

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 2016

The Tuberous Sclerosis Association

Contents of the Financial Statements
for the Year Ended 31 December 2016

	Page
Report of the Trustees	1 to 8
Statement of Trustees' Responsibilities	9
Report of the Independent Auditors	10 to 11
Statement of Financial Activities	12
Balance Sheet	13 to 14
Notes to the Financial Statements	15 to 30

Report of the Trustees
for the Year Ended 31 December 2016

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 2016. 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 2015). 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.

This was the second year of our five-year strategy which is directed to meet the hopes and aspirations of people with or directly affected by TSC. All key decisions are made by the Trustee Board (or, within appropriate delegated authorities, its Committees).

The Association maintains serviced offices as shown on page seven, but most of its employees work from home.

The benefits of our activities are briefly summarised below (ending after 'Future Plans' on page 5) 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 239 families for the first time. In 2016 our TSA Advisers were present at 174 meetings (an increase of 45%) representing the TSA. Throughout 2016, 341 members attended some of the 27 regional group meetings across the country. We awarded £5,892 to families in grants as part of TSA Support Fund. We also awarded £1,200 as part of the Janet Medcalf Award Trust.

In 2016 more than 48 delegates attended our Outlook weekend, an event for members who are mildly affected by TSC. The event allows them to share their experiences, build friendships and have fun in a supportive environment.

Report of the Trustees
for the Year Ended 31 December 2016

OBJECTIVES AND ACTIVITIES

Activities and performance in relation to 'Support' (continued)

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 have increased our social media presence and successfully piloted six Live Facebook Q&A events with leading experts across a range of disciplines. 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.

Activities and performance in relation to 'Influencing Policy'

We responded to all relevant consultations in order to ensure that we consistently promote the interests of the TSC community in policy development, highlighting our issues and presenting potential solutions. We have contributed to a range of external and collaborative initiatives that have kept TSC at the heart of the rare diseases / healthcare debate.

In 2016 our #Fight4Treatment campaign engaged the TSC community and our message was taken to the heart of government. We secured access to an effective treatment, Everolimus, for those with TSC-related kidney tumours, but this medicine for people with inoperable TSC brain tumours was deemed 'unaffordable' by NHS England. To challenge this decision, we attended All-Party Parliamentary Group Meetings on medicine access; 13 consultants wrote a letter of objection that was published in The Times; we hosted a parliamentary reception event attended by many MPs; we engaged with regional and national media; we launched an e-petition which garnered over 17,000 signatories; we hosted a protest outside Parliament; and 94 people wrote to their MPs on the issue, with the consequence that 12 MPs wrote directly to the Secretary of State for Health. This resulted in over 40 mentions of the issue in parliamentary debates, questions and early day motions. NHS England overturned their original decision in December 2016, and the medicine will now be routinely prescribed for people with inoperable TSC brain tumours.

Activities and performance in relation to 'Information & awareness'

We've been delighted by the launch of the TSC clinic and the implementation of an agreement on access to medicine for TSC in Wales. 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.

Raising awareness of the organisation and our services has been key to reaching new families (during 2016 this equated to around 20 new families each month accessing our services). 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.

Our successful CPD-accredited learning module on the diagnosis and management of TSC (developed in association with BMJ-online) has now been completed by 2,623 professionals. We provide TSC-specific Red Book (Infant Health Record) to families with a new diagnosis. We have supported the clinical community in the development of a UK service specification for future publication.

Report of the Trustees
for the Year Ended 31 December 2016

OBJECTIVES AND ACTIVITIES

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

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

- * 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.

During 2016 we continued to increase our social media presence reaching 2368 likes on Facebook and more than 894 twitter followers. We built relationships with key journalists and appeared in 28 regional and two national newspapers, we appeared on two regional radio stations, one regional and two national TV programmes and in one national magazine. We produced eight in-house videos which were viewed over 8000 times. In May 2016, we ran our awareness and fundraising campaign 'Tea and Scones for TSC' which raised more than £7,000 (33% uplift on 2015) and coincided with TSC Global Awareness Day.

In September 2016, 179 people attended our TSA Big Day. 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 also conducted a Community Survey in September 2016 in partnership with Loughborough University School of Business and Economics. We had 565 households take part with 87% saying their overall experience of the TSA was good. The survey gave great insight into the issues that families face, and useful feedback on our services and outputs. This is being used to inform our strategy going forward.

Activities and performance in relation to 'Research'

In 2016, we committed to supporting a further three new research projects to increase the understanding of TSC. This has taken our full portfolio to 18 live grants, two of which are jointly funded. We have steadily grown our grant programme and our portfolio. The TSA is the only UK charity dedicated to supporting TSC research, with an in-year commitment of £434,000. Our portfolio of ongoing projects is worth £1.8million.

Our funded research projects have appeared in 4 academic journals, 9 poster presentations and 14 oral presentations at academic conferences or professional meetings. We also continue our membership of Association of Medical Research Charities and the UK child Health Collaboration. Several new scientific members and lay members from the TSC community joined our Research Committee in 2016.

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 2016, the total return on the portfolio was 1.76% as against the benchmark of 1.16%. 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 our investment managers, with whom the Trustees have agreed a formal investment policy reflecting the investment objective stated above.

Activities and performance in relation to 'Volunteering'

We have continued to develop our volunteering programme with five talent pool volunteers assisting with photography, writing and social media, 17 formal volunteers organising regional groups and acting as TSA ambassadors, and 17 supporter volunteers attending one-off events to raise awareness of TSC.

Report of the Trustees
for the Year Ended 31 December 2016

FINANCIAL REVIEW

Grant making policy

Research grants are given for purposes directly concerned with furthering an understanding of Tuberos 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 a group of Trustees 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 2016 amounted to £2.279m (31 December 2015 - £2.330m). Restricted reserves were £11.6k (31 December 2015 - £40.7k) and other reserves included £571k (31 December 2015 - £632.5k) 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 £418k (2015 £1.176m). During the year, the income of the Association decreased significantly as a result of the single donation of £632.5k from The Lady Kilmaine in 2015.

Our total investment gains were £490k (31 December 2015 deficit - £60k). 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 £159k (2015 - Surplus - £27k).

Risk Management

The Trustees have established procedures to ensure that strategic planning and risk management processes become part of the operating processes of the Association. The Trustees have identified the major risks to which the Association is exposed, determined the relative significance of those risks, and reviewed the adequacy of the systems that have been established to mitigate those risks.

The Finance and Investment Committee (FINCOM) has been given prime responsibility for the risk management process. Further details are given in the section headed 'Structure, Governance and Management' of the Report of the Trustees.

Report of the Trustees
for the Year Ended 31 December 2016

FUTURE PLANS

Our current five-year strategy runs to 31 December 2020 and was developed with the input of volunteers and service users. The strategy will be formally reviewed at its mid-term. The strategy guides our annual planning and reporting. In addition to the commitments delivered in this, the first year of our new strategic period we plan to:

- * Review and refresh our research strategy, ensuring that we are fully able to monitor and demonstrate the impact of the research we fund. We further aim to have played a major role in bringing an early intervention trial to the clinic through our international collaborations and, following the success of the 2015 International Research Conference to have hosted a further event here in the UK.
- * Build on our successes in support, developing a portfolio of flexible services that recognise different levels of need and develop formal working relationships with NHS clinics. We plan to work in collaboration with healthcare professionals to ensure that the NHS is able to deliver against the recommendations of the 2012 International Guidelines. We plan to continue to run our national and local events and to achieve accreditation of our information products.
- * Continue fighting for access to treatment and services for people with TSC. By the end of 2020 there will be increased awareness of TSC, with demonstrable improvements in access to diagnosis, treatment and care. The TSA will have the reputation of making its presence felt for the benefit of people affected by TSC and the credibility with key influential parties to deliver change.
- * Grow our income by developing new income streams and strengthening our fundraising activities. We plan to improve stewardship to encourage repeat and regular giving, championing fundraising and actively engaging as staff and volunteers with a range of fundraising initiatives. We will continue to work with our international partners on collaborative projects to raise global awareness of TSC. We plan to use the opportunity of our 40th Anniversary in 2017 to showcase our work, raise awareness and generate funds.

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 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 2016

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 seven.

At each Annual General Meeting, one-third of the Trustees retire by choice or rotation. Martin Balfour-Allen, Tom Carter and Rob Vaughan will accordingly be proposed for re-election at the 2017 AGM. In addition, Jayne Spink (who was formerly our Chief Executive Officer, and was appointed a Trustee shortly after she ceased to be so) will be proposed for election.

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

Report of the Trustees
for the Year Ended 31 December 2016

STRUCTURE, GOVERNANCE AND MANAGEMENT

Induction and training of new trustees

There are policies for the induction and training of Trustees. This involves meeting with the Chair and Deputy Chair to discuss what the role involves, and having discussions with other Trustees and Association Staff as appropriate. Attention is drawn to the guidance issued by the Charity Commission - "The Essential Trustee".

A performance review process is in place to ensure the effectiveness of those Trustees, who are approaching re-election.

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

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		
Isabel DiVanna	Deputy Chair	- appointed 17/9/16
	(from 11/3/17)	
Nicholas Peter Dale		- resigned 19/3/16
Thomas Edmund Carter		
John Christopher Kingswood		
Jean Ellen Willson		
Sophie Christine Lording		
Lisa Suchet		
Patrick Ferrar Bolton		- appointed 19/3/16
Jayne Spink		- appointed 1/5/17

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

Report of the Trustees
for the Year Ended 31 December 2016

REFERENCE AND ADMINISTRATIVE DETAILS

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

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 2015).

This report was approved by the Board of Trustees and signed on its behalf on 2 August 2017 by:


.....
David Robin Vaughan - Trustee

The Tuberos Sclerosis Association

Statement of Trustees Responsibilities
for the Year Ended 31 December 2016

The Trustees (who are also the Directors of The Tuberos 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 for the year ended 31 December 2016 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 Accounting and Reporting by Charities Statement of Recommended Practice in accordance with FRS 102 (effective January 2015).

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 section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006 (as amended). Our audit work has been undertaken so that we might state to the charitable company's members and its 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 and the charitable company's members as a body and its trustees as a body, for our audit work, for this report, or for the opinion we have formed.

Respective responsibilities of trustees and auditor

As explained more fully in the Statement of Trustees Responsibilities set out on page 9, 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.

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 responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatements, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Report of the Trustees to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

Opinion on financial statements

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 2016 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).

Opinion on other matter prescribed by the Companies Act 2006

In our opinion, 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.

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

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you, if in our opinion:

- * the charitable company has not kept proper and adequate accounting records 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 take advantage of the small companies exemption from the requirement to prepare a Strategic Report.



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

Date:16/8/17.....

The Tuberos Sclerosis Association

Statement of Financial Activities
(Incorporating an Income and Expenditure Account)
for the Year Ended 31 December 2016

	Note	Unrestricted funds £	Restricted funds £	2016 Total funds £	2015 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	248,647	-	248,647	911,543
Charitable activities	5				
Family care & support		10,123	-	10,123	-
Research		-	-	-	115,461
Education		-	23,754	23,754	31,629
Other trading activities	3	7,246	-	7,246	6,243
Investment income	4	<u>128,708</u>	-	<u>128,708</u>	<u>111,188</u>
Total		394,724	23,754	418,478	1,176,064
EXPENDITURE ON					
Raising funds	6	138,493	2,445	140,938	115,258
Charitable activities	7				
Family care & support		219,280	5,683	224,963	230,445
Research		501,031	4,483	505,514	611,326
Promoting awareness		84,973	27,333	112,306	67,048
Education		<u>71,459</u>	<u>12,899</u>	<u>84,358</u>	<u>65,215</u>
Total		1,015,236	52,843	1,068,079	1,089,292
Net gains/(losses) on investments		<u>490,334</u>	-	<u>490,334</u>	<u>(59,860)</u>
NET INCOME/(EXPENDITURE)		(130,178)	(29,089)	(159,267)	26,912
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>2,980,568</u>	<u>40,751</u>	<u>3,021,319</u>	<u>2,994,407</u>
TOTAL FUNDS CARRIED FORWARD		<u>2,850,390</u>	<u>11,662</u>	<u>2,862,052</u>	<u>3,021,319</u>

CONTINUING OPERATIONS

Under the Companies Act, the Charity made a deficit of **£490,826** (2015 - surplus **£99,847**) being the reported deficit of **£159,267** (31 December 2015 - surplus **£26,912**) adjusted for the unrealised surplus of **£331,559** (2015 - deficit **£72,935**).

The notes form part of these financial statements

The Tuberos Sclerosis Association (Registered number: 02900107)

Balance Sheet
At 31 December 2016

	Note	2016 £	2015 £
FIXED ASSETS			
Intangible assets	15	5,218	9,142
Investments	16	<u>3,418,169</u>	<u>3,055,425</u>
		3,423,387	3,064,567
CURRENT ASSETS			
Debtors	17	37,798	27,457
Cash at bank and in hand		<u>140,750</u>	<u>715,370</u>
		178,548	742,827
CREDITORS			
Amounts falling due within one year	18	<u>(739,883)</u>	<u>(786,075)</u>
NET CURRENT ASSETS/(LIABILITIES)		<u>(561,335)</u>	<u>(43,248)</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>2,862,052</u>	<u>3,021,319</u>
NET ASSETS		<u>2,862,052</u>	<u>3,021,319</u>
FUNDS	20		
Unrestricted funds:			
Endowment Fund		2,279,475	2,330,068
Ann Hunt Research Fellowship		-	18,000
Kilmaine Family Research Fellowship		<u>570,914</u>	<u>632,500</u>
		2,850,389	2,980,568
Restricted funds:			
Jane Medcalf Memorial		1,756	2,956
Family Care and Support		6,166	6,166
Education		<u>3,741</u>	<u>31,629</u>
		<u>11,663</u>	<u>40,751</u>
TOTAL FUNDS		<u>2,862,052</u>	<u>3,021,319</u>

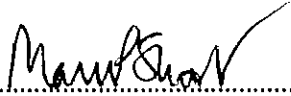
The notes form part of these financial statements

Balance Sheet - continued

At 31 December 2016

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

The financial statements were approved and authorised for issue by the Board of Trustees and were signed on its behalf on 2 August 2017 by:



.....
Martin Peter Short -Trustee

The Tuberous Sclerosis Association

Notes to the Financial Statements
for the Year Ended 31 December 2016

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

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

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.

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

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**

	2016	2015
	£	£
Donations and subscriptions	247,647	861,543
Legacies	<u>1,000</u>	<u>50,000</u>
	<u>248,647</u>	<u>911,543</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

3. OTHER TRADING ACTIVITIES

	2016	2015
	£	£
Christmas card & other miscellaneous sales	1,297	6,243
Other activities	<u>5,949</u>	<u>-</u>
	<u>7,246</u>	<u>6,243</u>

4. INVESTMENT INCOME

	2016	2015
	£	£
Bank interest	653	666
Income from managed portfolio	<u>128,055</u>	<u>110,522</u>
	<u>128,708</u>	<u>111,188</u>

5. INCOME FROM CHARITABLE ACTIVITIES

	Activity	2016	2015
		£	£
Family days and weekends	Family care & support	10,123	-
Research conferences	Research	-	115,461
Grants received - Novartis Pharmaceuticals UK Limited	Education	<u>23,754</u>	<u>31,629</u>
		<u>33,877</u>	<u>147,090</u>

6. RAISING FUNDS

Raising donations and legacies

	2016	2015
	£	£
Staff costs	73,108	49,010
Sundries	9,899	6,577
Travel, communications and other costs	11,916	9,524
Recruitment costs	(111)	2,906
Staff training	1,653	3,806
Support costs	<u>19,478</u>	<u>17,316</u>
	<u>115,943</u>	<u>89,139</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

6. RAISING FUNDS - continued

Other trading activities

	2016	2015
	£	£
Purchases	<u>2,405</u>	<u>1,532</u>

Investment management costs

	2016	2015
	£	£
Portfolio management	<u>22,590</u>	<u>24,587</u>

Aggregate amounts	<u>140,938</u>	<u>115,258</u>
-------------------	----------------	----------------

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	189,256	-	35,707	224,963
Research	35,747	434,059	35,708	505,514
Promoting awareness	76,598	-	35,708	112,306
Education	<u>48,650</u>	-	<u>35,708</u>	<u>84,358</u>
	<u>350,251</u>	<u>434,059</u>	<u>142,831</u>	<u>927,141</u>

8. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2016	2015
	£	£
Staff costs	249,601	221,670
Research	-	101,991
Travel, communications and other costs	32,441	27,961
Study days	8,415	-
Publications	15,746	33,417
Benevolent grants	9,084	5,169
Family days and weekends	11,066	8,798
Sundries	<u>23,898</u>	-
	<u>350,251</u>	<u>399,006</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

9. GRANTS PAYABLE

	2016	2015
	£	£
Family care & support	-	11,188
Research	<u>434,059</u>	<u>436,851</u>
	<u>434,059</u>	<u>448,039</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

9. **GRANTS PAYABLE - continued**

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

	2016	2015
	£	£
* 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	25,754	-
* Institute of Psychiatry, Kings College, London - Autism Spectrum & ADHD in the TSC 2000 Cohort Study	-	26,667
* Institute of Cancer & Genetics, Cardiff - Investigating mTORC1 independent functions of TSC2	-	62,777
* Institute of Cancer & Genetics, Cardiff - Prevention of renal lesions by fine tuning mTOR signalling in a mouse model of tuberous sclerosis	-	58,935
* Addenbrooke's Hospital - TSC Psychology	-	11,188
* Department of Neuroscience, Erasmus Medical Centre, Netherlands - Towards a better understanding and better treatment of TSC-related epilepsy	49,289	48,093
* Centre for Integrative Physiology, University of Edinburgh - Targeting the mGluR5-FMRP signalling pathway for the treatment of TSC	53,410	51,289
* Division of Child & Adolescent Psychiatry, University of Cape Town - PhD Studentship; Understanding and Treating TSC-Associated Neuropsychiatric Disorders (TAND)	18,000	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	22,000
* School of Psychology, University of Birmingham - Junior fellowship: Delineating impulsive behaviour in Tuberous Sclerosis Complex	1,400	25,666
* School of Psychology, University of Birmingham - PhD Studentship: Problem behaviours in Tuberous Sclerosis Complex	11,338	11,338
* Institute of Psychiatry, Kings College London - Designing a protocol to measure the developmental trajectory of infants with Tuberous Sclerosis	61,586	59,923
* Cardiff University - New drug therapies to kill Tsc2-deficient cell lines	19,407	19,204
* University College London - The TSC1 and TSC2 variation Databases	34,616	32,959
* University of Manchester - Exploiting Notch regulation to probe alternative mechanisms of TSC signalling.	60,775	-
* University of Nottingham - Inflammatory cell recruitment into LAM nodules drives tissue destruction TSC lung disease: opportunities for drug repurposing	53,689	-
* Department 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.	<u>22,795</u>	-
	<u>434,059</u>	<u>448,039</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

9. GRANTS PAYABLE - continued

Grants awarded prior to 1 April 2013 are of three or four years' duration and are charged against designated or restricted funds in full when awarded. Grants awarded after 31 March 2013 are on an annual basis and are only renewed after an annual review. In accordance with the SORP, only the first year of the grant is charged against the relevant fund up to the committed amount of the grant.

10. SUPPORT COSTS

	Management	Finance	Other	Governance costs	Totals
	£	£	£	£	£
Raising donations and legacies	7,404	816	8,509	2,749	19,478
Family care & support	13,574	1,491	15,604	5,038	35,707
Research	13,575	1,491	15,604	5,038	35,708
Promoting awareness	13,575	1,491	15,604	5,038	35,708
Education	<u>13,575</u>	<u>1,491</u>	<u>15,604</u>	<u>5,038</u>	<u>35,708</u>
	<u>61,703</u>	<u>6,780</u>	<u>70,925</u>	<u>22,901</u>	<u>162,309</u>

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

Support costs have been allocated between 'Raising 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 SORP 2015.

11. NET INCOME/(EXPENDITURE)

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

	2016	2015
	£	£
Auditors' remuneration	6,600	6,600
Database costs amortisation	<u>3,924</u>	<u>3,924</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

12. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2016 nor for the year ended 31 December 2015.

Trustees' expenses

	2016	2015
	£	£
Trustees' expenses	<u>4,300</u>	<u>5,178</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. Fourteen (2015 - Nine) Trustees received payments for reimbursement of expenses during the year/ period.

13. STAFF COSTS

	2016	2015
	£	£
Wages and salaries	354,849	285,710
Social security costs	28,086	23,907
Other pension costs	<u>13,233</u>	<u>30,000</u>
	<u>396,168</u>	<u>339,617</u>

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

	2016	2015
Raising finance	3	2
Promoting awareness	2	1
Family care and support	6	6
Support - general	4	2
Research	<u>1</u>	<u>1</u>
	<u>16</u>	<u>12</u>

No employees received emoluments in excess of £60,000 (31 December 2015 - none).

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

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

14. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	873,143	38,400	911,543
Charitable activities			
Research	115,461	-	115,461
Education	-	31,629	31,629
Other trading activities	6,243	-	6,243
Investment income	<u>111,188</u>	<u>-</u>	<u>111,188</u>
Total	1,106,035	70,029	1,176,064
EXPENDITURE ON			
Raising funds	115,258	-	115,258
Charitable activities			
Family care & support	220,411	10,034	230,445
Research	572,861	38,465	611,326
Promoting awareness	67,048	-	67,048
Education	<u>65,215</u>	<u>-</u>	<u>65,215</u>
Total	1,040,793	48,499	1,089,292
Net gains/(losses) on investments	<u>(59,860)</u>	<u>-</u>	<u>(59,860)</u>
NET INCOME/(EXPENDITURE)	5,382	21,530	26,912
RECONCILIATION OF FUNDS			
Total funds brought forward	<u>2,975,186</u>	<u>19,221</u>	<u>2,994,407</u>
TOTAL FUNDS CARRIED FORWARD	<u>2,980,568</u>	<u>40,751</u>	<u>3,021,319</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

15. INTANGIBLE FIXED ASSETS

	Database costs £
COST	
At 1 January 2016	<u>19,624</u>
AMORTISATION	
At 1 January 2016	10,482
Charge for year	<u>3,924</u>
At 31 December 2016	<u>14,406</u>
NET BOOK VALUE	
At 31 December 2016	<u>5,218</u>
At 31 December 2015	<u>9,142</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

16. FIXED ASSET INVESTMENTS

	2016	2015
	£	£
Shares	3,361,249	3,039,015
Cash held by investment manager for reinvestment	<u>56,920</u>	<u>16,410</u>
	<u>3,418,169</u>	<u>3,055,425</u>

Additional information as follows:

	Quoted shares and unit trusts £
MARKET VALUE	
At 1 January 2016	3,039,015
Additions	348,962
Disposals	(517,062)
Revaluations	<u>490,334</u>
At 31 December 2016	<u>3,361,249</u>
NET BOOK VALUE	
At 31 December 2016	<u>3,361,249</u>
At 31 December 2015	<u>3,039,015</u>

The gains on investment assets of £490,334 (2015 - losses £59,860) are made up of realised gains of £158,775 (2015 - £13,075) and unrealised gains of £331,559 (2015 - losses £72,935).

Investments held in companies outside the UK amounted to £1,187,459 (2015 - £1,117,477).

Investments (neither listed nor unlisted) were as follows:

	2016	2015
	£	£
Brewin Dolphin capital account	<u>56,920</u>	<u>16,410</u>

The capital account represents un-invested cash held by the broker.

	2016	2015
	£	£
The historical cost of the investments at the year end is:	<u>2,052,225</u>	<u>2,036,009</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

17. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2016	2015
	£	£
Other debtors	<u>37,798</u>	<u>27,457</u>

18. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2016	2015
	£	£
Social security and other taxes	8,040	7,425
Grants awarded	650,614	639,580
Pension fund	-	34,787
Accrued expenses	<u>81,229</u>	<u>104,283</u>
	<u>739,883</u>	<u>786,075</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 2016

CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR (continued)

	At 1/1/16	SOFA	Paid	At 31/12/16
	£	£	£	£
* 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	7,580	25,754	(21,284)	12,050
* University College London	11,443	-	(11,443)	-
* Institute of Medical Genetics, Cardiff	92,304	-	(66,483)	25,821
* Institute of Medical Genetics, Cardiff	104,764	-	(57,043)	47,721
* Institute of Medical Genetics, Cardiff	19,157	-	(7,526)	11,631
* Addenbrooke's Hospital, Cambridge	13,053	-	-	13,053
* Department of Neuroscience, Erasmus Medical Centre, Netherlands	67,645	49,289	(48,293)	68,641
* Centre for Integrative Physiology, University of Edinburgh	78,333	53,410	(48,042)	83,701
* Division of Child & Adolescent Psychiatry, University of Cape Town, South Africa	18,000	18,000	(18,000)	18,000
* Institute of Medical Genetics, Cardiff	31,461	22,000	(21,611)	31,850
School of Psychology, University of Birmingham	32,483	1,400	(25,966)	7,917
* School of Psychology, University of Birmingham	14,172	11,338	(11,338)	14,172
* Institute of Psychiatry, Kings College, London	59,922	61,586	(59,922)	61,584
* Cardiff University	19,204	19,407	(18,787)	19,824
* Research Department of Genetics, University College, London	32,959	34,616	-	67,575
* University of Manchester, Faculty of Life Sciences	-	60,775	(3,635)	57,140
* University of Nottingham, Division of Respiratory Medicine	-	53,689	(3,650)	50,039
* Erasmus MC, Department of Clinical Genetics	-	22,795	-	22,795
	<u>639,580</u>	<u>434,059</u>	<u>(423,023)</u>	<u>650,614</u>

Analysis:

Falling due within one year 650,614

Falling due after more than one year (note 20) -

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

19. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted funds	Restricted funds	2016 Total funds	2015 Total funds
	£	£	£	£
Fixed assets	5,218	-	5,218	9,142
Investments	3,418,169	-	3,418,169	3,055,425
Current assets	166,885	11,663	178,548	742,827
Current liabilities	(739,883)	-	(739,883)	(786,075)
	<u>2,850,389</u>	<u>11,663</u>	<u>2,862,052</u>	<u>3,021,319</u>

20. MOVEMENT IN FUNDS

	At 1/1/16 £	Net movement in funds £	Transfers between funds £	At 31/12/16 £
Unrestricted funds				
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
	2,980,568	(130,179)	-	2,850,389
Restricted funds				
Jane Medcalf Memorial	2,956	(1,200)	-	1,756
Family Care and Support	6,166	-	-	6,166
Education	31,629	(27,888)	-	3,741
	40,751	(29,088)	-	11,663
TOTAL FUNDS	<u>3,021,319</u>	<u>(159,267)</u>	<u>-</u>	<u>2,862,052</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

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 £
Unrestricted funds				
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>
Restricted funds				
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>
TOTAL FUNDS	<u>418,478</u>	<u>(1,068,079)</u>	<u>490,334</u>	<u>(159,267)</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

During the year the Association received a significant donation from The Lady Kilmaine. The Trustees have 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 2016 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 in the main used to help fund the salaries of support workers.

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Year Ended 31 December 2016

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 £291,918 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 £14,195 (Year ended 31 December 2015 - £13,000) 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.