISTERED CHARITY NUMBERS: 1039549, SC042780**

The Tuberous Sclerosis Association

Report of the Trustees and

Audited Financial Statements for the Year Ended 31 December 2019

The Tuberous Sclerosis Association

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for the Year Ended 31 December 2019

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Report of the Trustees  
for the Year Ended 31 December 2019

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 2019. 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 102 (effective 1 January 2016)". The Report of the Trustees also comprises a Directors' Report as required by Company Law.

## **OBJECTIVES AND ACTIVITIES**

### **Objectives and aims, including public benefit**

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.

The Association has three main objectives:

- \* to support individuals affected by TSC, together with their families or carers;
- \* to encourage and support research into the causes and management of TSC; and
- \* to provide education, publicity and information to promote awareness of the problems caused by the condition.

In 2019 the TSA began to implement its five-year strategy for 2019-2023 which was approved by Trustees in the previous year. The strategy sets out a clear vision (a world where TSC and its effects are conquered), continues the charity's mission (to provide help for today and a cure for tomorrow), and states that we will:

- \* REACH more people - significantly increasing the number of people being supported by the TSA by 2023;
- \* Drive more REseArCH - stimulating 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.

Our strategic aims (what we will do) are to:

- \* Make a positive impact on the health and wellbeing of people living with TSC and their 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:

- \* Provide good quality, easily accessible and timely information about TSC and about living with the condition.
- \* Provide the opportunity for people with TSC and their families to connect, support and learn together.
- \* Capacity build the knowledge and expertise of professionals working with people with TSC.
- \* Drive the research agenda with the aim of improving 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.

Report of the Trustees  
for the Year Ended 31 December 2019

**Objectives and aims, including public benefit (continued)**

**Our strategic enablers (the things that will make it possible) to deliver the strategy 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.

Our strategic values (the things we believe are important) are to be inclusive, ambitious and effective.

2019 was the first year of implementing the new five-year strategy. This was a year of transition for the TSA resulting in significant changes to how we work internally, what we deliver for our beneficiaries, and who we work with externally. Our 2019 Business Plan set the following priorities:

Prioritising access to good quality, accessible and timely information:

- \* We will develop and launch a high-quality new website to reach more people with online information.
- \* We will scope and deliver a new Support Line ready for launch in January 2020.
- \* We will disseminate and support the implementation of new UK clinical guidelines on TSC.

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

- \* We will develop and deliver a smaller number of high-quality events with more attendees at each event across England and the devolved nations.

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

- \* We will develop and implement a new approach to driving investment in TSC research through joint working with partners and funders.
- \* We will seek to fund and establish a UK TSC Registry which will pull together information from patients who have TSC.
- \* We will continue to fund our existing research commitments during this period.

Campaigning for better access to treatments and care.

- \* Following a successful campaign, access to Everolimus for TSC-related refractory epilepsy was secured in England from April 2019, and we assisted patients continuing to seek access in Wales and Northern Ireland. (We successfully secured access in Scotland during 2018).
- \* We will identify and support existing third sector partnerships seeking to improve care for people with autism and learning disabilities.

The 2019 Business Plan stated that the TSA would continue to run a deficit budget for 2019 and 2020, with a view to running a balanced budget from 2021 and on an ongoing basis from that point forward.

We were notified by our landlords in 2018 that the TSA's shared offices were scheduled for demolition the following year. We initiated a project to identify a new office space for the charity and moved to Unit 56, 1 Emma Street, London E2 9FP during May 2019.

The benefits of our activities are briefly summarised below (ending after 'Future Plans' on pages 9 and 10) and relate directly to our objectives. This summary constitutes our 'Strategic Report'.

Report of the Trustees  
for the Year Ended 31 December 2019

**OBJECTIVES AND ACTIVITIES**

**Activities and performance in relation to our five-year strategy**

The Trustees are monitoring performance against three headline indicators and a broader set of key performance indicators to determine the success of our new five-year strategy.

**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 entered into, and ideally in the longer term raising sufficient funds to cover the research commitments. During 2019 the Trustees took a number of steps to address the structural and recurring loss that is accelerating the reduction in the Designated Endowment Fund of the charity. In the first year of our new strategy we initiated operational changes that will generate savings or increase income in future years, including reducing planned headcount from 21 to 13 posts, reviewing our expenditure, refreshing our approach to income generation to broaden the ways that we raise money to fund our work, and approving a new research partnership strategy.

**Reaching more people.** In 2018 the TSA had 1,600 people living with TSC and family members on our database. We believe there are somewhere 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 the first year of our new strategy we increased the number of people on our database by 15 per cent (793 new contacts) and increased the number of people following the TSA on Facebook by 17 per cent (572 new followers).

**Driving more research.** During the past five years (2014-2018) the TSA has invested £1,775,000 in research. We aim to drive the same amount of investment into TSC research during 2019-2023 as we invested directly over the last five years. In the first year of our new strategy the TSA invested £152,000 which unlocked £728,000 of co-funding from external partners including the King Baudouin Foundation, the US Ministry of Defence and an anonymous major donor, driving a total new investment of £890,000 in TSC research.

Report of the Trustees  
for the Year Ended 31 December 2019

## **OBJECTIVES AND ACTIVITIES**

### **Activities and Performance in relation to Support**

Our commitment is to offer support to everyone affected by TSC based on individual needs and preferences. We aim to address diversity, including geographical and cultural diversity, of need. Key to our success is making the support we offer as flexible as possible, enabling individuals, families and carers access to the support and information they need in the way that suits them best.

During 2019 we responded to 961 enquiries from members of the TSC community who contacted the TSA asking for information and support. 19% of enquiries came from adults living with TSC, 16% from parent carers of adults living with TSC, 29% from parent carers of children living with TSC, and 11% from professionals supporting individuals and families living with TSC.

In 2019 the Trustees made the difficult decision to move from a regional support service to a Support Line which could be delivered by a smaller number of staff. The support services team was restructured from nine posts to four, and sadly we said goodbye to seven hardworking and valued members of staff whose regionally focused posts were made redundant. Their loss was keenly felt by trustees, staff and the wider TSC community.

During Autumn 2019 we began the transition to the new Support Line which launched as a pilot in early 2020. The Support Line enables the TSC community across the UK to contact our small team of friendly and professional advisers confidentially by telephone, email and post from 9am to 5pm on Monday to Friday each week. The TSA joined the Helplines Partnership to access high quality advice and training and ensure that the development of our new service is informed by best practice across the health and social care charity sector.

We continue to build our relationship with NHS TSC clinics through our annual TSC Clinics Day which brings 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:

- \* 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.
- \* Signposting patients with wider support needs to external agencies across social care, education and welfare.
- \* Signposting to and facilitating engagement with the portfolio of TSA services.

During 2019 we awarded £5,700 in grants from the TSA Support Fund to individuals and families.

### **Activities and performance in relation to 'Influencing Policy'**

NHS England funded everolimus for TSC-related epilepsy from April 2019 onwards as a result of intense campaigning from people living with TSC, their families and the TSA, to reverse their earlier decision due to the clear clinical evidence shown to commission the medicine. During 2019 we continued to support members of the TSC community in Wales and Northern Ireland who wished to access everolimus for TSC-related epilepsy. We also met with NHS England to focus on finding solutions for the practical challenges faced by NHS trusts when implementing the recommendations to fund everolimus for TSC-related epilepsy.

Report of the Trustees  
for the Year Ended 31 December 2019

**OBJECTIVES AND ACTIVITIES**

We supported the implementation of new UK clinical guidelines on TSC, which are an evidence-based tool aiming to improve the consistency and quality of care across the NHS. We worked with the UK experts who developed the guideline to produce a summary version for clinicians which was disseminated to NHS clinics and professionals across the UK, and distributed the summary version to patients and carers with our Spring Scan magazine to facilitate informed conversations with the professionals caring for them. We also published an easy read version of the summary clinical guideline to help individuals with learning disabilities and their family carers to discuss and understand the recommendations.

We have 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 2019 we continued to work closely with colleagues from the Specialised Healthcare Commissioning Alliance (SHCA) and Genetic Alliance to raise awareness of the need for NHS England and NICE to listen to the views of patients and families when making decisions about treatments and services for people living with rare diseases. We joined the Embracing Complexity Coalition to raise awareness of the need for joined up support from health and social care for people with complex conditions, and continued our membership of the Council for Disabled Children to improve access to services and care for children living with TSC and their families.

**Activities and performance in relation to 'Information & awareness'**

We worked hard to make all of our information and resources available on a new website ([www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)) for individuals with TSC, their families and the professionals who support them. The website also showcases our new five-year strategy to external charity funders and partners, demonstrates our research credentials to potential research funders and partners, and makes it easier for people to donate money to us or raise funds for the charity. The website was funded by £13,000 of grants from trusts and foundations to develop a website with a simple back-end system that can be updated in-house to make savings year on year. We also produced and published three editions of our SCAN magazine to ensure continued access for members of our community who may be less comfortable with online communications.

Raising awareness of the TSA and our services has been key to reaching new families. The more professionals, opinion leaders, politicians, policy makers and the media know about TSC, the more likely we are to bring about positive change. During 2019 there were 10 articles about TSC in the regional and local media, and 7 articles across the medical and third sector press.

During 2019 we received an amazing boost to our awareness-raising from award-winning actor Sir David Suchet CBE who hosted a black-tie fundraising dinner for 70 guests which raised £17,982 for the charity. Sir David used the launch of his new book 'Behind the Lens' to raise awareness of TSC and the TSA across print and broadcast media, generating coverage in Hello magazine, seven national newspapers, ITV's This Morning, BBC Radio 4 and BBC Radio 2. Sir David raised a further £3,220 for the charity during his book launch and tour events and decided to donate any profits that his book makes in future to the TSA for us to invest in TSC research. We would like to thank Sir David and his wife Sheila for their incredible generosity and kindness to the charity and the individuals and families who we support.

In May 2019 we ran our awareness and fundraising campaign 'Tea and SCones for TSC' which raised £4,655 and coincided with TSC Global Awareness Day. Our fantastic runners and riders raised funds for the TSA at the London Marathon (£15,473), Great North Run (£10,133) and Ride100 (£10,583)

Report of the Trustees  
for the Year Ended 31 December 2019

## **OBJECTIVES AND ACTIVITIES**

In line with our new strategy, we delivered a smaller number of high-quality events across England (the Big Day, Outlook and a Family Fun Day), Scotland (Scottish Get Together), Wales (Welsh Information Day) and Northern Ireland (Northern Ireland Study Day). Our aim was to increase the number of people attending each event to facilitate networking between individuals and families with lived experience of TSC who are able to support one another, and 274 people registered to attend at least one of our events in 2019.

### **Activities and performance in relation to 'Research'**

The Association is the only UK charity dedicated to supporting TSC research, with an in-year Research Grant commitment in 2019 of £265,618, as shown in note nine to the financial statements.

In 2019, of the nine awards that submitted data, four awards reported six publications in four different academic journals. Five awards reported 13 other forms of engagement, such as oral and poster presentations at academic conferences or professional meetings.

During the year the Trustees approved a new research partnership strategy based on working with external partners who share our goals and can co-fund TSC research projects. During 2019 we invested in three new research projects where the TSA will inject a total of £152,000 to unlock £728,000 of co-funding from external partners, driving a total new investment of £890,000 in TSC research.

### **Co Funded Projects**

<b>Investigator</b>	<b>Institution</b>	<b>Title</b>	<b>Co Funder</b>
Dr Elaine Dunlop	Cardiff University	A model of cell invasion in TSC-LAM	US Ministry of Defence
Professor Petrus de Vries and Professor Anna Janssen	University of Cape Town and	The TANDem Project	King Baudouin Foundation
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	Anonymous major donor

In addition we agreed to fund the Early Development in Tuberous Sclerosis (EDiTS) study being carried out by the Institute of Psychiatry, Psychology and Neuroscience with a commitment of £16,740 and renewed three projects - two with Cardiff University and one with the Whitehead Institute - with commitments of £116,074.

Full details of the commitments reached during 2019 are shown in note nine and 19 to the financial statements.

This takes our full portfolio in 2019 to 12 live grants, three of which are jointly funded. Our portfolio of ongoing projects is worth £1,227,576.

We continue our membership of Association of Medical Research Charities and the UK Child Health Collaboration.



Report of the Trustees  
for the Year Ended 31 December 2019

**OBJECTIVES AND ACTIVITIES**

**Activities and performance in relation to '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 2019, the total return on the portfolio was 16.16% as against the benchmark of 15.65%. Over the longer term, our investment managers have consistently out-performed the benchmark. Their performance continues to be kept under review and those Trustees who are members of FINCOM have an annual review meeting with them. The Trustees have agreed a formal investment policy reflecting the investment objective stated above.

**Activities and performance in relation to 'Volunteering'**

The Association benefits from the contribution given by volunteers and would like to take this opportunity of thanking all volunteers who have helped it work towards meeting its objectives.

**FINANCIAL REVIEW**

**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 and Information Services 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.

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**FINANCIAL REVIEW**

**Statement on reserves & review of financial position**

At the end of the year the Association has total funds of £1,218,696. This included Restricted funds of £4,700, not available for the general purposes of the Association and designated funds of £1,023,996, further details of which are given below. It is anticipated that the designated funds will be fully spent by 31 December 2022.

The reserves of the Association amounted to £190,000 at 31 December 2019, representing three months of expenditure excluding any research commitments entered into. A transfer of £686,057 has been made from the Designated Endowment Fund to cover the deficit for the year and to provide these reserves.

**Designated Fund**

The funds of the Association includes 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; and
- \* to 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 31 December 2022. The trustees of the opinion that this minimum designated fund balance should be retained 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 £303k (2018 £324k).

Our total investment gains/ (losses) were £208k (2018 - £219k). 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/ losses, the overall deficit for the year was £489k (2018 - £871k).

Report of the Trustees  
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### **Risk Management**

The Trustees have established procedures to 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 relative significance of those risks, and reviewed the adequacy of the systems that have been established to mitigate those risks.

Further details are given in the section headed 'Structure, Governance and Management' of the Report of the Trustees.

### **FUTURE PLANS**

#### **2020 Business Plan**

The 2020 Business Plan was approved in November 2019. In the second year of implementing the new five-year strategy 2019-2020, we planned to reach more people and drive more research by prioritising delivery of the following strategic objectives:

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 to build high-quality new 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 that people living with TSC and their families can get together informally to talk and network.
- \* Hold a TSC Community Education Afternoon so that people living with TSC and their families see the latest research from international experts on TSC.

Capacity build 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 Epidiolex (cannabidiol) for TSC-related epilepsy.
- \* Support 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**

The Trustees carried out an urgent review of the 2020 Business Plan in April 2020 as a result of unprecedented changes in the external environment due to the coronavirus pandemic. We paused delivery of our planned strategic objectives, and agreed a revised 2020 Business Plan with a focus on the following priorities:

Report of the Trustees  
for the Year Ended 31 December 2019

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.
- \* Proactively sharing high quality, timely online content developed by larger charities when it will be 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 and innovative ways for the TSC community to keep in touch with one-another through digital channels, including bringing people together virtually (for example for virtual Tea and SCones or virtual Outlook) to reassure them that they are not alone while socially-isolating or self-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 socially-isolating or self-shielding.

Ensuring the survival of the charity by:

- \* Furloughing six members of staff to maximise income and safeguard future employment, and asking senior staff to work reduced hours to generate further savings
- \* Reviewing the 2020 non-pay budget to make savings against the strategic objectives that have been paused
- \* Sending out a 'direct mail' fundraising ask for regular direct debit support or one-off donations during a period when people can clearly see the value that we are adding.
- \* Sharing consistent fundraising asks to the TSC community via digital channels about indoor activities that can still take place during the pandemic.
- \* Rebuilding our trusts and foundations fundraising, since the funding given is less likely to be affected even if the mechanisms for decision-making may cause some delays during this period.

We have moved the 2020 International Research Conference from November 2020 to July 2021 to minimise the likely impact of the pandemic on delegate numbers, delegate income and sponsorship.

In June 2020, in light of significantly reduced income as a result of Covid-19, the Trustees made the difficult decision to make staffing cuts of 30% and to continue to ask remaining staff to work reduced hours to enable us to run sustainably at a projected much-reduced income level until 2022. The Designated Endowment Fund will be used to fund the already sunk costs of hosting the International Research Conference which has been postponed to 2021 and to cover the cost of our ongoing research grants programme in 2020/2021. The Trustees goal is to retain our reserves at a sensible level so that we give ourselves the best possible start in 2022 to grow the charity and deliver the ambitions set out in the five-year strategy 2019-2023. Further details are given in the Financial Review on page 7.

The TSA's Trustees and staff remain ambitious about what we want to achieve for the TSC community. We're determined to ensure that Coronavirus won't stop us being here for individuals living with TSC and their families, and 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.

Report of the Trustees  
for the Year Ended 31 December 2019

## **STRUCTURE, GOVERNANCE AND MANAGEMENT**

### **Organisational structure**

A list of the Officers and other Trustees who served for all or part of the year, or who have been appointed before the date of this report, appears on page ten.

At each Annual General Meeting, a maximum of one-third of the Trustees retire by choice or rotation. In 2020, this is Tom Carter, who offers himself for re-election; after an appraisal process the Board recommends his re-election. Rajan Khullar who has been appointed to the Board since the 2019 Annual General Meeting, offers himself for re-election and is likewise so recommended.

The Trustees meet as a Board three or four times a year.

Subsequent to the year end it was decided that the responsibilities of FINCOM should be passed to the Board as a whole. FINCOM was accountable to the Board and conducted its business as needed and by such means as it considered appropriate (face to face meetings, teleconference and e-mail). It oversaw the financial affairs of the Association and comprised the Chair, the Treasurer, the Vice Chair and Tom Carter. A quorum for any meeting was three members. The Chief Executive was not a member of FINCOM, but had a standing invitation to attend meetings, other than at times when there would be a clear conflict of interest. The responsibilities of FINCOM included:

- \* monitoring and overseeing the financial performance of the Association and making appropriate reports to the Board;
- \* submitting to the Board in advance of each financial year a Budget for that year;
- \* approving unbudgeted expenditure for items or projects of more than £5k;
- \* ensuring that proper books of accounts are kept;
- \* reviewing and overseeing the preparation of the statutory Annual Report and Accounts, ensuring compliance with accounting standards and legal requirements;
- \* having responsibility for the oversight and evaluation of the external audit function;
- \* ensuring the consistency of other financial information, including summary financial statements;
- \* monitoring and reviewing the performance of the investment portfolio and reviewing and reappointing investment managers as appropriate;

FINCOM also had power to take urgent decisions between Board Meetings.

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 twice a year. The responsibilities of RESCOM include:

- \* overseeing, guiding and monitoring the delivery of the Association's research strategy;
- \* reviewing commitments to research and advising on strategic prioritisation of funding for grant rounds;
- \* fostering relationships between funded researchers and the Association;
- \* evaluating peer reviewed applications and making recommendations to FINCOM and the Board of the Association for the award of research grants;
- \* promoting and supporting TSC research with external audiences; and
- \* supporting the planning and delivery of national and international research conferences.

Report of the Trustees  
for the Year Ended 31 December 2019

**REFERENCE AND ADMINISTRATIVE DETAILS**

**Registered Company number**

02900107 (England and Wales)

**Registered Charity numbers**

1039549, SC042780

**Registered office**

Unit 56  
1 Emma Street  
London  
E2 9FP

**Trustees**

Sanjay Sethi - Chair  
Martin Peter Short - Deputy Chair  
David Robin Vaughan - Treasurer  
Thomas Edmund Carter  
John Christopher Kingswood  
Lisa Suchet  
Patrick Ferrar Bolton  
Philip Goldenberg (resigned 8/6/19)  
Robert Woodthorpe Browne  
Frances Elmslie (appointed 8/6/19)  
Jane Rogers (appointed 8/6/19)  
Annemarie Cotton (appointed 8/6/19)

**Honorary Life Vice Presidents**

Esther Galbraith  
Thomas Edmund Carter  
Anne Carter  
The Lady Kilmaine  
John Christopher Kingswood

**Chief Executive and company secretary**

Louise Fish

**Auditors**

Wellden Turnbull Limited  
Albany House  
Claremont Lane  
Esher  
Surrey  
KT10 9FQ

Report of the Trustees  
for the Year Ended 31 December 2019

**REFERENCE AND ADMINISTRATIVE DETAILS**

**Office Address**

Unit 56, 1 Emma Street, London, E2 9FP

**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 4PU

**Website**

www.tuberous-sclerosis.org

**EVENTS SINCE THE END OF THE YEAR**

Information relating to events since the end of the year is given in the notes to the financial statements.

**STATEMENT AS TO DISCLOSURE OF INFORMATION TO AUDITORS**

So far as the trustees are aware, there is no relevant information (as defined by Section 418 of the Companies Act 2006) of which the charitable company's auditors are unaware, and each trustee has taken all the steps that they ought to have taken as a trustee in order to make them aware of any audit information and to establish that the charitable company's auditors are aware of that information.

The report of the trustees has been prepared in accordance with the special provisions of part 15 of the Companies Act 2006 relating to small companies, in accordance with the Charities SORP (FRS102) and in accordance with the Financial Reporting Standard 102 (effective 1 January 2016).

This report was approved by the Board of Trustees and signed on its behalf on 21 October 2020  
by:



.....  
David Robin Vaughan - Trustee

The Tuberous Sclerosis Association

Statement of Trustees' Responsibilities  
for the Year Ended 31 December 2019

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

Company law 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 charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

- \* select suitable accounting policies and then apply them consistently;
- \* observe the methods and principles in the Charity SORP;
- \* make judgements and estimates that are reasonable and prudent;
- \* state whether applicable accounting standards 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 charitable company will continue in business.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006, the Trustee Investment (Scotland) Act 2005 and Charities Accounts (Scotland) Regulations 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.



Report of the Independent Auditors to the Members of  
The Tuberous Sclerosis Association

We have audited the financial statements of the Tuberous Sclerosis Association (the 'charitable company') for the year ended 31 December 2019 which comprise Statement of Financial Activities (incorporating the Income and Expenditure Account), the Balance Sheet and related notes. 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 charitable company's affairs as at 31 December 2019 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 applicable to Smaller Entities; and
- \* have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

**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 Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC'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**

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- \* the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- \* the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

**Emphasis of matter**

We draw your attention to Note 1 and Note 23, which describe the effects of the Covid-19 Pandemic and to the 'Revisions to the 2020 Business Plan as a result of Covid-19' made by the Trustees. Our opinion is not modified in respect of this matter.

Report of the Independent Auditors to the Members of  
The Tuberous Sclerosis Association

**Other information**

The trustees are responsible for the other information. The other information comprises the information included in the Report of the Trustees, other than the financial statements and our auditor's report thereon. 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.

In connection with our audit of the financial statements, 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 audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. 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.

**Opinions 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 Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- \* the Report of the Trustees 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 charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Trustees. We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- \* adequate and proper 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' exemption in preparing the Report of the Trustees and from the requirement to prepare a strategic report.

**Responsibilities of trustees**

As explained more fully in the trustees' responsibilities statement set out on page 14, 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 being satisfied that they give a true and fair view, 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.

Report of the Independent Auditors to the Members of  
The Tuberous Sclerosis Association

In preparing the financial statements, the trustees are responsible for assessing the charitable company'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 charitable company or to cease operations, or have no realistic alternative but to do so.

**Auditor's responsibilities for the audit of the financial statements**

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

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 auditor's 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.

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](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

**Use of our report**

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, and to the charitable company's trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members and trustees those matters we are required to state to them in an auditor's 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 charitable company, the charitable company's members as a body and the charitable company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.



Mark Nelligan FCA (Senior Statutory Auditor)  
for and on behalf of Wellden Turnbull Limited  
Albany House  
Claremont Lane  
Esher  
KT10 9FQ

Date: 21 October 2020

The Tuberos Sclerosis Association

Statement of Financial Activities  
(Incorporating an Income and Expenditure Account)  
for the Year Ended 31 December 2019

	Notes	Unrestricted funds £	Restricted funds £	2019 Total funds £	2018 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies	2	229,674	4,700	234,374	208,515
<b>Charitable activities</b>					
Family care & support	5	1,510	-	1,510	2,690
Education		-	-	-	19,849
<b>Other income</b>					
Other trading activities	3	1,756	-	1,756	8,235
Investment income	4	<u>65,176</u>	-	<u>65,176</u>	<u>84,532</u>
<b>Total</b>		298,116	4,700	302,816	323,821
<b>EXPENDITURE ON</b>					
Raising funds	6	157,232	-	157,232	153,301
<b>Charitable activities</b>					
Family care & support	7	260,465	-	260,465	287,111
Research		385,572	-	385,572	386,875
Promoting awareness		133,138	-	133,138	92,916
Education		58,633	5,421	64,054	54,443
<b>Total</b>		<u>995,040</u>	5,421	1,000,461	974,646
Net gains/(losses) on investments	17	<u>208,190</u>	-	<u>208,190</u>	<u>(219,967)</u>
<b>NET INCOME/(EXPENDITURE)</b>		(488,734)	(721)	(489,455)	(870,792)
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>	21	<u>1,702,730</u>	5,421	1,708,151	2,578,943
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u><u>1,213,996</u></u>	<u><u>4,700</u></u>	<u><u>1,218,696</u></u>	<u><u>1,708,151</u></u>

The notes form part of these financial statements

The Tuberos Sclerosis Association (Registered number: 02900107)

Balance Sheet  
31 December 2019

	Notes	2019 £	2018 £
<b>FIXED ASSETS</b>			
Tangible assets	16	851	-
Investments	17	<u>1,268,946</u>	<u>1,914,135</u>
		1,269,797	1,914,135
<b>CURRENT ASSETS</b>			
Debtors	18	98,608	21,292
Cash at bank and in hand		<u>264,938</u>	<u>196,226</u>
		363,546	217,518
<b>CREDITORS</b>			
Amounts falling due within one year	19	(414,647)	(423,502)
		<u>(51,101)</u>	<u>(205,984)</u>
<b>NET CURRENT ASSETS</b>			
		<u>(51,101)</u>	<u>(205,984)</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>			
		<u>1,218,696</u>	<u>1,708,151</u>
<b>NET ASSETS</b>			
		<u><u>1,218,696</u></u>	<u><u>1,708,151</u></u>
<b>FUNDS</b>			
Unrestricted funds:			
General fund	21	190,000	-
Designated Endowment Fund		1,023,996	1,473,818
Kilmaine Family Research Fellowship		<u>-</u>	<u>228,912</u>
		1,213,996	1,702,730
Restricted funds:			
Research		4,700	-
Education		<u>-</u>	<u>5,421</u>
		4,700	5,421
<b>TOTAL FUNDS</b>			
		<u><u>1,218,696</u></u>	<u><u>1,708,151</u></u>

The notes form part of these financial statements

Balance Sheet - continued

31 December 2019

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 ....**21 October 2020**..... and were signed on its behalf by:



.....  
Sanjay Sethi - Trustee

## 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. The financial statements are presented in sterling, which is the functional currency of the company rounded to the nearest £.

### **Compliance with accounting standards**

The accounts have been prepared in accordance with the provisions of the Charities SORP (FRS 102) and FRS102. There were no material departures from the standards.

### **Public benefit entity**

The charitable company meets the definition of a public benefit entity under FRS 102.

### **Going Concern**

In assessing the appropriateness of the going concern basis of preparation, the Trustees have taken into account the key risks to the Charitable Company, including the uncertainty surrounding COVID-19 and its potential impact on the Charitable Company's financial position. In doing so, the Trustees have considered the Charitable Company's financial plans and its availability of cash resources, the potential impact on its investment portfolio as a result of market volatility and carried out a risk analysis of the factors affecting the charity's ability to continue to fundraise income and to make grants to fund research. In June 2020 in light of significantly reduced income as a result of Covid-19, the Trustees enacted 'Revisions to 2020 Business Plan as a result of Covid-19' resulting in the difficult decision to make staffing cuts of 30% and to continue to ask remaining staff to work reduced hours to enable us to run sustainably at a projected much-reduced income level until 2022.

Having undertaken this assessment, the Trustees believe the current market conditions will not have any material impact and that there are no material uncertainties about the charitable company's ability to continue as a going concern. The Charitable Company can draw upon its investment portfolio if required, and has sufficient resources to meet its liabilities as they fall due for a period of at least 12 months from the date of approval of the financial statements. Accordingly the Trustees consider it appropriate to therefore prepare the Financial Statements on a going concern basis.

### **Income**

All income is recognised in the Statement of Financial Activities once the Association 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 that must be met before the Association has entitlement to the resources.

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**1. ACCOUNTING POLICIES - continued**

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

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

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

**Expenditure**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

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

**Investments**

Investments are stated at market value and are normally included in Fixed Asset Investments. As a result, the Statement of Financial Activities includes unrealised gains and losses arising from the revaluation of the investment portfolio throughout the year.

Investments sold after the year end, as a result of instructions to the Investment Managers prior to the year end, are included in Current Asset Investments, where the intention is for those funds to be expended in furtherance of the Association's objectives.

**Intangible assets**

Intangible assets comprise costs incurred in establishing a database. The cost is being written off on a straight line basis over a period of five years.

**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**

Restricted funds comprise unexpended balances of donations and/or grants held on trust to be applied for specific purposes.

Designated funds comprise the funds that have been set aside at the discretion of the Trustees for specific purposes. The purpose and use of the designated unrestricted funds is set out in the notes to the accounts.



The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**1. ACCOUNTING POLICIES - continued**

**Fund accounting (continued)**

General funds are available for use at the discretion of the Trustees in furtherance of the general activities of the Association. The Association's policy is to hold three months of expenditure in the general fund.

**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 in hand**

Cash at bank and cash 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 and trade discounts due

**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.

**Pension costs and other post-retirement benefits**

Contributions paid or payable to personal pension funds of members of staff are accounted for when due.

**2. DONATIONS, LEGACIES AND GRANTS**

	2019	2018
	£	£
Donations and subscriptions	230,180	194,015
Legacies	-	14,500
Grants	<u>4,194</u>	<u>-</u>
	<u>234,374</u>	<u>208,515</u>

During the year the Association received an Access to Work Grant of £4,194.

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

<b>3. OTHER TRADING ACTIVITIES</b>		2019	2018
		£	£
Christmas card & other miscellaneous sales		<u>1,756</u>	<u>8,235</u>
<b>4. INVESTMENT INCOME</b>		2019	2018
		£	£
Bank interest		201	164
Income from managed portfolio		<u>64,975</u>	<u>84,368</u>
		<u>65,176</u>	<u>84,532</u>
<b>5. INCOME FROM CHARITABLE ACTIVITIES</b>		2019	2018
		£	£
Family days and weekends	Activity Family care & support	1,510	2,690
Grants received - Novartis Pharmaceuticals UK Limited	Education	-	<u>19,850</u>
		<u>1,510</u>	<u>22,540</u>
<b>6. RAISING FUNDS</b>			
<b>Raising donations and legacies</b>		2019	2018
		£	£
Staff costs		86,956	86,599
Event fees		11,823	4,666
Sundries		1,956	796
Travel, communications and other costs		7,458	12,634
Staff training		3,325	7,177
Support costs		<u>31,604</u>	<u>22,486</u>
		<u>143,122</u>	<u>134,358</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**6. RAISING FUNDS - continued**

**Other trading activities**

	2019	2018
	£	£
Purchases	<u>2,315</u>	<u>2,070</u>

**Investment management costs**

	2019	2018
	£	£
Portfolio management	<u>11,795</u>	<u>16,873</u>

Total Aggregate amounts	<u>157,232</u>	<u>153,301</u>
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**7. CHARITABLE ACTIVITIES COSTS**

	Direct Costs (see note 8)	Grant funding of activities (see note 9)	Support costs (see note 10)	Totals
	£	£	£	£
Family care & support	202,535	-	57,930	260,465
Research	62,024	265,618	57,930	385,572
Promoting awareness	75,208	-	57,930	133,138
Education	<u>19,177</u>	<u>(13,053)</u>	<u>57,930</u>	<u>64,054</u>
	<u>358,944</u>	<u>252,565</u>	<u>231,720</u>	<u>843,229</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**8. DIRECT COSTS OF CHARITABLE ACTIVITIES**

	2019	2018
	£	£
Staff costs	308,551	329,078
Travel, communications and other costs	22,577	29,261
Publications	18,704	10,543
Benevolent grants	5,700	5,386
Family days and weekends	1,175	1,218
Sundries	<u>2,237</u>	<u>3,251</u>
	<u>358,944</u>	<u>378,737</u>

**9. GRANTS PAYABLE**

	2019	2018
	£	£
Research	265,618	277,713
Education	<u>(13,053)</u>	<u>-</u>
	<u>252,565</u>	<u>277,713</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**9. GRANTS PAYABLE - continued**

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

	2019	2018
	£	£
* Brighton TS Registry	(100)	-
* Institute of Cancer & Genetics, Cardiff - Prevention of renal lesions by fine tuning mTOR signalling in a mouse model of tuberous sclerosis	-	540
* Addenbrooke's Hospital - TSC Psychology	(13,053)	-
* Department of Neuroscience, Erasmus Medical Centre, Netherlands - Towards a better understanding and better treatment of TSC-related epilepsy	-	22
* University of Manchester - Exploiting Notch regulation to probe alternative mechanisms of TSC signalling.	-	64,762
* Dept of Clinical Genetics, Erasmus MC - Functional and structural characterisation of the TSC complex; improved functional assessment of TSC1 and TSC2 variants associated with TSC	-	51,310
* University College London - The TSC1 and TSC2 Variation Databases	-	45,353
* 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	32,537	32,363
* Cardiff University - Characterising the Role of Exosomes in Tuberous Sclerosis Complex.	32,537	32,363
* Cardiff University - An innovative model system of cell invasion in TSC/LAM to uncover new drug targets and therapies	29,207	-
* 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 Tuberous Sclerosis Complex	<u>62,000</u>	<u>-</u>
	<u>252,565</u>	<u>277,713</u>

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

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

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**10. SUPPORT COSTS**

	Management £	Finance £	Other £	Governance costs £	Totals £
Raising donations and legacies	7,373	841	16,721	6,669	31,604
Family care & support	13,518	1,535	30,654	12,223	57,930
Research	13,518	1,534	30,654	12,224	57,930
Promoting awareness	13,518	1,534	30,654	12,224	57,930
Education	<u>13,518</u>	<u>1,534</u>	<u>30,654</u>	<u>12,224</u>	<u>57,930</u>
	<u>61,445</u>	<u>6,978</u>	<u>139,337</u>	<u>55,564</u>	<u>263,324</u>

Activity	Basis of allocation
Management	See below
Finance	See below
Other	See below
Governance costs	See below

Support costs have been allocated between 'Raising donations and legacies' and the Activities of the Association on the basis of time spent by the staff members of the Association. Governance costs are now part of the Support Costs under Charities SORP (FRS 102).

**11. NET INCOME/(EXPENDITURE)**

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

	2019 £	2018 £
Auditors' remuneration	7,224	6,924
Depreciation - owned assets	284	-
Database costs amortisation	<u>-</u>	<u>773</u>

**12. TRUSTEES' REMUNERATION AND BENEFITS**

There were no trustees' remuneration or other benefits for the year ended 31 December 2019 nor for the year ended 31 December 2018.

**Trustees' expenses**

	2019 £	2018 £
Trustees' expenses	<u>3,450</u>	<u>1,639</u>

The Trustees are entitled to be paid expenses they incur in the governance of the Association. This may include travel, accommodation and similar expenses. Five (2018 - Seven) Trustees received payments for reimbursement of expenses during the year.

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**13. STAFF COSTS**

	2019	2018
	£	£
Wages and salaries	397,223	415,440
Social security costs	35,294	36,376
Other pension costs	<u>21,705</u>	<u>22,881</u>
	<u>454,222</u>	<u>474,697</u>

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

	2019	2018
Fundraising	3	3
Promoting awareness	1	2
Family care and support	8	7
Support - general	2	2
Research	<u>2</u>	<u>2</u>
	<u>16</u>	<u>16</u>

No employees received emoluments in excess of £60,000 (31 December 2018 - none).

Pension costs relate to employer contributions to a Standard Life Workplace Pension.

**14. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES**

	Unrestricted funds £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	208,515	-	208,515
<b>Charitable activities</b>			
Family care & support	2,690	-	2,690
Education	-	19,849	19,849
Other trading activities	8,235	-	8,235
Investment income	<u>84,532</u>	<u>-</u>	<u>84,532</u>
<b>Total</b>	303,972	19,849	323,821
<b>EXPENDITURE ON</b>			
Raising funds	147,593	5,708	153,301
<b>Charitable activities</b>			
Family care & support	284,449	2,662	287,111
Research	384,789	2,086	386,875
Promoting awareness	90,830	2,086	92,916
Education	48,260	6,183	54,443

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

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

	Unrestricted funds £	Total funds £	Restricted funds £
	<u>          </u>	<u>          </u>	<u>          </u>
<b>Total expenditure</b>	955,921	18,725	974,646
Net gains/(losses) on investments	<u>(219,967)</u>	<u>-</u>	<u>(219,967)</u>
<b>NET INCOME/(EXPENDITURE)</b>	(871,916)	1,124	(870,792)
 <b>RECONCILIATION OF FUNDS</b>			
<b>Total funds brought forward</b>	2,574,646	4,297	2,578,943
	<u>          </u>	<u>          </u>	<u>          </u>
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u>1,702,730</u>	<u>5,421</u>	<u>1,708,151</u>

**15. INTANGIBLE FIXED ASSETS**

	Database costs £
<b>COST</b>	
At 1 January 2019 and 31 December 2019	<u>19,624</u>
<b>AMORTISATION</b>	
At 1 January 2019 and 31 December 2019	<u>19,624</u>
<b>NET BOOK VALUE</b>	
At 31 December 2019	<u>-</u>
At 31 December 2018	<u>-</u>



The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**16. TANGIBLE FIXED ASSETS**

	Fixtures and fittings £
<b>COST</b>	
Additions	<u>1,135</u>
<b>DEPRECIATION</b>	
Charge for year	<u>284</u>
<b>NET BOOK VALUE</b>	
At 31 December 2019	<u>851</u>
At 31 December 2018	<u>-</u>

**17. FIXED ASSET INVESTMENTS**

	2019 £	2018 £
Investments in shares and funds	1,259,896	1,839,741
Cash held by investment manager for reinvestment	<u>9,050</u>	<u>74,394</u>
	<u>1,268,946</u>	<u>1,914,135</u>

Additional information as follows:

	Quoted shares and unit trusts £
<b>MARKET VALUE</b>	
At 1 January 2019	1,839,741
Additions	314,729
Disposals	(1,102,764)
Revaluations	<u>208,190</u>
At 31 December 2019	<u>1,259,896</u>
<b>NET BOOK VALUE</b>	
At 31 December 2019	<u>1,259,896</u>
At 31 December 2018	<u>1,839,741</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**17. FIXED ASSET INVESTMENTS - continued**

Investments held in companies outside the UK amounted to £517,637 (2018 - £648,209).

Investments (neither listed nor unlisted) were as follows:

	2019	2018
	£	£
Brewin Dolphin capital account	<u>9,050</u>	<u>74,394</u>

The capital account represents uninvested cash held by the broker.

	2019	2018
	£	£
The historical cost of the investments at the year end is:	<u>721,783</u>	<u>1,027,355</u>

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

	2019	2018
	£	£
Other debtors	<u>98,608</u>	<u>21,292</u>

**19. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	2019	2018
	£	£
Trade creditors	36,410	11,203
Social security and other taxes	8,892	9,893
Grants awarded	356,943	388,184
Pension fund	1,945	-
Accrued expenses	<u>10,457</u>	<u>14,222</u>
	<u>414,647</u>	<u>423,502</u>

The provision for grants awarded is for the full amount of future expenditure up to the committed amount of each grant. The following table shows the research institution, a breakdown of the unexpended commitment brought forward, the amount paid, the commitments arising during the year (and hence recognised in the Statement of Financial Activities (SOFA)) and the unexpended commitment carried forward at the end of the year in respect of each grant. Further detail in respect of each grant is given in note 9.

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The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**19. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR - continued**

	At 1/1/19 £	SOFA £	Paid £	At 31/12/19 £
* University of Birmingham	3,499	-	-	3,499
* Brighton TS Registry	100	(100)	-	-
* 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	8,561	-	(7,190)	1,371
* Addenbrooke's Hospital, Cambridge	13,053	(13,053)	-	-
* Centre for Integrative Physiology, University of Edinburgh	335	-	-	335
* Institute of Medical Genetics, Cardiff	1,055	-	(1,055)	-
* Institute of Psychiatry, Kings College, London	14,153	-	-	14,153
* Cardiff University	2,452	-	(1,834)	618
* Research Department of Genetics, University College, London	513	-	-	513
* University of Manchester, Faculty of Life Sciences	87,312	-	(62,633)	24,679
* University of Nottingham, Division of Respiratory Medicine	13,671	-	(13,671)	-
* Erasmus MC, Department of Clinical Genetics	51,450	-	(51,270)	180
* University College London - The TSC1 and TSC2 Variation Databases	73,492	-	(43,547)	29,945
* Whitehead Institute. Towards specific Mtor Inhibitors capable of rescuing Tuberous Sclerosis Complex loss-of- function	29,205	51,000	(44,884)	35,321
* Cardiff University. Targeting the Ref1/STAT3 axis to treat Tuberous Sclerosis Complex	32,363	32,537	(28,241)	36,659
* Cardiff University. Characterising the roles of exosomes in Tuberous Sclerosis Complex	32,363	32,537	(28,627)	36,273
* University of Bristol NHS Foundation Trust - Randomised Controlled Trial of Acceptance and Commitment Therapy in Tuberous Sclerosis Complex	-	62,000	-	62,000
* Institute of Psychiatry Psychology and Neuroscience - Neurocognitive predictors of neurodevelopmental impairment in infants and toddlers with TSC	-	16,740	-	16,740
* University of Cape Town - Empowering Families through Technology: a mobile- health project to reduce the TAND identification and treatment gap	-	41,697	-	41,697

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**19. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR - continued**

\* Cardiff University - An innovative model system of cell invasion in TSC/LAM to uncover new drug targets and therapies

	-	29,207	(854)	28,353
	<u>388,184</u>	<u>252,565</u>	<u>(283,806)</u>	<u>356,942</u>

Analysis:

Falling due within one year				<u>356,942</u>
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**20. ANALYSIS OF NET ASSETS BETWEEN FUNDS**

	Unrestricted funds £	Restricted funds £	2019 Total funds £	2018 Total funds £
Fixed assets	851	-	851	-
Investments	1,268,946	-	1,268,946	1,914,135
Current assets	358,846	4,700	363,546	217,518
Current liabilities	<u>(414,647)</u>	<u>-</u>	<u>(414,647)</u>	<u>(423,502)</u>
	<u>1,213,996</u>	<u>4,700</u>	<u>1,218,696</u>	<u>1,708,151</u>

**21. MOVEMENT IN FUNDS**

	At 1/1/19 £	Net movement in funds £	Transfers between funds £	At 31/12/19 £
<b>Unrestricted funds</b>				
General fund	-	(496,057)	686,057	190,000
Designated Endowment Fund	1,473,818	236,235	(686,057)	1,023,996
Kilmaine Family Research Fellowship	<u>228,912</u>	<u>(228,912)</u>	<u>-</u>	<u>-</u>
	1,702,730	(488,734)	-	1,213,996
<b>Restricted funds</b>				
Research	-	4,700	-	4,700
Education	<u>5,421</u>	<u>(5,421)</u>	<u>-</u>	<u>-</u>
	<u>5,421</u>	<u>(721)</u>	<u>-</u>	<u>4,700</u>
<b>TOTAL FUNDS</b>	<u>1,708,151</u>	<u>(489,455)</u>	<u>-</u>	<u>1,218,696</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**21. MOVEMENT IN FUNDS - continued**

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

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
<b>Unrestricted funds</b>				
General fund	233,141	(729,198)	-	(496,057)
Designated Endowment Fund	64,975	(36,930)	208,190	236,235
Kilmaine Family Research Fellowship	-	(228,912)	-	(228,912)
	<u>298,116</u>	<u>(995,040)</u>	<u>208,190</u>	<u>(488,734)</u>
<b>Restricted funds</b>				
Research	4,700	-	-	4,700
Education	-	(5,421)	-	(5,421)
	<u>4,700</u>	<u>(5,421)</u>	<u>-</u>	<u>(721)</u>
<b>TOTAL FUNDS</b>	<u><u>302,816</u></u>	<u><u>(1,000,461)</u></u>	<u><u>208,190</u></u>	<u><u>(489,455)</u></u>

**Comparatives for movement in funds**

	At 1/1/18 £	Net movement in funds £	Transfers between funds £	At 31/12/18 £
<b>Unrestricted funds</b>				
General fund	-	(441,729)	441,729	-
Designated Endowment Fund	2,068,021	(152,474)	(441,729)	1,473,818
Kilmaine Family Research Fellowship	506,625	(277,713)	-	228,912
	<u>2,574,646</u>	<u>(871,916)</u>	<u>-</u>	<u>1,702,730</u>
<b>Restricted funds</b>				
Janet Medcalf Memorial	556	(556)	-	-
Education	3,741	1,680	-	5,421
	<u>4,297</u>	<u>1,124</u>	<u>-</u>	<u>5,421</u>
<b>TOTAL FUNDS</b>	<u><u>2,578,943</u></u>	<u><u>(870,792)</u></u>	<u><u>-</u></u>	<u><u>1,708,151</u></u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**21. MOVEMENT IN FUNDS - continued**

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

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
<b>Unrestricted funds</b>				
General fund	219,606	(661,335)	-	(441,729)
Designated Endowment Fund	84,366	(16,873)	(219,967)	(152,474)
Kilmaine Family Research Fellowship	<u>-</u>	<u>(277,713)</u>	<u>-</u>	<u>(277,713)</u>
	303,972	(955,921)	(219,967)	(871,916)
<b>Restricted funds</b>				
Janet Medcalf Memorial	-	(556)	-	(556)
Education	<u>19,849</u>	<u>(18,169)</u>	<u>-</u>	<u>1,680</u>
	<u>19,849</u>	<u>(18,725)</u>	<u>-</u>	<u>1,124</u>
<b>TOTAL FUNDS</b>	<u><u>323,821</u></u>	<u><u>(974,646)</u></u>	<u><u>(219,967)</u></u>	<u><u>(870,792)</u></u>

A current year 12 months and prior year 12 months combined position is as follows:

	At 1/1/18 £	Net movement in funds £	Transfers between funds £	At 31/12/19 £
<b>Unrestricted funds</b>				
General fund	-	(937,786)	1,127,786	190,000
Designated Endowment Fund	2,068,021	83,761	(1,127,786)	1,023,996
Kilmaine Family Research Fellowship	<u>506,625</u>	<u>(506,625)</u>	<u>-</u>	<u>-</u>
	2,574,646	(1,360,650)	-	1,213,996
<b>Restricted funds</b>				
Janet Medcalf Memorial	556	(556)	-	-
Research	-	4,700	-	4,700
Education	<u>3,741</u>	<u>(3,741)</u>	<u>-</u>	<u>-</u>
	<u>4,297</u>	<u>403</u>	<u>-</u>	<u>4,700</u>
<b>TOTAL FUNDS</b>	<u><u>2,578,943</u></u>	<u><u>(1,360,247)</u></u>	<u><u>-</u></u>	<u><u>1,218,696</u></u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2019

**21. MOVEMENT IN FUNDS - continued**

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
<b>Unrestricted funds</b>				
General fund	452,747	(1,390,533)	-	(937,786)
Designated Endowment Fund	149,341	(53,803)	(11,777)	83,761
Kilmaine Family Research Fellowship	<u>-</u>	<u>(506,625)</u>	<u>-</u>	<u>(506,625)</u>
	602,088	(1,950,961)	(11,777)	(1,360,650)
<b>Restricted funds</b>				
Janet Medcalf Memorial	-	(556)	-	(556)
Research	4,700	-	-	4,700
Education	<u>19,849</u>	<u>(23,590)</u>	<u>-</u>	<u>(3,741)</u>
	<u>24,549</u>	<u>(24,146)</u>	<u>-</u>	<u>403</u>
<b>TOTAL FUNDS</b>	<u><u>626,637</u></u>	<u><u>(1,975,107)</u></u>	<u><u>(11,777)</u></u>	<u><u>(1,360,247)</u></u>

The Association's Reserves Policy is shown on page 8.

**Unrestricted funds**

**Designated Endowment Fund**

The Designated Endowment Fund consists of the unspent balance of the bequest received from the late Mr H I Leech in 1993. Further details are given in the Trustees Report.

**Kilmaine Family Research Fellowship**

In 2015 the Association received a significant donation from The Lady Kilmaine. The Trustees decided that this fellowship should fund the research into "designing a protocol to measure the development trajectory of infants with Tuberous Sclerosis".

At the start of 2018, the above project having been fully funded, the Trustees decided that the remaining funds should be used to fund all future research of the Association until the fund was spent in full. The remainder of the fund was fully spent during the year.

**Restricted Funds**

The restricted funds relate to donations and grants, which were given to the Association for specific purposes. The restricted funds held at 31 December 2019 relate to the unspent portion of specific donations.

The remaining balance on a donation from Novartis towards "Education" was fully spent during the year.

**21. MOVEMENT IN FUNDS - continued**

**Transfers between funds**

During the year, the Designated Endowment Fund has also been used to meet the deficit arising on the general fund, in accordance with the Association's policy. A transfer of £686,057 has been made from the Designated Endowment Fund in this regard.

**22. RELATED PARTY DISCLOSURES**

As permitted by the Memorandum and Articles of Association, payments can be made to Trustees and other related parties for services provided to the charity.

Ashmole & Co, a firm of Chartered Certified Accountants of whom the Treasurer Mr D R Vaughan is a Partner, received VAT inclusive payments of £11,664 (2018 - £13,220) for services relating to the bookkeeping and accountancy work of the charity. This work is carried out in a separate office from the one in which Mr Vaughan operates and under the supervision of another Partner in the firm.

There were no other related party transactions.

**23. POST BALANCE SHEET EVENTS**

Subsequent to the year end, global economies have been affected by the negative financial impact of the spread of the COVID-19 virus pandemic. This is considered a non-adjusting event at the year end date and details of the Trustees' going concern assessments are included in note 1.