

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

The Tuberous Sclerosis Association
Report of the Trustees and
Financial Statements for the Period 1 April 2014 to 31 December 2014

The Tuberous Sclerosis Association
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for the Period 1 April 2014 to 31 December 2014

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The Tuberous Sclerosis Association

Report of the Trustees
for the Period 1 April 2014 to 31 December 2014

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 period ended 31 December 2014. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in March 2005 (revised 2008).

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number
02900107 (England and Wales)

Registered Charity number
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 Chairman
David Robin Vaughan	Treasurer and Company Secretary

Martin J P Balfour-Allen

Janet Bower

Nicholas Peter Dale

Alexandra Campbell

- resigned 7/3/15

Thomas Edmund Carter

Ann Marie James

Perry James

John Christopher Kingswood

Jean Ellen Willson

Annie Margaret Jones

Sophie Christine Lording

Lisa Suchet

- appointed 7/3/15

Honorary Life Vice Presidents

Esther Galbraith

Ann Hunt MBE

- died 25/06/14

Thomas Edmund Carter

Anne Carter

Chief Executive

Jayne Spink

Auditors

BDO LLP

125 Colmore Row

Birmingham

B3 3SD

The Tuberous Sclerosis Association

Report of the Trustees
for the Period 1 April 2014 to 31 December 2014

REFERENCE AND ADMINISTRATIVE DETAILS

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

STRUCTURE, GOVERNANCE AND MANAGEMENT

Constitution

The Association was incorporated under the Companies Act 1985 as a company limited by guarantee, registered in England, No 2900107, 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).

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 Trustees meet for Board meetings 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 President, the Chair, the Deputy Chair, the Treasurer 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;

The Tuberous Sclerosis Association

Report of the Trustees for the Period 1 April 2014 to 31 December 2014

STRUCTURE, GOVERNANCE AND MANAGEMENT

Risk management (continued)

The Research Committee (RESCOM) is an advisory committee to the Association's Board that is made up of a minimum of 5 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;
- Supporting the planning and delivery of national and international research conferences.

The Trustees

A list of the Officers and other Trustees who served for all or part of the period, or who have been appointed before the date of this report, appears on page 1.

At each Annual General Meeting, one-third of the Trustees retire by choice or rotation. The following three Trustees retire by rotation, and will be proposed for re-election at the 2015 AGM: Christine Ann Naylor, John Christopher Kingswood and Martin Peter Short. Janet Bower and Perry James also retire by rotation but do not seek re-election; the Board is grateful for their service.

There are policies for the induction and training of Trustees.

This year we adopted a new trustee induction and performance review process.

OBJECTIVES AND ACTIVITIES

Objectives and aims

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.

We moved the end of the financial year to 31 December (thereafter to match our accounting periods to the calendar year) in order to simplify our accounting and reporting. We abolished our membership subscription fee to enable all people affected by TSC to fully engage with the TSA, regardless of their financial means. Towards the end of the year we launched a consultation amongst our membership on our newly developed 5-year strategy for implementation from 2015 to 2020.

All key decisions are made by the Trustee Board (or, within appropriate delegated authorities, its Committees). The Association maintains serviced offices as shown above, but most of its employees work from home.

The Tuberous Sclerosis Association

Report of the Trustees
for the Period 1 April 2014 to 31 December 2014

OBJECTIVES AND ACTIVITIES

Objectives and aims (continued)

The benefits of our activities are briefly summarised below and relate directly to our objectives.

Support

Supporting families and individuals is core to our objectives. This year, the TSA provided direct support to around 50 families each month, around a third of whom were previously unknown to the charity. This has included supporting members with access to healthcare and treatment, as well as helping them to solve problems in relating to access to educational support, welfare and social care. We made £2,475 in grants to 11 families through our Support Fund and awarded £900 from the Janet Medcalf Memorial Fund.

In November 2014 we welcomed our members to our family conference in Birmingham. The conference included workshop sessions on volunteering, campaigning and research as well as on coping and caring, exploring support for school age children and dealing with the psycho-social aspects of living with TSC. Exhibitors were on hand to provide information in relation to a range of issues, including establishing trust funds for non-independent adults with TSC and on understanding and accessing welfare entitlements. Our annual Scottish get together took place in October 2014 and support group meetings have taken place for the first time in Northern Ireland and Wales. We have published 3 issues of our membership magazine SCAN, making this available in hard copy and online as well as three quarterly editions of our Scottish Newsletter.

Influencing Policy

We responded to all relevant consultations, including the Wales, Scotland and Northern Ireland Rare Disease Strategy Implementation Plans, in order to ensure that we consistently promote the interests of the TSC community in policy development, highlighting our issues and presenting potential solutions. In Wales we successfully petitioned the Welsh Government, securing a debate on the issue of access to medicines and the problems with individual funding requests. We have contributed to a range of external and collaborative initiatives that have kept TSC at the heart of the rare diseases / healthcare debate.

With the aim of vastly improving access to evidence-based care, we supported the clinical community in drafting and submitting policies to NHS England for access to the medicine Everolimus. Alongside this we implemented a public affairs and campaigning strategy as a result of which two extremely important gains have been made: Firstly NHSE published a policy on urgent and critical need which means that patients who cannot wait for a national policy to be developed should now get NHS Funding. Secondly, NHSE confirmed the accelerated development of national policies for the prescribing of Everolimus; if agreed, funding will be made available immediately.

The Tuberous Sclerosis Association

Report of the Trustees

for the Period 1 April 2014 to 31 December 2014

OBJECTIVES AND ACTIVITIES

Information and awareness

In addition to participating in and promoting international awareness week activities in May, we ran our awareness and fundraising campaign "Tea and Scones for TSC". This year we recruited bloggers to publicise awareness week, reaching new audiences at zero cost, added a social media and digital awareness campaign and sent out a specific e-newsletter.

Social media is becoming an increasingly popular way through which our beneficiaries engage with the charity. Not everyone can travel to our local or national events and for this reason we hosted our first live Q&A session with TSC researchers on Facebook and Twitter. We also produced our first campaign video highlighting the lack of funding for TSC treatment in the NHS, reaching an audience in excess of 14,000 viewers. We secured a grant for video equipment and training in response to community engagement with digital media, and worked with award winning PR firm 3 Monkeys Communications to maximise our social media reach.

Volunteering

We have further developed our volunteering programme, including recruiting volunteers with specific talents and expertise to help raise awareness and better deliver against our objectives. By the end of the reporting year 10 viable volunteer-led local support groups had been established working with volunteers from across the TSC community. In May 2014 we provided access to self-directed support training for volunteers in Scotland.

Research

Our research programme has grown considerably. This year the TSA independently made 5 research awards and co-funded a further PhD studentship with the Cerebra Centre for Neurodevelopmental Disorders in Birmingham bringing the total number of ongoing awards to 14. We have continued to support volunteer expenses for the TRON clinical trial in Cardiff, enabling participants from across the UK to take part.

We are helping to lead the search for a cure for TSC at the international level by co-facilitating the TSCure research programme with our international partners and have agreement with our sister organisation in the USA (Tuberous Sclerosis Alliance) to co-host the TSC International Research Conference in the UK in September 2015.

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 period ended 31 December 2014, the total annualised return on the portfolio was 4.04% as against the benchmark of 6.3%. Over the longer term, our investment managers have consistently out-performed the benchmark and performance continues to be kept under review. Those Trustees who are members of the 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.

The Tuberous Sclerosis Association

Report of the Trustees for the Period 1 April 2014 to 31 December 2014

FINANCIAL REVIEW

Statement on reserves

The Association's reserves largely comprise a Designated Capital Fund, arising from a bequest in 1993 by the late Mr H I Leech, and consisting of an investment portfolio managed as above. The Trustees have resolved to use the income from this Designated Capital Fund to further the work of the Association, and in particular to enable the Association to provide a support service for TSA families; and they have accordingly decided over the longer term to maintain its capital so far as possible, as to expend that capital would adversely affect this key aspect of the Association's work. However, in the current economic climate, they are prepared to deploy some reserves to maintain services through a period where income targets are inevitably more difficult to achieve.

Since 1 April 2005, the Trustees have also used this Designated Capital Fund as a 'buffer' for the provisions, required under SORP 2005, for research grant commitments. Due to a change in the terms and conditions of grants awarded from April 2013 (see notes 10 and 20 of the financial statements) the Association no longer requires this 'buffer' as each grant is awarded on an annual basis and extension of the grant is subject to a satisfactory review. When the grant payments are made, they are allocated to designated or restricted reserves as appropriate. The effect of this is shown in Notes 10, 20, 21 and 22 to the Financial Statements.

The balance on the Designated Capital Fund at 31 December 2014 amounted to £2.98m (31 March 2014 : £3.35m). Restricted reserves were £19.2k (31 March 2014 - £5.7k) - see note 22. Our policy is to hold no unrestricted reserves other than the Designated Capital Fund and therefore the deficit on the general fund has been made up from transfers from the designated reserve. Future deficits (and grant commitments) will be funded from this designated reserve. The Trustees consider that this reserve is adequate to meet these obligations.

The Association's total income for the nine month period was £356,114, compared with £405,027 in the previous twelve months.

Our total investment gains were £26k (31 March 2014 - £96k). To fund deficits and payments relating to research commitments entered into during the year, some investments needed to be sold to provide the charity with additional working capital. Transfers of £100,000 were made from the investment portfolio to the main bank account prior to the balance sheet date, and an additional £350,000 (included in "current asset investments") was transferred a few days after the year end.

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 a group of Trustees and grants awarded on a basis of confidentiality, where deemed appropriate, based on the Association's guidelines. Trustees are eligible to apply for such grants and are dealt with in the same way as any other applicant.

The Tuberous Sclerosis Association

Report of the Trustees
for the Period 1 April 2014 to 31 December 2014

STATEMENT AS TO DISCLOSURE OF INFORMATION TO AUDITORS

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

- So far as the Trustees are aware, there is no relevant information of which the Association's auditor 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 information needed by the Association's auditor in connection with preparing its report and to establish that the Association's auditor is aware of that information.

The charitable company is exempt from the requirement to prepare a strategic report, due to the fact that it qualifies as a small charitable company.

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 and in accordance with the Statement of Recommended Practice - Accounting and reporting by Charities 2005 (revised 2008).

This report was approved by the Board of Trustees on 10 August 2015 and agreed on its behalf by:



.....
David Robin Vaughan - Trustee

The Tuberous Sclerosis Association

Statement of Trustees Responsibilities
for the Period 1 April 2014 to 31 December 2014

The Trustees are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and regulations.

Company law requires the Trustees to prepare financial statements for each financial year in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under Company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period.

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

- select suitable accounting policies and then apply them consistently;
- make judgements and accounting estimates that are reasonable and prudent;
- state whether applicable UK 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 charity will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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

**INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES AND MEMBERS OF THE
TUBEROUS SCLEROSIS ASSOCIATION**

We have audited the financial statements of The Tuberous Sclerosis Association for the period ended 31 December 2014 which comprise Statement of Financial Activities (incorporating the Income and Expenditure Account), the Balance Sheet, and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the charity's trustees and members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the charity's trustees and members 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 charity and the charity's trustees and members as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of trustees and auditor

As explained more fully in the Statement of Trustees' Responsibilities, 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 Financial Reporting Council's (FRC's) Ethical Standards for Auditors.

Scope of the audit of the financial statements

A description of the scope of an audit of financial statements is provided on the FRC's website at www.frc.org.uk/auditscopeukprivate.

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 2014 and of its incoming resources and application of resources, including its income and expenditure, for the period then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; 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 Trustees' Annual Report for the financial period for which the financial statements are prepared is consistent with the financial statements.

Report of the Independent Auditors to the Members of
The Tuberous 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, take advantage of the small companies exemption in preparing the directors' report or the exemption from the requirements to prepare a strategic report.

BDO LLP

Tobias Stephenson (Senior Statutory Auditor)
for and on behalf of BDO LLP, Statutory Auditor
Birmingham
United Kingdom
Date:

BDO LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

BDO LLP is a limited liability partnership registered in England and Wales (with registered number OC305127).

Date: 11 August 2015

The Tuberos Sclerosis Association

Statement of Financial Activities
(Incorporating an Income and Expenditure Account)
for the Period 1 April 2014 to 31 December 2014

	Notes	Unrestricted funds £	Restricted funds £	PERIOD 1/4/14 TO 31/12/14 Total funds £	YEAR ENDED 31/3/14 Total funds £
INCOMING RESOURCES					
Incoming resources from generated funds					
Voluntary income	2	207,316	36,847	244,163	289,782
Activities for generating funds	3	2,180	-	2,180	3,873
Investment income	4	90,031	-	90,031	111,372
Incoming resources from charitable activities					
Education	5	-	19,740	19,740	-
Total incoming resources		299,527	56,587	356,114	405,027
RESOURCES EXPENDED					
Costs of generating funds					
Costs of generating voluntary income	6	54,111	-	54,111	79,708
Fundraising trading: cost of goods sold and other costs	7	3,063	-	3,063	5,189
Investment management costs		18,980	-	18,980	15,590
Charitable activities					
Family care & support	8	119,248	3,375	122,623	156,845
Research		379,647	19,962	399,609	321,524
Promoting awareness		49,478	-	49,478	91,721
Education		56,447	19,740	76,187	80,891
Governance costs	12	20,759	-	20,759	28,942
Total resources expended		701,733	43,077	744,810	780,410
NET INCOMING/(OUTGOING) RESOURCES					
		(402,206)	13,510	(388,696)	(375,383)
Other recognised gains/losses					
Gains/losses on investment assets		26,558	-	26,558	96,338
Net movement in funds – carried forward to page 12		(375,648)	13,510	(362,138)	(279,045)

The notes form part of these financial statements

The Tuberos Sclerosis Association

Statement of Financial Activities - continued
(Incorporating an Income and Expenditure Account)
for the Period 1 April 2014 to 31 December 2014

	Notes	Unrestricted funds	Restricted funds	PERIOD 1/4/14 TO 31/12/14 Total funds £	YEAR ENDED 31/3/14 Total funds £
RECONCILIATION OF FUNDS					
Net movement in funds – brought forward from page 11		(375,648)	13,510	(362,138)	(279,045)
Total funds brought forward		3,350,834	5,711	3,356,545	3,635,590
TOTAL FUNDS CARRIED FORWARD		<u>2,975,186</u>	<u>19,221</u>	<u>2,994,407</u>	<u>3,356,545</u>

CONTINUING OPERATIONS

All incoming resources and resources expended arise from continuing activities.

Under the Companies Act, the Charity made a deficit of £354,075 (31 March 2014 - £236,351) being the reported deficit of £362,138 (31 March 2014 - deficit of £279,045) adjusted for the unrealised deficit of £8,063 (2014 - deficit of £42,694).

The notes form part of these financial statements

The Tuberos Sclerosis Association

Balance Sheet
At 31 December 2014

	Notes	31/12/14 £	31/3/14 £
FIXED ASSETS			
Intangible assets	16	11,074	12,528
Investments	17	<u>3,138,073</u>	<u>3,580,255</u>
		3,149,147	3,592,783
CURRENT ASSETS			
Debtors	18	25,591	19,468
Investments	19	350,000	-
Cash at bank and in hand		<u>69,772</u>	<u>120,425</u>
		445,363	139,893
CREDITORS			
Amounts falling due within one year	20	<u>(600,103)</u>	<u>(376,131)</u>
NET CURRENT ASSETS/(LIABILITIES)			
		<u>(154,740)</u>	<u>(236,238)</u>
TOTAL ASSETS LESS CURRENT LIABILITIES			
		<u>2,994,407</u>	<u>3,356,545</u>
NET ASSETS			
		<u>2,994,407</u>	<u>3,356,545</u>
FUNDS			
Unrestricted funds:	22		
Designated Capital Fund		2,975,186	3,350,834
Restricted funds:			
Restricted Funds		<u>19,221</u>	<u>5,711</u>
TOTAL FUNDS			
		<u>2,994,407</u>	<u>3,356,545</u>

The notes form part of these financial statements

The Tuberous Sclerosis Association

Balance Sheet - continued

At 31 December 2014

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 on 10 August 2015 and were signed on its behalf by:



.....
Martin Peter Short -Trustee

The notes form part of these financial statements

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

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 fund.

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. **VOLUNTARY INCOME**

	PERIOD 1/4/14 TO 31/12/14 £	YEAR ENDED 31/3/14 £
Donations and subscriptions	214,916	250,108
Legacies	<u>29,247</u>	<u>39,674</u>
	<u>244,163</u>	<u>289,782</u>

3. **ACTIVITIES FOR GENERATING FUNDS**

	PERIOD 1/4/14 TO 31/12/14 £	YEAR ENDED 31/3/14 £
Christmas card sales	<u>2,180</u>	<u>3,873</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements
for the Period 1 April 2014 to 31 December 2014

1. ACCOUNTING POLICIES

Accounting convention

The financial statements have been prepared under the historical cost convention, as modified by the revaluation of investments which are included at market value, the Companies Act 2006 and the requirements of the Statement of Recommended Practice, Accounting and Reporting by Charities issued in 2005 (revised 2008), and applicable accounting standards.

Financial reporting standard number 1

Exemption has been taken from preparing a cash flow statement on the grounds that the charitable company qualifies as a small charitable company.

Incoming resources

All incoming resources are included on the Statement of Financial Activities when the charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. It is reported gross of related expenditure.

Resources expended

Expenditure is recognised on an accruals basis as and when it is incurred, and is reported gross of related income. Direct costs are allocated to the appropriate category of activity. Staff costs and their related expenditure are allocated to the activities in which they are engaged on an individual basis. Governance costs comprise those associated with the constitutional and statutory requirements of the charity. Support costs including central financial control and accounting, are apportioned between other activities on the basis of estimated usage.

Research grant expenditure is accounted for in the first instance by reference to amounts claimed or accrued in respect of costs incurred up to the balance sheet date. Further provision is made for future costs to be incurred up to the total amount of the grant approved and committed in each case.

Equipment costing less than £1,000 is written off through the Statement of Financial Activities. 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. As a result the Statement of Financial Activities includes unrealised gains and losses arising from the revaluation of the investment portfolio throughout the period.

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 Period 1 April 2014 to 31 December 2014

4. INVESTMENT INCOME

	PERIOD 1/4/14 TO 31/12/14 £	YEAR ENDED 31/3/14 £
Bank interest	90	131
Income from managed portfolio	<u>89,941</u>	<u>111,241</u>
	<u>90,031</u>	<u>111,372</u>

5. INCOMING RESOURCES FROM CHARITABLE ACTIVITIES

	Activity	PERIOD 1/4/14 TO 31/12/14 £	YEAR ENDED 31/3/14 £
Grants received - Novartis Phamaceuticals UK Limited	Education	<u>19,740</u>	-

6. COSTS OF GENERATING VOLUNTARY INCOME

	PERIOD 1/4/14 TO 31/12/14 £	YEAR ENDED 31/3/14 £
Direct staff costs	34,444	49,361
Sundries	4,319	4,302
Travel, communications and other costs	9,263	17,433
Support costs	<u>6,085</u>	<u>8,612</u>
	<u>54,111</u>	<u>79,708</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

7. FUNDRAISING TRADING: COST OF GOODS SOLD AND OTHER COSTS

	PERIOD 1/4/14 TO 31/12/14 £	YEAR ENDED 31/3/14 £
Christmas card sales	2,007	3,793
Support costs	<u>1,056</u>	<u>1,396</u>
	<u>3,063</u>	<u>5,189</u>

8. CHARITABLE ACTIVITIES COSTS

	Direct costs (See note 9) £	Grant funding of activities (See note 10) £	Support costs (See note 11) £	Totals £
Family care & support	95,373	11,188	16,062	122,623
Research	25,534	358,013	16,062	399,609
Promoting awareness	33,416	-	16,062	49,478
Education	<u>59,859</u>	<u>-</u>	<u>16,328</u>	<u>76,187</u>
	<u>214,182</u>	<u>369,201</u>	<u>64,514</u>	<u>647,897</u>

9. DIRECT COSTS OF CHARITABLE ACTIVITIES

	PERIOD 1/4/14 TO 31/12/14 £	YEAR ENDED 31/3/14 £
Staff costs	123,641	155,712
Research	650	184
Travel, communications and other costs	28,085	40,374
Study days	21,534	26,839
Publications	32,693	38,192
Benevolent grants	4,175	3,033
Family days and weekends	<u>3,404</u>	<u>1,155</u>
	<u>214,182</u>	<u>265,489</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

10. GRANTS PAYABLE

	PERIOD	YEAR
	1/4/14	ENDED
	TO	31/3/14
	31/12/14	31/3/14
	£	£
Family care & support	11,188	11,188
Research	<u>358,013</u>	<u>283,114</u>
	<u>369,201</u>	<u>294,302</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

10. GRANTS PAYABLE - continued

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

	PERIOD	YEAR
	1/4/14	ENDED
	TO	31/3/14
	31/12/14	31/3/14
	£	£
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	-	40,000
Institute of Psychiatry, Kings College, London - Autism Spectrum & ADHD in the TSC 2000 Cohort Study	26,667	26,667
University College London - TSC1 and TSC2 variation databases	44,356	44,356
Institute of Cancer & Genetics, Cardiff - Investigating mTORC1 independent functions of TSC2	53,251	53,251
Institute of Cancer & Genetics, Cardiff - Prevention of renal lesions by fine tuning mTOR signaling in a mouse model of tuberous sclerosis	58,935	58,935
Institute of Cancer & Genetics, Cardiff - Restoring TSC pathology through autophagy induction and mTORC1	-	59,905
Addenbrooke's Hospital - TSC Psychology	11,188	11,188
Department of Neuroscience, Erasmus Medical Centre, Netherlands - Towards a better understanding and better treatment of TSC-related epilepsy	46,926	-
Centre for Integrative Physiology, University of Edinburgh - Targeting the mGluR5-FMRP signalling pathway for the treatment of TSC	49,272	-
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	27,268	-
School of Psychology, University of Birmingham - PhD Studentship: Problem behaviours in Tuberous Sclerosis Complex	11,338	-
	<u>369,201</u>	<u>294,302</u>

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.

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

11. SUPPORT COSTS

	Management	Finance	Admin	Totals
	£	£	£	£
Costs of generating voluntary income	3,409	287	2,389	6,085
Fundraising trading; cost of goods sold and other costs	974	82	-	1,056
Governance costs	7,302	615	-	7,917
Family care & support	9,249	778	6,035	16,062
Research	9,249	778	6,035	16,062
Promoting awareness	9,249	778	6,035	16,062
Education	<u>9,249</u>	<u>778</u>	<u>6,301</u>	<u>16,328</u>
	<u>48,681</u>	<u>4,096</u>	<u>26,795</u>	<u>79,572</u>

Activity	Basis of allocation
Management	See below
Finance	See below
Admin	See below

Support costs have been allocated between the Cost of Generating Voluntary Income, Fundraising trading, Governance Costs and the Activities of the Association on the basis of time spent by the staff members of the Association.

12. GOVERNANCE COSTS

	PERIOD	YEAR
	1/4/14	ENDED
	TO	31/3/14
	31/12/14	£
	£	£
Trustees' expenses	1,251	3,750
AGM and annual report costs	4,410	5,245
Auditors' remuneration	7,181	6,180
Support costs	<u>7,917</u>	<u>13,767</u>
	<u>20,759</u>	<u>28,942</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

13. NET INCOMING/(OUTGOING) RESOURCES

Net resources are stated after charging/(crediting):

	PERIOD 1/4/14 TO 31/12/14	YEAR ENDED 31/3/14
	£	£
Auditor's remuneration	7,181	6,180
Other operating leases	240	301
Database costs amortisation	<u>3,426</u>	<u>3,132</u>

14. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the period ended 31 December 2014 nor for the year ended 31 March 2014.

Trustees' expenses

	PERIOD 1/4/14 TO 31/12/14	YEAR ENDED 31/3/14
	£	£
Trustees' expenses	<u>1,251</u>	<u>3,750</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

15. DIRECT STAFF COSTS

	PERIOD 1/4/14 TO 31/12/14 £	YEAR ENDED 31/3/14 £
Wages and salaries	189,985	243,687
Social security costs	16,816	20,932
Other pension costs	-	2,706
	<u>206,801</u>	<u>267,325</u>

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

	PERIOD 1/4/14 TO 31/12/14	YEAR ENDED 31/3/14
Generating voluntary income	2	1
Promoting awareness	1	1
Family care and support	5	5
Support - general	2	2
Research	<u>1</u>	<u>1</u>
	<u>11</u>	<u>10</u>

No employees received emoluments in excess of £60,000 (31 March 2014 - none).

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

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

16. INTANGIBLE FIXED ASSETS

	Database costs £
COST	
At 1 April 2014	15,660
Additions	<u>1,972</u>
At 31 December 2014	<u>17,632</u>
 AMORTISATION	
At 1 April 2014	3,132
Charge for year	<u>3,426</u>
At 31 December 2014	<u>6,558</u>
 NET BOOK VALUE	
At 31 December 2014	<u>11,074</u>
At 31 March 2014	<u>12,528</u>

17. FIXED ASSET INVESTMENTS

	PERIOD	YEAR
	1/4/14	ENDED
	TO	31/3/14
	31/12/14	31/3/14
	£	£
Shares	3,126,181	3,532,243
Cash held by investment manager for reinvestment	<u>11,892</u>	<u>48,012</u>
	<u>3,138,073</u>	<u>3,580,255</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

17. FIXED ASSET INVESTMENTS - continued

	Quoted shares and unit trusts £
MARKET VALUE	
At 1 April 2014	3,532,243
Additions	187,492
Disposals	(585,491)
Revaluations	<u>(8,063)</u>
At 31 December 2014	<u>3,126,181</u>
NET BOOK VALUE	
At 31 December 2014	<u>3,126,181</u>
At 31 March 2014	<u>3,532,243</u>

The gains on investment assets of £26,558 are made up of realised gains of £34,621 and unrealised losses of £8,063.

Investments held in companies outside the UK amounted to £1,089,404 (2014 -£1,219,698).

	PERIOD 1/4/14 TO 31/12/14 £	YEAR ENDED 31/3/14 £
Brewin Dolphin capital account	<u>11,892</u>	<u>48,012</u>

The capital account represents uninvested cash held by the broker.

	31/12/14 £	31/3/14 £
The historical cost of the investments at the year end is:	<u>2,050,239</u>	<u>2,333,736</u>

18. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31/12/14 £	31/3/14 £
Other debtors	<u>25,591</u>	<u>19,468</u>

The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

19. CURRENT ASSET INVESTMENTS

	31/12/14	31/3/14
Cash held on deposit at Brokers	<u>350,000</u>	<u>-</u>

20. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31/12/14	31/3/14
	£	£
Social security and other taxes	6,822	6,230
Grants awarded	500,467	311,704
Pension fund	4,787	4,787
Accrued expenses	<u>88,027</u>	<u>53,410</u>
	<u>600,103</u>	<u>376,131</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 10.

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The Tuberous Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR (continued)

	At 1/4/14 £	SOFA £	Paid £	At 31/12/14 £
University of Birmingham	31,998	-	(25,032)	6,966
Brighton TS Registry	100	-	-	100
Institute of Psychiatry, Kings College London	21,311	26,667	(17,141)	30,837
Institute of Medical Genetics, Cardiff	30,660	-	(10,987)	19,673
University College London	44,356	44,356	(32,203)	56,509
Institute of Medical Genetics, Cardiff	53,251	53,251	(35,039)	71,463
Institute of Medical Genetics, Cardiff	58,935	58,935	(27,935)	89,935
Institute of Medical Genetics, Cardiff	59,905	-	(14,387)	45,518
Addenbrooke's Hospital, Cambridge	11,188	11,188	(17,714)	4,662
Department of Neuroscience, Erasmus Medical Centre, Netherlands	-	46,926	-	46,926
Centre for Integrative Physiology, University of Edinburgh	-	49,272	-	49,272
Division of Child & Adolescent Psychiatry, University of Cape Town, South Africa	-	18,000	-	18,000
Institute of Medical Genetics, Cardiff	-	22,000	-	22,000
School of Psychology, University of Birmingham	-	27,268	-	27,268
School of Psychology, University of Birmingham	-	11,338	-	11,338
	<u>311,704</u>	<u>369,201</u>	<u>(167,895)</u>	<u>500,467</u>

21. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted funds £	Restricted funds £	31/12/14 Total funds £	31/3/14 Total funds £
Fixed assets	11,074	-	11,074	12,528
Investments	3,138,073	-	3,138,073	3,580,255
Current assets	406,402	38,961	445,363	139,893
Current liabilities	<u>(580,363)</u>	<u>(19,740)</u>	<u>(600,103)</u>	<u>(376,131)</u>
	<u>2,975,186</u>	<u>19,221</u>	<u>2,994,407</u>	<u>3,356,545</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

22. MOVEMENT IN FUNDS

	At 1/4/14 £	Net movement in funds £	Transfers between funds £	At 31/12/14 £
Unrestricted funds				
General fund	-	(135,356)	135,356	-
Designated Capital Fund	<u>3,350,834</u>	<u>(240,292)</u>	<u>(135,356)</u>	<u>2,975,186</u>
	3,350,834	(375,648)	-	2,975,186
Restricted funds				
Restricted Funds	5,711	13,510	-	19,221
	<u>3,356,545</u>	<u>(362,138)</u>	<u>-</u>	<u>2,994,407</u>

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	209,586	(344,942)	-	(135,356)
Designated Capital Fund	<u>89,941</u>	<u>(356,791)</u>	<u>26,558</u>	<u>(240,292)</u>
	299,527	(701,733)	26,558	(375,648)
Restricted funds				
Restricted Funds	56,587	(43,077)	-	13,510
	<u>356,114</u>	<u>(744,810)</u>	<u>26,558</u>	<u>(362,138)</u>

The Tuberos Sclerosis Association

Notes to the Financial Statements - continued
for the Period 1 April 2014 to 31 December 2014

22. MOVEMENT IN FUNDS - continued

The following table shows an analysis of the movement of restricted funds:

	At 1/4/14 £	Income £	Expenditure £	Transfers £	At 31/12/14 £
Research	280	19,747	(19,962)	-	65
Jane Medcalf Memorial	5,056	-	(900)	-	4,156
Family care & support	375	17,100	(2,475)	-	15,000
Education	-	19,740	19,740	-	-
	<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
Total	5,711	56,587	(43,077)	-	19,221

The restricted funds relate to donations and grants, which were given to the Association for specific purposes. The restricted funds held at 31 December 2014 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. Three 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.

Transfers between funds

The designated capital fund consists of the unspent balance of the bequest received from the late Mr H I Leech in 1993. As the Association is dependent on the income arising from the investments provided by this bequest, the Trustees consider that this money constitutes the capital of the Association and so has set aside this money as a designated fund. During the period the gain on the investments and the fees payable to the investment managers have been accounted for through this fund, as have changes in provisions for future grant commitments. During the period, the fund has also used to meet the deficit arising on the general fund, in accordance with the Association's policy.

23. 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 £10,000 (Year ended 31 March 2014 - £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.

