

**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 2018

The Tuberous Sclerosis Association

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for the Year Ended 31 December 2018

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Report of the Trustees  
for the Year Ended 31 December 2018

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 2018. 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 September 2018 the Trustees approved a new five-year strategy for 2019-2023. 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 REsArCH - 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 carer.
- \* Lead research into tools, technologies and treatments which eliminate the effects of TSC.
- \* Lead innovation in the integration of medical and social care services

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

1. Provide good quality, easily accessible and timely information about TSC and about living with the condition
2. Provide the opportunity for people with TSC and their families to connect, support and learn together
3. Capacity build the knowledge and expertise of professionals working with people with TSC
4. Drive the research agenda with the aim of improving outcomes and quality of life for people with TSC
5. Expand our understanding of the condition to accelerate diagnosis, intervention and development of new treatments
6. Disseminate and use evidence to influence NHS policy and practice
7. Campaign for better access to treatments and care from the NHS
8. Support the development of centres of excellence for supporting people with TSC and their families
9. Pilot, then roll out, innovative approaches to whole person, family and carer support.

Our strategic enablers (the things that will make it possible) to deliver the strategy are:

Report of the Trustees  
for the Year Ended 31 December 2018

**OBJECTIVES AND ACTIVITIES**

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

- \* 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.

During 2018 we carried out a Board skills audit to ensure that to make sure we have the right trustees with the right skills to drive forward the TSA's new five-year strategy. Following the skills audit we proactively sought to recruit to the Board younger people, women and people from diverse ethnic backgrounds; and people who have digital expertise, knowledge of the research investment landscape, and a strong understanding of social care, residential care and education issues.

We were notified by our landlords in 2018 that the TSA's shared offices were scheduled for demolition the following year, and we initiated a project to identify a new office space for the charity to move to in 2019.

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

**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.

As well as providing on-going support for families previously registered with us in relation to healthcare, social care, education and welfare, we provided direct support to 299 families for the first time. Throughout 2018, 327 members attended some of the 7 regional groups meetings and events taking place across the country. We awarded £4,440 to families in grants as part of TSA Support Fund. We also awarded £556 as the final awards from the Janet Medcalf Award Trust.

In 2018, 40 delegates attended our Outlook event for members who are mildly affected by TSC, which took place in Manchester. The event allows them to share their experiences, build friendships and have fun in a supportive environment.

As part of our pledge to keep our community informed of the latest developments, we produced and published three editions of our SCAN magazine. We produced monthly e-newsletters and devolved nations newsletters to give relevant information across England, Scotland, Northern Ireland and Wales. We made all printed materials available on our website and provided nine Facebook Live streams with TSC experts to make information accessible to all members of the TSC community. TSA videos were viewed 5,937 times by members of the community catching up online.

Report of the Trustees  
for the Year Ended 31 December 2018

**OBJECTIVES AND ACTIVITIES**

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

We campaigned to ensure both NHS England and the Scottish Medicines Consortium made positive decisions to fund a newly licensed medicine, everolimus, for TSC-related epilepsy.

In June 2018, the Scottish Medicines Consortium announced that everolimus for TSC-related epilepsy would be available to patients living in Scotland. The TSA had an opportunity to speak directly to the decision-making panel along with our patient representative. His first-hand experience was key to helping the SMC make an informed decision about the benefits of taking everolimus for TSC-related refractory epilepsy.

In July 2018, NHS England announced that it would not fund everolimus for TSC-related epilepsy. This announcement was followed by intense campaigning from people living with TSC, their families and the TSA to reverse this decision due to the clear clinical evidence shown to commission the medicine. Over 6,700 people signed our petition, 30 people wrote to their MP, 15 MPs supported our campaign, there were 22 pieces of local media coverage, 7 pieces of specialist media coverage and 5 pieces of national media coverage of the campaign. The TSA and our patient representative also met with decision-makers at NHS England to discuss our concerns and ask them to consider the evidence from patients and their families about the benefits of this medicine.

In December 2018, the TSA was delighted to announce that NHS England backed recommendations from the Clinical Priorities Advisory Group to fund everolimus for the treatment of refractory epilepsy in people with TSC in England from April 2019.

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

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 2018 we worked closely with colleagues from the Specialised Healthcare Commissioning Alliance (SHCA) and Genetic Alliance to raise awareness of the need for NHS England to listen to the views of patients and families when making decisions about treatments and services for people living with rare diseases.

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 2018 there were 14 articles about TSC in the national and local media, and TSC was featured four times on radio news programmes and twice on television news programmes.

We continue to work to develop our relationship with TSC clinics, developing a core offering that includes:

- \* Working in partnership with the clinics, supporting patients and their families.
- \* Providing support and information to the clinic 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.

In May 2018, we ran our awareness and fundraising campaign 'Tea and Scones for TSC' which raised over £3,000 and coincided with TSC Global Awareness Day.

Report of the Trustees  
for the Year Ended 31 December 2018

**OBJECTIVES AND ACTIVITIES**

**Activities and performance in relation to 'Information & awareness' (continued)**

In November 2018, 179 people attended our TSA Big Day at Sheffield Hallam University. This family conference brought together the TSC community with leading researchers, clinicians, and experts in social care and education and many speakers were streamed live to people not able to attend via Facebook Live. We launched our new five-year strategy 2019-2023 to members of the TSC community attending the Big Day, streamed the presentation live on Facebook and published details of the strategy in Scan magazine and on the TSA's website for those unable to attend. Thirteen experts shared their work at the Big Day, five specialist workshops were delivered, and 15 children with TSC and their siblings enjoyed the creche.

We brought people in the devolved nations together at a Scottish Get Together attended by 37 individuals in Glasgow, and a Tuberous Sclerosis Study Day attended by 58 education, health and social care professionals in Cardiff.

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

The Association is the only UK charity dedicated to supporting TSC research, with an in-year commitment in 2018 of £277,713.

In 2018, outcomes from our funded research projects have appeared in nine academic journals, three poster presentations and eleven oral presentations at academic conferences or professional meetings. Three awards were completed in 2017.

The 2018 Research Award Round received nine applications and the Board chose to fund 3 new research awards from January 2018 onwards to increase the understanding of TSC. These new projects are:

<b>Investigator</b>	<b>Institution</b>	<b>Title</b>	<b>Project type</b>
Kacper Rogala	Cambridge Institute, USA	Towards specific mTORC1 inhibitors capable of rescuing TSC loss of function	Fellowship
Elaine Dunlop	Cardiff University	Characterising the role of exosomes in Tuberous Sclerosis Complex	PhD student
Andrew Tee	Cardiff University	Targeting the Ref1/STAT3 axis to treat Tuberous Sclerosis	PhD student

This will take our full portfolio in 2018 to 14 live grants, four of which are jointly funded. Our portfolio of ongoing projects is worth £1.1 million.

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 2018

**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 2018, the total return on the portfolio was -5.15% as against the benchmark of -4.47%. 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 before a decision is made.

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 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.

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

The Association's reserves largely arise from a bequest in 1993 by the late Mr H I Leech, which is held as an endowment invested in fixed assets. This endowment provides 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 fund, out of income from the capital, services to the TSC community where income raised by the Association's fund-raising activities is inadequate in any particular period.

The balance on this endowment as at 31 December 2018 amounted to £1.474m (31 December 2017 - £2.068m). Restricted reserves were £5.4k (31 December 2017 - £4.3k) and other reserves included £229k (31 December 2017 - £506k in respect of the Kilmaine Family Research Fellowship - see note 20. Our policy is to hold no unrestricted reserves other than this endowment and accordingly the deficit on the general fund has been made up from a transfer from this endowment.

The deficit on the General Fund arises as a result of the Association's policy to fund part of the research activities from the general reserves of the Association.

Report of the Trustees  
for the Year Ended 31 December 2018

**FINANCIAL REVIEW**

**Result for the year**

The Association's total income for the year was £324k (2017 £440k).

Our total investment losses were £220k (2017 - gains 302k). 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 loss, the overall deficit for the year was £871k (2017 - £283k).

**FUTURE PLANS**

The 2019 Business Plan was approved in November 2018. 2019 will be the first year of implementing the new five-year strategy 2019-2023. It will be 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. It will be exciting but also challenging for staff, trustees, beneficiaries and partners as we work through these changes.

During 2019 we will start to reach more people and drive more research by prioritising delivery of the following strategic objectives:

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 rather than using the TSA's own reserves.
- \* 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.

- \* We will continue to lobby for the NHS in England, Wales and Northern Ireland to fund everolimus for TSC-related epilepsy where needed.
- \* We will identify and support existing third sector partnerships seeking to improve care for people with autism and learning disabilities.

We will 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 then onwards.



Report of the Trustees  
for the Year Ended 31 December 2018

## **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 through personal recommendations or through a recruitment campaign where appropriate.

### **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.

Jean Willson and Christine Naylor retired from the Board at the 2018 Annual General Meeting after being at the heart of the Association's work for long period. Philip Goldenberg retired from the Board in June 2019. The Board is most grateful to them for all their work and commitment to the TSA.

At each Annual General Meeting, one-third of the Trustees retire by choice or rotation. In 2019, these are Patrick Bolton and Rob Vaughan, who offer themselves for re-election; after an appraisal process, the Board recommends their re-election. Sanjay Sethi, Frances Elmslie, Jane Rogers and Annemarie Cotton who have been appointed to the Board since the 2018 Annual General Meeting, offer themselves for election, and are likewise so recommended.

### **Risk management**

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

The Finance and Investment Committee (FINCOM) has been given prime responsibility for the risk management process. FINCOM is accountable to the Board and conducts its business as needed and by such means as it considers appropriate (face to face meetings, teleconference and e-mail). It oversees the financial affairs of the Association and currently comprises the Chair, the Treasurer, the new Vice Chair Sanjay Sethi (who chairs it), and Tom Carter. A quorum for any meeting is three members. The Chief Executive is not a member of FINCOM, but has a standing invitation to attend meetings, other than at times when there would be a clear conflict of interest. The responsibilities of FINCOM include:

Report of the Trustees  
for the Year Ended 31 December 2018

**STRUCTURE, GOVERNANCE AND MANAGEMENT**

**Organisational structure (continued)**

- \* 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 has 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.

**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

Report of the Trustees  
for the Year Ended 31 December 2018

**REFERENCE AND ADMINISTRATIVE DETAILS**

**Trustees**

John Christopher Kingswood	President (elected 9/3/19)	
Martin Peter Short	Chairman	
Sanjay Sethi	Deputy Chair	- appointed 10/12/18
David Robin Vaughan	Treasurer	
	Company Secretary (until 26/11/18)	
Thomas Edmund Carter		
Lisa Suchet		
Patrick Ferrar Bolton		
Robert Woodthorpe Browne		- appointed 10/3/18
Frances Elmslie		- appointed 8/6/19
Jane Rogers		- appointed 8/6/19
Annemarie Cotton		- appointed 8/6/19
Christine Ann Naylor	(formerly President)	- resigned 10/12/18
Philip Goldenberg		- resigned 8/6/19
Martin J P Balfour-Allen		- resigned 23/6/18
Isabel DiVanna	(formerly Deputy Chair)	- resigned 5/7/18
Jean Ellen Willson		- resigned 10/12/18
Jayne Spink		- resigned 15/3/18

**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  
Munro House  
Portsmouth Road  
Cobham  
Surrey  
KT11 1PP

**Office Address**

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

**Investment Managers**

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

Report of the Trustees  
for the Year Ended 31 December 2018

**REFERENCE AND ADMINISTRATIVE DETAILS**

**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**

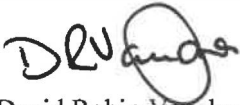
[www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)

**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 14 September 2019 by:



David Robin Vaughan - Trustee

The Tuberous Sclerosis Association

Statement of Trustees Responsibilities  
for the Year Ended 31 December 2018

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 Trustees and 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 2018 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 2018 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.

Report of the Independent Auditors to the Trustees and 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 11, 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.

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.

**Report of the Independent Auditors to the Trustees and Members of  
The Tuberous Sclerosis Association**

**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.



Robin John FCA, CTA (Senior Statutory Auditor)  
for and on behalf of Wellden Turnbull Limited  
Chartered Accountants and Statutory Auditor  
Munro House  
Portsmouth Road  
Cobham  
KT11 1PP

Date: .....18/5/11.....



The Tuberos Sclerosis Association

Statement of Financial Activities  
(Incorporating an Income and Expenditure Account)  
for the Year Ended 31 December 2018

		Unrestrict ed funds	Restricted funds	2018 Total funds	2017 Total funds
	Notes	£	£	£	£
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies	2	208,515	-	208,515	303,812
<b>Charitable activities</b>	5				
Family care & support		2,690	-	2,690	7,236
Education		-	19,849	19,849	-
Other trading activities	3	8,235	-	8,235	5,960
Investment income	4	<u>84,532</u>	<u>-</u>	<u>84,532</u>	<u>123,386</u>
<b>Total</b>		303,972	19,849	323,821	440,394
<b>EXPENDITURE ON</b>					
Raising funds	6	147,593	5,708	153,301	160,784
<b>Charitable activities</b>	7				
Family care & support		284,449	2,662	287,111	248,855
Research		384,789	2,086	386,875	411,210
Promoting awareness		90,830	2,086	92,916	135,298
Education		<u>48,260</u>	<u>6,183</u>	<u>54,443</u>	<u>69,693</u>
<b>Total</b>		955,921	18,725	974,646	1,025,840
Net gains/(losses) on investments		<u>(219,967)</u>	<u>-</u>	<u>(219,967)</u>	<u>302,337</u>
<b>NET INCOME/(EXPENDITURE)</b>		(871,916)	1,124	(870,792)	(283,109)
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		<u>2,574,646</u>	<u>4,297</u>	<u>2,578,943</u>	<u>2,862,052</u>
<b>TOTAL FUNDS CARRIED FORWARD</b>		<u><u>1,702,730</u></u>	<u><u>5,421</u></u>	<u><u>1,708,151</u></u>	<u><u>2,578,943</u></u>

**CONTINUING OPERATIONS**

Under the Companies Act, the Charity made a deficit of **£863,062 (2017 - 221,941)** being the reported deficit of **£870,792 (2017 - £283,109)** adjusted for the unrealised losses on investment assets of **£7,730 (2017 - £61,168)**.

The notes form part of these financial statements

The Tuberous Sclerosis Association (Registered number: 02900107)

Balance Sheet  
At 31 December 2018

	Notes	2018 £	2017 £
<b>FIXED ASSETS</b>			
Intangible assets	15	-	773
Investments	16	<u>1,914,135</u>	<u>2,932,504</u>
		1,914,135	2,933,277
 <b>CURRENT ASSETS</b>			
Debtors	17	21,292	45,409
Cash at bank and in hand		<u>196,226</u>	<u>178,453</u>
		217,518	223,862
 <b>CREDITORS</b>			
Amounts falling due within one year	18	(423,502)	(578,196)
		<u>                    </u>	<u>                    </u>
<b>NET CURRENT ASSETS/(LIABILITIES)</b>		<u>(205,984)</u>	<u>(354,334)</u>
 <b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		 <u>1,708,151</u>	 <u>2,578,943</u>
 <b>NET ASSETS</b>		 <u><u>1,708,151</u></u>	 <u><u>2,578,943</u></u>
 <b>FUNDS</b>			
Unrestricted funds:			
Endowment Fund		1,473,818	2,068,021
Kilmaine Family Research Fellowship		<u>228,912</u>	<u>506,625</u>
		1,702,730	2,574,646
Restricted funds:			
Jane Medcalf Memorial Education		-	556
		<u>5,421</u>	<u>3,741</u>
		<u>5,421</u>	<u>4,297</u>
 <b>TOTAL FUNDS</b>		 <u><u>1,708,151</u></u>	 <u><u>2,578,943</u></u>

The notes form part of these financial statements

The Tuberous Sclerosis Association (Registered number: 02900107)

Balance Sheet - continued  
At 31 December 2018

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 on 14 September 2019 and were signed on its behalf by:



Martin Peter Short - Trustee

The notes form part of these financial statements

## 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 2015)', 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 £.

### **Public benefit entity**

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

### **Going concern**

The trustees consider that there are no material uncertainties about the charitable company's ability to continue as a going concern.

Key judgements that the charitable company has made which have a significant effect on the accounts include reviewing and carrying out a risk analysis of the factors affecting the charity's ability to continue to fundraise income and its ability to continue to make grants to fund research.

The trustees do not consider that there are any sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next reporting period.

### **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.

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.

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**1. ACCOUNTING POLICIES - continued**

**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.

**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.

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 no general funds other than the designated funds.

**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

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**1. ACCOUNTING POLICIES - continued**

**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 AND LEGACIES**

	2018	2017
	£	£
Donations and subscriptions	194,014	289,847
Legacies	<u>14,500</u>	<u>13,965</u>
	<u><u>208,514</u></u>	<u><u>303,812</u></u>

**3. OTHER TRADING ACTIVITIES**

	2018	2017
	£	£
Christmas card & other miscellaneous sales	6,339	2,511
Other activities	<u>1,896</u>	<u>3,449</u>
	<u><u>8,235</u></u>	<u><u>5,960</u></u>

**4. INVESTMENT INCOME**

	2018	2017
	£	£
Bank interest	164	62
Income from managed portfolio	<u>84,368</u>	<u>123,324</u>
	<u><u>84,532</u></u>	<u><u>123,386</u></u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**5. INCOME FROM CHARITABLE ACTIVITIES**

		2018	2017
	<b>Activity</b>	£	£
Family days and weekends	Family care & support	2,690	7,236
Grants received - Novartis Pharmaceuticals UK Limited	Education	<u>19,850</u>	<u>-</u>
		<u>22,540</u>	<u>7,236</u>
		<u>=====</u>	<u>=====</u>

**6. RAISING FUNDS**

**Raising donations and legacies**

		2018	2017
		£	£
Staff costs		86,599	80,570
Sundries		5,462	8,441
Travel, communications and other costs		12,634	12,614
Staff training		7,177	4,296
Support costs		<u>22,486</u>	<u>27,922</u>
		<u>134,358</u>	<u>133,843</u>

**Other trading activities**

		2018	2017
		£	£
Purchases		<u>2,070</u>	<u>3,940</u>

**Investment management costs**

		2018	2017
		£	£
Portfolio management		<u>16,873</u>	<u>23,001</u>

Aggregate amounts		153,301	160,784
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The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**7. CHARITABLE ACTIVITIES COSTS**

	Direct costs	Grant funding of activities	Support costs	Totals
	(See note 8)	(See note 9)	(See note 10)	
	£	£	£	£
Family care & support	245,888	-	41,223	287,111
Research	67,938	277,713	41,224	386,875
Promoting awareness	51,692	-	41,224	92,916
Education	<u>13,219</u>	<u>-</u>	<u>41,224</u>	<u>54,443</u>
	<u>378,737</u>	<u>277,713</u>	<u>164,895</u>	<u>821,345</u>

**8. DIRECT COSTS OF CHARITABLE ACTIVITIES**

	2018	2017
	£	£
Staff costs	329,078	281,822
Research	-	1,800
Travel, communications and other costs	29,261	30,976
Publications	10,543	18,298
Benevolent grants	5,386	7,869
Family days and weekends	1,218	6,592
Sundries	<u>3,251</u>	<u>199</u>
	<u>378,737</u>	<u>347,556</u>



The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**9. GRANTS PAYABLE**

	2018	2017
	£	£
Research	<u>277,713</u>	<u>312,715</u>

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

	2018	2017
	£	£
* Institute of Medical Genetics, Cardiff -TRON: A randomised, double blind placebo-controlled study of RAD001 (Everolimus) in the treatment of neurocognitive problems in tuberous sclerosis	-	14,728
* Institute of Cancer & Genetics, Cardiff - Prevention of renal lesions by fine tuning mTOR signalling in a mouse model of tuberous sclerosis	540	-
* Department of Neuroscience, Erasmus Medical Centre, Netherlands - Towards a better understanding and better treatment of TSC-related epilepsy	22	-
* Institute of Psychiatry, Kings College London - Designing a protocol to measure the developmental trajectory of infants with Tuberous Sclerosis	-	64,289
* Cardiff University - New drug therapies to kill Tsc2-deficient cell lines	-	19,644
* University of Manchester - Exploiting Notch regulation to probe alternative mechanisms of TSC signalling.	64,762	64,220
* University of Nottingham - Inflammatory cell recruitment into LAM nodules drives tissue destruction TSC lung disease: opportunities for drug repurposing	-	55,946
* Dept of Clinical Genetics, Erasmus MC - Functional and structural characterisation of the TSC complex; improved functional assessment of TSC1 and TSC2 variants associated with tuberous sclerosis complex.	51,310	50,582
*University College London - The TSC1 and TSC2 Variation Databases	45,353	43,306
* 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	32,363	-
* Cardiff University. Characterising the Role of Exosomesin Tuberous Sclerosis Complex.	<u>32,363</u>	<u>-</u>
	<u>277,713</u>	<u>312,715</u>

Grants are awarded 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.

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**10. SUPPORT COSTS**

	Management £	Finance £	Other £	Governance costs £	Totals £
Raising donations and legacies	7,590	818	8,690	5,388	22,486
Family care & support	13,920	1,495	15,933	9,875	41,223
Research	13,921	1,495	15,933	9,875	41,224
Promoting awareness	13,921	1,495	15,933	9,875	41,224
Education	<u>13,921</u>	<u>1,495</u>	<u>15,933</u>	<u>9,875</u>	<u>41,224</u>
	<u>63,273</u>	<u>6,798</u>	<u>72,422</u>	<u>44,888</u>	<u>187,381</u>

<b>Activity</b>	<b>Basis of allocation</b>
Management	See below
Finance	See below
Other	See below
Governance costs	See below

Support costs have been allocated between 'Raising finance' 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):

	2018 £	2017 £
Auditors' remuneration	6,924	7,104
Database costs amortisation	<u>773</u>	<u>4,445</u>

**12. TRUSTEES' REMUNERATION AND BENEFITS**

There were no trustees' remuneration or other benefits for the year ended 31 December 2018 nor for the year ended 31 December 2017.

**Trustees' expenses**

	2018 £	2017 £
Trustees' expenses	<u>1,639</u>	<u>1,990</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. Seven (2017 - Seven) Trustees received payments for reimbursement of expenses during the year/ period.

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**13. STAFF COSTS**

	2018	2017
	£	£
Wages and salaries	415,440	374,908
Social security costs	36,376	30,281
Other pension costs	<u>22,881</u>	<u>19,000</u>
	<u>474,697</u>	<u>424,189</u>

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

	2018	2017
Raising finance	3	3
Promoting awareness	2	2
Family care and support	7	6
Support - general	2	2
Research	<u>2</u>	<u>2</u>
	<u>16</u>	<u>15</u>

No employees received emoluments in excess of £60,000 (31 December 2017 - none).

Pension costs relate to employer contributions to Stakeholder Pension Plans of employees.

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

	Unrestricted funds £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	303,812	-	303,812
<b>Charitable activities</b>			
Family care & support	7,236	-	7,236
Other trading activities	5,960	-	5,960
Investment income	<u>123,386</u>	<u>-</u>	<u>123,386</u>
<b>Total</b>	440,394	-	440,394
<b>EXPENDITURE ON</b>			
Raising funds	160,784	-	160,784
<b>Charitable activities</b>			
Family care & support	247,655	1,200	248,855
Research	411,210	-	411,210
Promoting awareness	135,298	-	135,298
Education	<u>69,693</u>	<u>-</u>	<u>69,693</u>
<b>Total</b>	1,024,640	1,200	1,025,840

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

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

	Unrestricted funds £	Restricted funds £	Total funds £
<b>Net gains/(losses) on investments</b>	<u>302,337</u>	<u>-</u>	<u>302,337</u>
<b>NET INCOME/(EXPENDITURE)</b>	(281,909)	(1,200)	(283,109)
<b>Transfers between funds</b>	<u>6,166</u>	<u>(6,166)</u>	<u>-</u>
<b>Net movement in funds</b>	(275,743)	(7,366)	(283,109)
<b>RECONCILIATION OF FUNDS</b>			
<b>Total funds brought forward</b>	<u>2,850,389</u>	<u>11,663</u>	<u>2,862,052</u>
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u><u>2,574,646</u></u>	<u><u>4,297</u></u>	<u><u>2,578,943</u></u>

**15. INTANGIBLE FIXED ASSETS**

	Database costs £
<b>COST</b>	
At 1 January 2018	<u>19,624</u>
<b>AMORTISATION</b>	
At 1 January 2018	18,851
Charge for year	<u>773</u>
At 31 December 2018	<u>19,624</u>
<b>NET BOOK VALUE</b>	
At 31 December 2018	<u>-</u>
At 31 December 2017	<u><u>773</u></u>

**16. FIXED ASSET INVESTMENTS**

	2018 £	2017 £
Shares	1,839,741	2,900,691
Cash held by investment manager for reinvestment	<u>74,394</u>	<u>31,813</u>
	<u><u>1,914,135</u></u>	<u><u>2,932,504</u></u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**16. FIXED ASSET INVESTMENTS - continued**

Additional information as follows:

	Quoted shares and unit trusts £
<b>MARKET VALUE</b>	
At 1 January 2018	2,900,691
Additions	142,215
Disposals	( 983,198)
Revaluations	<u>(219,667)</u>
At 31 December 2018	<u>1,839,741</u>
 <b>NET BOOK VALUE</b>	
At 31 December 2018	<u>1,839,741</u>
At 31 December 2017	<u>2,900,691</u>

The losses on investment assets of £219,667 (2017- gains £302,337) are made up of realised losses of £212,237 (2017 - gains £363,505) and unrealised losses of £7,730 (2017 - £61,168).

Investments held in companies outside the UK amounted to £648,209 (2017 - £1,020,707).

Investments (neither listed nor unlisted) were as follows:

	2018	2017
	£	£
Brewin Dolphin capital account	<u>74,394</u>	<u>31,813</u>

The capital account represents uninvested cash held by the broker.

	2018	2017
	£	£
The historical cost of the investments at the year end is:	<u>1,027,355</u>	<u>1,652,835</u>

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

	2018	2017
	£	£
Other debtors	<u>21,292</u>	<u>45,409</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

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

	2018	2017
	£	£
Social security and other taxes	9,893	8,098
Grants awarded	388,184	492,868
Accrued expenses	<u>25,425</u>	<u>77,230</u>
	<u>423,502</u>	<u>578,196</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.

/ continued

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

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

	At 1/1/18 £	SOFA £	Paid £	At 31/12/18 £
* University of Birmingham	3,500	-	-	3,500
* Brighton TS Registry	100	-	-	100
* Institute of Psychiatry, Kings College London	33,500	-	(8,893)	24,607
* Institute of Medical Genetics, Cardiff	2,503	-	(2,503)	-
* Institute of Medical Genetics, Cardiff	13,987	-	(13,987)	-
* Institute of Medical Genetics, Cardiff	12,172	540	(12,711)	-
* Institute of Medical Genetics, Cardiff	11,631	-	(3,070)	8,561
* Addenbrooke's Hospital, Cambridge	13,053	-	-	13,053
* Department of Neuroscience, Erasmus Medical Centre, Netherlands	7,518	22	(7,540)	-
* Centre for Integrative Physiology, University of Edinburgh	19,265	-	(18,930)	335
* Institute of Medical Genetics, Cardiff	8,702	-	(7,647)	1,055
* School of Psychology, University of Birmingham	2,834	-	(2,834)	-
* Institute of Psychiatry, Kings College, London	91,668	-	(77,515)	14,153
* Cardiff University	19,008	-	(16,556)	2,452
* Research Department of Genetics, University College, London	18,689	-	(18,176)	513
* University of Manchester, Faculty of Life Sciences	81,772	64,762	(59,222)	87,312
* University of Nottingham, Division of Respiratory Medicine	53,319	-	(39,648)	13,671
* Erasmus MC, Department of Clinical Genetics	56,341	51,310	(56,201)	51,450
* Mark Thomas & Rosemary Ekong TSC1 and TSC2 variation databases	43,306	45,353	(15,167)	73,492
* Whitehead Institute. Towards specific Mtor Inhibitors capable of rescuing Tuberous Sclerosis Complex loss-of- function	-	51,000	(21,795)	29,205
* Cardiff University. Targeting the Ref1/STAT3 axis to treat Tuberous Sclerosis Complex	-	32,363	-	32,363
* Cardiff University. Characterising the roles of exosomes in Tuberous Sclerosis Complex	-	32,363	-	32,363
	<u>492,868</u>	<u>277,713</u>	<u>(379,279)</u>	<u>388,184</u>

Analysis:

Falling due within one year

388,184

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**19. ANALYSIS OF NET ASSETS BETWEEN FUNDS**

	Unrestricted funds £	Restricted funds £	2018 Total funds £	2017 Total funds £
Fixed assets	-	-	-	773
Investments	1,914,135	-	1,914,135	2,932,504
Current assets	212,097	5,421	217,518	223,862
Current liabilities	<u>(423,502)</u>	<u>-</u>	<u>(423,502)</u>	<u>(578,196)</u>
	<u>1,702,730</u>	<u>5,421</u>	<u>1,708,151</u>	<u>2,578,943</u>

**20. 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	-
Endowment Fund	2,068,021	(152,474)	(441,729)	1,473,818
Kilmaine Family Research Fellowship	<u>506,625</u>	<u>(277,713)</u>	<u>-</u>	<u>228,912</u>
	2,574,646	(871,916)	-	1,702,730
<b>Restricted funds</b>				
Jane Medcalf Memorial Education	556	(556)	-	-
	<u>3,741</u>	<u>1,680</u>	<u>-</u>	<u>5,421</u>
	4,297	1,124	-	5,421
	<u>4,297</u>	<u>1,124</u>	<u>-</u>	<u>5,421</u>
<b>TOTAL FUNDS</b>	<u>2,578,943</u>	<u>(870,792)</u>	<u>-</u>	<u>1,708,151</u>



The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**20. 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	219,606	(661,335)	-	(441,729)
Endowment Fund	84,366	(16,873)	(219,967)	(152,474)
Kilmaine Family Research Fellowship	-	(277,713)	-	(277,713)
	<u>303,972</u>	<u>(955,921)</u>	<u>(219,967)</u>	<u>(871,916)</u>
<b>Restricted funds</b>				
Education	19,849	(18,169)	-	1,680
Jane Medcalf Memorial	-	(556)	-	(556)
	<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>

**Comparatives for movement in funds**

	At 1/1/17 £	Net movement in funds £	Transfers between funds £	At 31/12/17 £
<b>Unrestricted Funds</b>				
General fund	-	(371,854)	371,854	-
Endowment Fund	2,279,475	154,234	(365,688)	2,068,021
Kilmaine Family Research Fellowship	570,914	(64,289)	-	506,625
	<u>2,850,389</u>	<u>(281,909)</u>	<u>6,166</u>	<u>2,574,646</u>
<b>Restricted Funds</b>				
Jane Medcalf Memorial	1,756	(1,200)	-	556
Family Care and Support	6,166	-	(6,166)	-
Education	3,741	-	-	3,741
	<u>11,663</u>	<u>(1,200)</u>	<u>(6,166)</u>	<u>4,297</u>
<b>TOTAL FUNDS</b>	<u><u>2,862,052</u></u>	<u><u>(283,109)</u></u>	<u><u>-</u></u>	<u><u>2,578,943</u></u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**20. 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	317,070	(688,924)	-	(371,854)
Endowment Fund	123,324	(271,427)	302,337	154,234
Kilmaine Family Research Fellowship	-	(64,289)	-	(64,289)
	<u>440,394</u>	<u>(1,024,640)</u>	<u>302,337</u>	<u>(281,909)</u>
<b>Restricted funds</b>				
Jane Medcalf Memorial	-	(1,200)	-	(1,200)
	<u>-</u>	<u>(1,200)</u>	<u>-</u>	<u>(1,200)</u>
<b>TOTAL FUNDS</b>	<u><u>440,394</u></u>	<u><u>(1,025,840)</u></u>	<u><u>302,337</u></u>	<u><u>(283,109)</u></u>

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

	At 1/1/17 £	Net movement in funds £	Transfers between funds £	At 31/12/18 £
<b>Unrestricted funds</b>				
General fund	-	(813,583)	813,583	-
Endowment Fund	2,279,475	1,760	(807,417)	1,473,818
Kilmaine Family Research Fellowship	570,914	(342,002)	-	228,912
	<u>11,663</u>	<u>(76)</u>	<u>(6,166)</u>	<u>5,421</u>
<b>Restricted funds</b>				
Jane Medcalf Memorial	1,756	(1,756)	-	-
Family Care and Support	6,166	-	(6,166)	-
Education	3,741	1,680	-	5,421
	<u>11,663</u>	<u>(76)</u>	<u>(6,166)</u>	<u>5,421</u>
<b>TOTAL FUNDS</b>	<u><u>2,862,052</u></u>	<u><u>(1,153,901)</u></u>	<u><u>-</u></u>	<u><u>1,708,151</u></u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**20. 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	536,676	(1,350,259)	-	(813,583)
Endowment Fund	207,690	(288,300)	82,370	1,760
Kilmaine Family Research Fellowship	-	(342,002)	-	(342,002)
	<u>744,366</u>	<u>(1,980,561)</u>	<u>82,370</u>	<u>(1,153,825)</u>
<b>Restricted funds</b>				
Education	19,849	(18,169)	-	1,680
Jane Medcalf Memorial	-	(1,756)	-	(1,756)
	<u>19,849</u>	<u>(19,925)</u>	<u>-</u>	<u>(76)</u>
<b>TOTAL FUNDS</b>	<u><u>764,215</u></u>	<u><u>(2,000,486)</u></u>	<u><u>82,370</u></u>	<u><u>(1,153,901)</u></u>

**Unrestricted funds**

**Endowment Fund**

The 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 research of the Association during 2018.

**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 2018 relate to the unspent portion of specific donations.

The Janet Medcalf Memorial Fund is a fund set up to assist members by way of small grants of £300 each. Two such grants were awarded during the period, clearing the remaining balance on the fund.

A donation from Novartis towards "Education" have been partially spent during the year, with a balance of 5,421 being carried forward to 2019.

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2018

**20. MOVEMENT IN FUNDS - continued**

**Transfers between funds**

During the year, the 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 £441,729 has been made from the endowment fund in this regard.

**21. RELATED PARTY DISCLOSURES**

As permitted by the Memorandum and Articles of Association, payments are made to certain 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 £13,220 (2017 - £13,691) for services relating to the bookkeeping and accountancy work of the charity. This work is carried out in a separate office from the one from which Mr Vaughan operates and under the supervision of another Partner in the firm.

Miss B Vaughan, a daughter of the Treasurer is employed by the Association. The arrangement is on an Arms-Length basis.