

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

The Tuberous Sclerosis Association  
Report of the Trustees and  
Audited Financial Statements for the Year Ended 31 December 2017

The Tuberous Sclerosis Association

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for the Year Ended 31 December 2017

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Report of the Trustees  
for the Year Ended 31 December 2017

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 2017. 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.

The Association maintains serviced offices as shown on page eight, but most of its employees work from home. During 2017 we reviewed our policies on homeworking and lone working to provide appropriate support for staff. We took urgent action to ensure compliance with new legislation on data protection, including contracting with an external supplier to strengthen our IT systems. And we reviewed our safeguarding policies and invested in external safeguarding training to refresh the knowledge and skills of staff members working directly to support the TSC community.

The benefits of our activities are briefly summarised below (ending after 'Future Plans' on page five) 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 365 families for the first time. Throughout 2017, 420 members attended some of the 24 regional groups meetings and events taking place across the country. We awarded £9,110 to families in grants as part of TSA Support Fund. We also awarded £1,200 as part of the Janet Medcalf Award Trust.

In 2017, 46 delegates attended our Outlook event for members who are mildly affected by TSC, which took place in parallel to the TSA Big Day at The Belfry in Oxford. 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 continue to produce monthly e-newsletters, and have introduced devolved nations newsletters to give more relevant information where health, social care and education policy has changed in Scotland, Northern Ireland and Wales. We made all printed materials available on our website, and captured speakers and experts at our events to make material available to all members of the TSC community, not just those in attendance.

Report of the Trustees  
for the Year Ended 31 December 2017

**OBJECTIVES AND ACTIVITIES**

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

In June 2017, NHS England asked the National Institute for Health and Care Excellence (NICE) to review the evidence for everolimus for refractory seizures associated with TSC and provide support for the development of a clinical commissioning policy.

NICE made contact with the TSA to ask for our support in providing them with information to help them better understand the nature of the condition, patients' and carers' experiences and the current treatment pathways for refractory seizures associated with TSC in the NHS. The TSA made contact with over 1,000 individuals and families on our contact database asking them to get in touch if they had experience of taking everolimus and had noticed an impact on their epilepsy. We interviewed 15 people living with TSC and family carers to inform our response to NICE.

In addition to making a written submission to NICE setting out the views of patients and carers, the Chief Executive of the TSA joined the Policy Working Group which made a positive draft recommendation that everolimus for TSC-related epilepsy should be available on the NHS in England. NHS England is due to consult on the Policy Working Group's draft recommendation during 2018.

**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 2017 we broadened our links by reaching out to join the Council for Disabled Children, Disabled Children's Partnership and Network for Children with Exceptional Healthcare Needs (Scotland).

Raising awareness of the Association 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 be successful in our bid to bring about positive change. The more visible we are to those outside the TSC community, the greater our power to build a diverse and sustainable income base and successful partnerships.

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 Association's services.

During 2017 we continued to increase our social media presence holding five Facebook Live Q&As with experts in different aspects of TSC. In May 2017, we ran our awareness and fundraising campaign 'Tea and Scones for TSC' which raised more than £7,000 (an increase compared to 2016) and coincided with TSC Global Awareness Day.

Report of the Trustees  
for the Year Ended 31 December 2017

**OBJECTIVES AND ACTIVITIES**

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

In September 2017, 119 people attended our TSA Big Day at The Belfry in Oxford. 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. The conference also included a celebration of the 40th Anniversary of the Association, to thank the individuals and families who have supported the charity on its journey so far.

We brought people in the devolved nations together at a Northern Ireland Study Day for academics, researchers and families in Belfast, a Scottish Get Together attended by 25 individuals in Glasgow, and a Welsh Information and Get Together attended by 10 individuals 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 2017 of £312,715.

In 2017, outcomes from our funded research projects have appeared in nine academic journals, eight poster presentations and 17 oral presentations at academic conferences or professional meetings. Six awards were completed in 2017.

In 2017 we carried out the 2018 Research Award Round. Nine applications were received, and assessed through a rigorous process of external peer review and consideration by the Association's research committee. The Board chose to fund 3 new research awards from January 2018 onwards to increase the understanding of TSC. 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 also continue our membership of Association of Medical Research Charities and the UK Child Health Collaboration.

**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 2017, the total return on the portfolio was 14.0% as against the benchmark of 10.2%. 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.

Report of the Trustees  
for the Year Ended 31 December 2017

**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 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 2017 amounted to £2.068m (31 December 2016 - £2.279m). Restricted reserves were £4.3k (31 December 2016 - £11.6k) and other reserves included £507k (31 December 2016 - £571k) 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.

**Result for the year**

The Association's total income for the year was £440k (2016 £418k).

Our total investment gains were £302k (31 December 2016 - £490k). 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, the overall deficit for the year was £283k (2016 - Deficit - £159k).

Report of the Trustees  
for the Year Ended 31 December 2017

## **FUTURE PLANS**

Our last strategy was due to run until 31 December 2020, but a decision was made to review it in mid-term. In September 2017 we produced a draft five-year strategy which is directed to meet the hopes and aspirations of people with or directly affected by TSC. We consulted with the TSC Community to get their feedback on this. It is due to be reviewed and signed off by the Trustee Board in 2018.

The Strategy sets out a clear vision (a world where TSC and its effects are conquered) and mission (to provide help for today and a cure for tomorrow) for the Association. Its aims 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; and
- \* Lead innovation in the integration of medical and social care services.

During 2018 we will start to lay the groundwork for delivering our draft strategic objectives, which 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.

We plan for the Trustees to work with staff to ensure that they have a shared vision and a strong understanding of how the strategy will be implemented, and to launch the new strategy internally to the TSC community at the Big Day in November 2018. We will launch the new five-year strategy externally to our key stakeholders, funders and researchers in 2019.

During 2018 we will also review and refresh our research strategy, ensuring that we are fully able to monitor and demonstrate the impact of the research that we fund. We will campaign to ensure both NHS England and the Scottish Medicines Consortium make positive decisions to fund everolimus for TSC-related epilepsy. And during a period of change for the Association, we will ensure that we continue to provide effective support and help for people with TSC and their families.

## **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.

Report of the Trustees  
for the Year Ended 31 December 2017

**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 eight.

Three Trustees have left the Board since the 2017 Annual General Meeting.

Martin Balfour-Allen and Jayne Spink did so because the pressures of their other commitments: family in the former case, and work in the latter. Isabel diVanna had, following a selection process, been elected to the Board with a view to becoming Chair. A majority of the Board were not comfortable with her potential Leadership of the Association, whereafter she resigned, citing disagreements over the direction and management of the Association. The Board thanks all three for their service as Trustees.

In addition, Christine Naylor will retire from the Board at the 2018 Annual General Meeting after being at the heart of the Association's work for a long period, including serving as Chair then President. The Board is most grateful to her for all her work.

At each Annual General Meeting, one-third of the Trustees retire by choice or rotation. In 2018, these are Chris Kingswood, Martin Short and Lisa Suchet, who offer themselves for re-election; after an appraisal process, the Board recommends their re-election. Robert Woodthorpe Browne, who was appointed to the Board after the 2017 Annual General Meeting, offers himself for election, and is likewise so recommended.

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 immediate past Chair Philip Goldenberg (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:

- \* 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;

Report of the Trustees  
for the Year Ended 31 December 2017

**STRUCTURE, GOVERNANCE AND MANAGEMENT**

**Organisational structure**

- \* 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**

CAN Mezzanine  
32-36 Loman Street  
London  
SE1 0EH

Report of the Trustees  
for the Year Ended 31 December 2017

**REFERENCE AND ADMINISTRATIVE DETAILS**

**Trustees**

Christine Ann Naylor	President	
Martin Peter Short	Chairman	
Philip Goldenberg	Deputy Chair (until 11/3/17)	
David Robin Vaughan	Treasurer and Company Secretary	
Martin J P Balfour-Allen		- resigned 23/6/18
Isabel DiVanna	Deputy Chair	- resigned 5/7/18
Thomas Edmund Carter		
John Christopher Kingswood		
Jean Ellen Willson		
Sophie Christine Lording		- resigned 19/3/17
Lisa Suchet		
Patrick Ferrar Bolton		
Jayne Spink		- appointed 1/5/17 - resigned 15/3/18
Robert Woodthorpe Browne		- appointed 10/3/18

**Honorary Life Vice Presidents**

Esther Galbraith  
Thomas Edmund Carter  
Anne Carter  
The Lady Kilmaine

**Chief Executive**

Jayne Spink - resigned 13/4/17  
Louise Fish - appointed 5/6/17

**Auditors**

Wellden Turnbull Ltd  
Munro House  
Portsmouth Road  
Cobham  
Surrey  
KT11 1PP

**Office Address**

CAN Mezzanine, 32-36 Loman Street, London, SE1 0EH

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

Report of the Trustees  
for the Year Ended 31 December 2017

**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 24 September 2018 by::

David Robin Vaughan - Trustee

The Tuberous Sclerosis Association

Statement of Trustees Responsibilities  
for the Year Ended 31 December 2017

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. 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 2017 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).

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.

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 2017 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 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

**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, 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 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.

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

Date: ... September 2018

The Tuberos Sclerosis Association

Statement of Financial Activities  
(Incorporating an Income and Expenditure Account)  
for the Year Ended 31 December 2017

	Notes	Unrestricted funds £	Restricted funds £	2017 Total funds £	2016 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies	2	303,812	-	303,812	248,647
<b>Charitable activities</b>	5				
Family care & support		7,236	-	7,236	10,123
Education		-	-	-	23,754
Other trading activities	3	5,960	-	5,960	7,246
Investment income	4	123,386	-	123,386	128,708
<b>Total</b>		440,394	-	440,394	418,478
<b>EXPENDITURE ON</b>					
Raising funds	6	160,784	-	160,784	140,938
<b>Charitable activities</b>	7				
Family care & support		247,655	1,200	248,855	224,963
Research		411,210	-	411,210	505,514
Promoting awareness		135,298	-	135,298	112,306
Education		69,693	-	69,693	84,358
<b>Total</b>		1,024,640	1,200	1,025,840	1,068,079
Net gains/(losses) on investments		302,337	-	302,337	490,334
<b>NET INCOME/(EXPENDITURE)</b>		(281,909)	(1,200)	(283,109)	(159,267)
<b>Transfers between funds</b>	20	6,166	(6,166)	-	-
<b>Net movement in funds</b>		(275,743)	(7,366)	(283,109)	(159,267)
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		2,850,389	11,663	2,862,052	3,021,319
<b>TOTAL FUNDS CARRIED FORWARD</b>		2,574,646	4,297	2,578,943	2,862,052

**CONTINUING OPERATIONS**

Under the Companies Act, the Charity made a deficit of £221,941 (2016 - £318,042) being the reported deficit of £283,109 (31 December 2016 - £159,267 ) adjusted for the unrealised deficit of £61,168 (2016 -unrealised surplus £158,775 ).

The notes form part of these financial statements

Balance Sheet  
At 31 December 2017

	Notes	2017 £	2016 £
<b>FIXED ASSETS</b>			
Intangible assets	15	773	5,218
Investments	16	2,932,504	3,418,169
		<hr/>	<hr/>
		2,933,277	3,423,387
 <b>CURRENT ASSETS</b>			
Debtors	17	45,409	37,798
Cash at bank and in hand		178,453	140,750
		<hr/>	<hr/>
		223,862	178,548
 <b>CREDITORS</b>			
Amounts falling due within one year	18	(578,196)	(739,883)
		<hr/>	<hr/>
<b>NET CURRENT ASSETS/(LIABILITIES)</b>		<hr/> <b>(354,334)</b> <hr/>	<hr/> <b>(561,335)</b> <hr/>
 <b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>			
		2,578,943	2,862,052
 <b>NET ASSETS</b>			
		<hr/> <b>2,578,943</b> <hr/>	<hr/> <b>2,862,052</b> <hr/>
 <b>FUNDS</b>			
	20		
Unrestricted funds:			
Endowment Fund		2,068,021	2,279,475
Kilmaine Family Research Fellowship		506,625	570,914
		<hr/>	<hr/>
		2,574,646	2,850,389
Restricted funds:			
Jane Medcalf Memorial		556	1,756
Family Care and Support		-	6,166
Education		3,741	3,741
		<hr/>	<hr/>
		4,297	11,663
 <b>TOTAL FUNDS</b>			
		<hr/> <b>2,578,943</b> <hr/>	<hr/> <b>2,862,052</b> <hr/>

The notes form part of these financial statements

Balance Sheet - continued  
At 31 December 2017

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to charitable small companies.

The financial statements were approved and authorised for issue by the Board of Trustees and were signed on its behalf on .. September 2018 by:

Philip Goldenberg -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 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.

### **Financial reporting standard 102 - reduced disclosure exemptions**

The charity has taken advantage of the following disclosure exemptions in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

- the requirements of Section 7 Statement of Cash Flows;
- the requirement of Section 3 Financial Statement Presentation paragraph 3.17(d);
- the requirements of Section 11 Financial Instruments paragraphs 11.41(b), 11.41(c), 11.41(e), 11.41(f), 11.42, 11.44, 11.45, 11.47, 11.48(a)(iii), 11.48(a)(iv), 11.48(b) and 11.48(c);
- the requirements of Section 12 Other Financial Instruments paragraphs 12.26, 12.27, 12.29(a), 12.29(b) and 12.29A;
- the requirement of Section 33 Related Party Disclosure paragraph 33.7.

### **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

**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.

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

**1. ACCOUNTING POLICIES - continued**

**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

**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**

	2017	2016
	£	£
Donations and subscriptions	289,847	247,647
Legacies	13,965	1,000
	<u>303,812</u>	<u>248,647</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

**3. OTHER TRADING ACTIVITIES**

	2017	2016
	£	£
Christmas card & other miscellaneous sales	2,511	1,297
Other activities	3,449	5,949
	5,960	7,246
	5,960	7,246

**4. INVESTMENT INCOME**

	2017	2016
	£	£
Bank interest	62	653
Income from managed portfolio	123,324	128,055
	123,386	128,708
	123,386	128,708

**5. INCOME FROM CHARITABLE ACTIVITIES**

		2017	2016
	<b>Activity</b>	£	£
Family days and weekends	Family care & support	7,236	10,123
Family days and weekends	Education	-	23,754
		7,236	33,877
		7,236	33,877

**6. RAISING FUNDS**

**Raising donations and legacies**

	2017	2016
	£	£
Staff costs	80,570	73,108
Sundries	8,441	9,899
Travel, communications and other costs	12,614	11,916
Recruitment costs	-	(111)
Staff training	4,296	1,653
Support costs	27,922	19,478
	133,843	115,943
	133,843	115,943

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

**6. RAISING FUNDS - continued**

**Other trading activities**

	2017	2016
	£	£
Purchases	3,940	2,405
	<u>3,940</u>	<u>2,405</u>

**Investment management costs**

	2017	2016
	£	£
Portfolio management	23,001	22,590
	<u>23,001</u>	<u>22,590</u>

Aggregate amounts	<u>160,784</u>	<u>140,938</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	197,658	-	51,197	248,855
Research	47,299	312,715	51,196	411,210
Promoting awareness	84,102	-	51,196	135,298
Education	18,497	-	51,196	69,693
	<u>347,556</u>	<u>312,715</u>	<u>204,785</u>	<u>865,056</u>

**8. DIRECT COSTS OF CHARITABLE ACTIVITIES**

	2017	2016
	£	£
Staff costs	281,822	249,601
Research	1,800	-
Travel, communications and other costs	30,976	32,441
Study days	-	8,415
Publications	18,298	15,746
Benevolent grants	7,869	9,084
Family days and weekends	6,592	11,066
Sundries	199	23,898
	<u>347,556</u>	<u>350,251</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

**9. GRANTS PAYABLE**

	2017	2016
	£	£
Research	<u>312,715</u>	<u>434,059</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

**9. GRANTS PAYABLE - continued**

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

	2017	2016
	£	£
* 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	25,754
* Department of Neuroscience, Erasmus Medical Centre, Netherlands - Towards a better understanding and better treatment of TSC-related epilepsy	-	49,289
* Centre for Integrative Physiology, University of Edinburgh - Targeting the mGluR5-FMRP signalling pathway for the treatment of TSC	-	53,410
* Division of Child & Adolescent Psychiatry, University of Cape Town - PhD Studentship; Understanding and Treating TSC-Associated Neuropsychiatric Disorders (TAND)	-	18,000
* Institute of Cancer and Genetics, Cardiff - PhD Studentship : Dual inhibition of glycolysis and glutaminolysis for anti-tumour therapy in a TSC2 mouse model	-	22,000
* School of Psychology, University of Birmingham - Junior fellowship: Delineating impulsive behaviour in Tuberous Sclerosis Complex	-	1,400
* School of Psychology, University of Birmingham - PhD Studentship: Problem behaviours in Tuberous Sclerosis Complex	-	11,338
* Institute of Psychiatry, Kings College London - Designing a protocol to measure the developmental trajectory of infants with Tuberous Sclerosis	64,289	61,586
* Cardiff University - New drug therapies to kill Tsc2-deficient cell lines	19,644	19,407
* University College London - The TSC1 and TSC2 variation Databases	-	34,616
* University of Manchester - Exploiting Notch regulation to probe alternative mechanisms of TSC signalling.	64,220	60,775
* University of Nottingham - Inflammatory cell recruitment into LAM nodules drives tissue destruction TSC lung disease: opportunities for drug repurposing	55,946	53,689
* 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.	50,582	22,795
*University College London - The TSC1 and TSC2 Variation Databases	43,306	-
	<u>312,715</u>	<u>434,059</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 2017

**10. SUPPORT COSTS**

	Management	Finance	Other	Governance costs	Totals
	£	£	£	£	£
Raising donations and legacies	7,489	1,186	13,342	5,905	27,922
Family care & support	13,729	2,179	24,462	10,827	51,197
Research	13,728	2,179	24,462	10,827	51,196
Promoting awareness	13,728	2,179	24,462	10,827	51,196
Education	13,728	2,179	24,462	10,827	51,196
	<u>62,402</u>	<u>9,902</u>	<u>111,190</u>	<u>49,213</u>	<u>232,707</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):

	2017	2016
	£	£
Auditors' remuneration	7,104	6,600
Database costs amortisation	4,445	3,924
	<u>11,549</u>	<u>10,524</u>

**12. TRUSTEES' REMUNERATION AND BENEFITS**

There were no trustees' remuneration or other benefits for the year ended 31 December 2017 nor for the year ended 31 December 2016.

**Trustees' expenses**

	2017	2016
	£	£
Trustees' expenses	1,990	4,300
	<u>1,990</u>	<u>4,300</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 (2016 - Fourteen) Trustees received payments for reimbursement of expenses during the year/ period.

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

**13. STAFF COSTS**

	2017	2016
	£	£
Wages and salaries	374,908	354,849
Social security costs	30,281	28,086
Other pension costs	19,000	13,233
	424,189	396,168
	424,189	396,168

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

	2017	2016
Raising finance	3	3
Promoting awareness	2	2
Family care and support	6	6
Support - general	2	4
Research	2	1
	15	16
	15	16

No employees received emoluments in excess of £60,000 (31 December 2016 - 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	248,647	-	248,647
<b>Charitable activities</b>			
Family care & support	10,123	-	10,123
Education	-	23,754	23,754
Other trading activities	7,246	-	7,246
Investment income	128,708	-	128,708
	394,724	23,754	418,478
<b>Total</b>	394,724	23,754	418,478

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

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

	Unrestricted funds £	Restricted funds £	Total funds £
<b>EXPENDITURE ON</b>			
Raising funds	138,493	2,445	140,938
<b>Charitable activities</b>			
Family care & support	219,280	5,683	224,963
Research	501,031	4,483	505,514
Promoting awareness	84,973	27,333	112,306
Education	71,459	12,899	84,358
	1,015,236	52,843	1,068,079
<b>Total</b>			
<b>Net gains/(losses) on investments</b>	490,334	-	490,334
	(130,178)	(29,089)	(159,267)
<b>NET INCOME/(EXPENDITURE)</b>			
<b>RECONCILIATION OF FUNDS</b>			
<b>Total funds brought forward</b>	2,980,568	40,751	3,021,319
	2,850,390	11,662	2,862,052
<b>TOTAL FUNDS CARRIED FORWARD</b>	2,850,390	11,662	2,862,052

**15. INTANGIBLE FIXED ASSETS**

	Database costs £
<b>COST</b>	
At 1 January 2017	19,624
<b>AMORTISATION</b>	
At 1 January 2017	14,406
Charge for year	4,445
At 31 December 2017	18,851
<b>NET BOOK VALUE</b>	
At 31 December 2017	773
At 31 December 2016	5,218

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

**16. FIXED ASSET INVESTMENTS**

	2017	2016
	£	£
Shares	2,900,691	3,361,249
Cash held by investment manager for reinvestment	31,813	56,920
	2,932,504	3,418,169
	2,932,504	3,418,169

Additional information as follows:

	Quoted shares and unit trusts £
<b>MARKET VALUE</b>	
At 1 January 2017	3,361,249
Additions	67,091
Disposals	(829,986)
Revaluations	302,337
	2,900,691
At 31 December 2017	2,900,691
<b>NET BOOK VALUE</b>	
At 31 December 2017	2,900,691
At 31 December 2016	3,361,249

The gains on investment assets of £302,337 (2016 - £490,334 ) are made up of realised gains of £363,505 (2016 - £331,559) and unrealised losses of £68,168 (2016 - unrealised gains £158,775).

Investments held in companies outside the UK amounted to £1,020,707 (2016 - £1,187,459).

Investments (neither listed nor unlisted) were as follows:

	2017	2016
	£	£
Brewin Dolphin capital account	31,813	56,920
	31,813	56,920
	31,813	56,920

The capital account represents uninvested cash held by the broker.

	2017	2016
	£	£
The historical cost of the investments at the year end is:	1,652,835	2,052,225
	1,652,835	2,052,225
	1,652,835	2,052,225

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

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

	2017	2016
	£	£
Other debtors	45,409	37,798
	<u>45,409</u>	<u>37,798</u>

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

	2017	2016
	£	£
Social security and other taxes	8,098	8,040
Grants awarded	492,868	650,614
Accrued expenses	77,230	81,229
	<u>578,196</u>	<u>739,883</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 2017

**CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR (continued)**

	At 1/1/17 £	SOFA £	Paid £	At 31/12/17 £
* University of Birmingham	3,500	-	-	3,500
* Brighton TS Registry	100	-	-	100
* Institute of Psychiatry, Kings College London	33,500	-	-	33,500
* Institute of Medical Genetics, Cardiff	12,050	14,728	(24,275)	2,503
* Institute of Medical Genetics, Cardiff	25,821	-	(11,834)	13,987
* Institute of Medical Genetics, Cardiff	47,721	-	(35,549)	12,172
* Institute of Medical Genetics, Cardiff	11,631	-	-	11,631
* Addenbrooke's Hospital, Cambridge	13,053	-	-	13,053
* Department of Neuroscience, Erasmus Medical Centre, Netherlands	68,641	-	(61,123)	7,518
* Centre for Integrative Physiology, University of Edinburgh	83,701	-	(64,436)	19,265
* Division of Child & Adolescent Psychiatry, University of Cape Town, South Africa	18,000	-	(18,000)	-
* Institute of Medical Genetics, Cardiff School of Psychology, University of Birmingham	31,850	-	(23,148)	8,702
* School of Psychology, University of Birmingham	7,917	-	(7,917)	-
* Institute of Psychiatry, Kings College, London	14,172	-	(11,338)	2,834
* Cardiff University	61,584	64,289	(34,205)	91,668
* Research Department of Genetics, University College, London	19,824	19,644	(20,460)	19,008
* University of Manchester, Faculty of Life Sciences	67,575	-	(48,886)	18,689
* University of Nottingham, Division of Respiratory Medicine	57,140	64,220	(39,588)	81,772
* Erasmus MC, Department of Clinical Genetics	50,039	55,946	(52,666)	53,319
* Mark Thomas & Rosemary Ekong TSC1 and TSC2 variation databases	22,795	50,582	(17,036)	56,341
	-	43,306	-	43,306
	<u>650,614</u>	<u>312,715</u>	<u>(470,461)</u>	<u>492,868</u>
Analysis: Falling due within one year				<u>492,868</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

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

	Unrestricted funds £	Restricted funds £	2017 Total funds £	2016 Total funds £
Fixed assets	773	-	773	5,218
Investments	2,932,504	-	2,932,504	3,418,169
Current assets	219,565	4,297	223,862	178,548
Current liabilities	(578,196)	-	(578,196)	(739,883)
	<u>2,574,646</u>	<u>4,297</u>	<u>2,578,943</u>	<u>2,862,052</u>

**20. 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>2,862,052</u>	<u>(283,109)</u>	<u>-</u>	<u>2,578,943</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

**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	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>440,394</u>	<u>(1,025,840)</u>	<u>302,337</u>	<u>(283,109)</u>

**Comparatives for movement in funds**

	At 1/1/16 £	Net movement in funds £	Transfers between funds £	At 31/12/16 £
<b>Unrestricted Funds</b>				
General fund	-	(291,918)	291,918	-
Endowment Fund	2,330,068	241,325	(291,918)	2,279,475
Ann Hunt Research Fellowship	18,000	(18,000)	-	-
Kilmaine Family Research Fellowship	632,500	(61,586)	-	570,914
	<u>2,980,568</u>	<u>(130,179)</u>	<u>-</u>	<u>2,850,389</u>
<b>Restricted Funds</b>				
Jane Medcalf Memorial	2,956	(1,200)	-	1,756
Family Care and Support	6,166	-	-	6,166
Education	31,629	(27,888)	-	3,741
	<u>40,751</u>	<u>(29,088)</u>	<u>-</u>	<u>11,663</u>
<b>TOTAL FUNDS</b>	<u><u>3,021,319</u></u>	<u><u>(159,267)</u></u>	<u><u>-</u></u>	<u><u>2,862,052</u></u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued  
for the Year Ended 31 December 2017

**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	266,670	(558,588)	-	(291,918)
Endowment Fund	128,054	(377,063)	490,334	241,325
Ann Hunt Research Fellowship	-	(18,000)	-	(18,000)
Kilmaine Family Research Fellowship	-	(61,586)	-	(61,586)
	<u>394,724</u>	<u>(1,015,237)</u>	<u>490,334</u>	<u>(130,179)</u>
<b>Restricted funds</b>				
Education	23,754	(51,642)	-	(27,888)
Jane Medcalf Memorial	-	(1,200)	-	(1,200)
	<u>23,754</u>	<u>(52,842)</u>	<u>-</u>	<u>(29,088)</u>
<b>TOTAL FUNDS</b>	<u><u>418,478</u></u>	<u><u>(1,068,079)</u></u>	<u><u>490,334</u></u>	<u><u>(159,267)</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".

**Ann Hunt Research Fellowship**

This fellowship was used to fund a research grant "Understanding and Treating Neuropsychiatric Disorders". The final payment in respect of this fund was made 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 2017 relate to the unspent portion of specific donations.

Donations and grants towards research were used to help fund the research grants awarded during the year.

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

Donations and grants towards family care and support were used to extend the Family Support Programme to Wales.

**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 £371,854 has been made from the endowment fund in this regard.

The Family Care and Support Fund was expended in full in 2016 and a transfer of £6,166 has been made from the General 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 £13,691 (Year ended 31 December 2016 - £14,195) 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.