Tuberous Sclerosis Association (TSA) Annual Report 2018

Treasurer's Report

Strategic Report

tsa
tuberous sclerosis
association

Financial Activities and Balance Sheet

Impact Report

The Tuberous Sclerosis Association
Treasurer's Report 2018

Strategic Report with Supplementary Information

The attached Strategic Report is reproduced in full from, and forms part of, the Report of the Trustees for the year ended 31 December 2018.

We have also attached the Statement of Financial Activities (SOFA) for the year ended 31 December 2018 and the Balance Sheet as at that date.

The Strategic Report (together with the SOFA and Balance Sheet) forms only part of the Association's Annual Report and Accounts. Members can obtain full copies of the Report and Accounts by emailing the Treasurer at: admin@tuberous-sclerosis.org. In addition, the full report and accounts will be available via the website (**www.tuberous-sclerosis.org**) or from the Charity Commission (**www.gov.uk/government/organisations/charity-commission**).

The auditors' report on the Annual Accounts was unqualified. As part of the unqualified report the auditors confirmed that the information given in the Report of the Trustees (incorporating the Strategic Report) for the financial year for which the financial statements are prepared is consistent with such financial statements.

On behalf of the Trustees

D R Vaughan, Treasurer
Tuberous Sclerosis Association

OBJECTIVES AND ACTIVITIES

Objectives and aims, including public benefit

The Trustees confirm that they have complied with their duty, under the Charities Act 2011, to have regard to the Charity Commission's published public benefit guidelines in determining the activities undertaken by the Association.

The Association has three main objectives:

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

In September 2018 the Trustees approved a new five-year strategy for 2019-2023. The strategy sets out a clear vision (a world where TSC and its effects are conquered), continues the charity's mission (to provide help for today and a cure for tomorrow), and states that we will:

- REACH more people - significantly increasing the number of people being supported by the TSA by 2023;
- Drive more REsArCH - stimulating at least the same amount of investment in TSC research during 2019-2023 as was invested by the TSA over the last five years;
- Balance the TSA's finances by 2021 - having invested in research in recent years, we need to rein in expenditure and grow our income so that the charity is sustainable in the long-term.

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

- Make a positive impact on the health and wellbeing of people living with TSC and their families and carer
- Lead research into tools, technologies and treatments which eliminate the effects of TSC
- Lead innovation in the integration of medical and social care services

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

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

Objectives and aims, including public benefit (continued)

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

- Effective teamwork by staff working together to achieve a shared vision
- High quality, integrated financial management
- Digital transformation and smart working to reach more people
- An enterprising approach to income generation to drive more research

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

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

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

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

Activities and performance in relation to 'Support'

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

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

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

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

Activities and performance in relation to 'Influencing policy'

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

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

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

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

Activities and performance in relation to 'Information & awareness'

We have formed successful alliances with other charities and worked with them on a range of activities and initiatives with the common aim to raise the profile and importance of rare disease with parliamentarians and policy makers. During 2018 we worked closely with colleagues from the Specialised Healthcare Commissioning Alliance (SHCA) and Genetic Alliance to raise awareness of the need for NHS England to listen to the views of patients and families when making decisions about treatments and services for people living with rare diseases.

Raising awareness of the TSA and our services has been key to reaching new families. The more professionals, opinion leaders, politicians, policy makers and the media know about TSC, the more likely we are to bring about positive change. During 2018 there were 14 articles about TSC in the national and local media, and TSC was featured four times on radio news programmes and twice on television news programmes.

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

- Working in partnership with the clinics, supporting patients and their families
- Providing support and information to the clinic in relation to education, social care and welfare
- Signposting patients with wider support needs to external agencies across social care, education and welfare
- Signposting to and facilitating engagement with the portfolio of TSA services

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

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

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

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

Activities and performance in relation to 'Research'

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

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

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

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

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

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

Activities and performance in relation to 'Investment policy'

The Trustees have appointed investment managers to manage the Association's investment portfolio under a discretionary investment mandate. Our investment objective is to maximise total returns over the longer term and to provide a stable level of income to be generated with a medium level of risk. The level of risk applies to the portfolio as a whole rather than to individual stocks. To measure the performance of the investment portfolio the Association has, in common with other charities, adopted the WM Total Charity benchmark. In the year ended 31 December 2018, the total return on the portfolio was -5.15% as against the benchmark of -4.47%. Over the longer term, our investment managers have consistently out-performed the benchmark. Their performance continues to be kept under review and those Trustees who are members of FINCOM have an annual review meeting with them. The Trustees have agreed a formal investment policy reflecting the investment objective stated above.

Activities and performance in relation to 'Volunteering'

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

FINANCIAL REVIEW

Grant making policy

Research grants are given for purposes directly concerned with furthering an understanding of Tuberous Sclerosis Complex and its treatment. The Association is a member of the Association of Medical Research Charities (AMRC) and follows AMRC policy in the conditions attached to awarding grants. All applications are peer reviewed before a decision is made.

Benevolent grants are given to families to purchase necessary medical or household equipment, or to provide parents, carers and families with much-needed breaks. All applications for assistance are reviewed by the Head of Support and Information Services and grants awarded where deemed appropriate on a basis of confidentiality, based on the Association's guidelines. Trustees are eligible to apply for such grants and are dealt with in the same way as any other applicant.

Statement on reserves & review of financial position

The Association's reserves largely arise from a bequest in 1993 by the late Mr H I Leech, which is held as an endowment invested in fixed assets. This endowment provides a resource which supports the Association in delivering its charitable objectives. In particular, it enables the Trustees:

- to fund or co-fund out of capital (and, if need be, at short notice) major medical research projects which are determined by the Trustees to be crucial for the treatment of TSC; and
- to fund, out of income from the capital, services to the TSC community where income raised by the Association's fund-raising activities is inadequate in any particular period.

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

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

Result for the year

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

Our total investment losses were £220k (2017 - gains 302k). To fund deficits and payments relating to research commitments entered into during the year, some investments needed to be sold to provide the Association with additional working capital.

Taking into account the investment loss, the overall deficit for the year was £871k (2017 - £283k).

FUTURE PLANS

The 2019 Business Plan was approved in November 2018. 2019 will be the first year of implementing the new five-year strategy 2019-2023. It will be a year of transition for the TSA resulting in significant changes to how we work internally, what we deliver for our beneficiaries, and who we work with externally. It will be exciting but also challenging for staff, trustees, beneficiaries and partners as we work through these changes.

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

Prioritising access to good quality, accessible and timely information

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

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

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

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

- We will develop and implement a new approach to driving investment in TSC research through joint working with partners and funders rather than using the TSA's own reserves
- We will seek to fund and establish a UK TSC Registry which will pull together information from patients who have TSC
- We will continue to fund our existing research commitments during this period

Campaigning for better access to treatments and care.

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

We will continue to run a deficit budget for 2019 and 2020, with a view to running a balanced budget from 2021 and on an ongoing basis from then onwards.

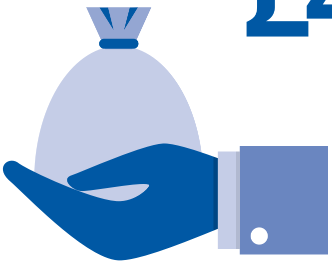
The Tuberous Sclerosis Association
Summary Statement of Financial Activities
For the year ended 31 December 2018

	Year ended 31/12/18 £	Year ended 31/12/17 £
INCOME AND ENDOWMENTS		
Donations and legacies	208,515	303,812
Charitable activities:		
Family Care & Support	2,690	7,236
Education	19,849	-
Other trading activities	8,235	5,960
Investment income	84,532	123,386
Total	323,821	440,394
EXPENDITURE		
Raising funds	153,301	160,784
Charitable activities:		
Family care & support	287,111	248,855
Research	386,875	411,210
Promoting awareness	92,916	135,298
Education	54,443	69,693
Total	974,646	1,025,840
Gains (losses) on investment assets	(219,967)	302,337
NET INCOME/(EXPENDITURE)	**(870,792)**	**(283,109)**
Total funds brought forward	**2,578,943**	**2,862,052**
Total funds carried forward	**1,708,151**	**2,578,943**

The Tuberous Sclerosis Association
Summary Balance Sheet
As at 31 December 2018

	31/12/18	31/12/17
	£	**£**
FIXED ASSETS		
Intangible assets	-	773
Investments	1,914,135	2,932,504
Total Fixed Assets	1,914,135	2,933,277
CURRENT ASSETS		
Debtors	21,292	45,409
Cash at bank and in hand	196,226	178,453
Total Current Assets	217,518	223,862
CURRENT LIABILITIES		
Research grants due within one year	(388,184)	(492,868)
Other creditors due within one year	(35,318)	(85,328)
Total Current Liabilities	(423,502)	(578,196)
Net current liabilities	(205,984)	(354,334)
Total Assets less Current Liabilities	1,708,151	2,578,943
NET ASSETS	1,708,151	2,578,943
FUNDS		
Unrestricted funds		
Endowment Fund	1,473,818	2,068,021
Kilmaine Family Research Fellowship	228,912	506,625
	1,702,730	2,574,646
Restricted funds	5,421	4,297
TOTAL FUNDS	**1,708,151**	**2,578,943**

IMPACT REPORT 2018



£4,440

awarded to TSC community
members from the Support Fund

‘A big thank you for the support fund for making it possible to buy our daughter a new mattress and bed, this has made a big difference to us’

299

new cases dealt with
throughout the UK

2,948

interventions on
behalf of patients

£556

awarded from the
Janet Medcalf
Award

Feedback on TSA Care service –
‘Many thanks for all the valuable information and help, from the bottom of our hearts. Thank you so much for being there.’

327

attendees at **7**
TSA regional
support groups
across the UK

TS Care

Our commitment to supporting people living with TSC and their families

IMPACT REPORT 2018

3 new research projects

9 publications in academic journals

3 poster presentations

3 NEW RESEARCH PROJECTS WERE FUNDED IN 2018		The 2018 research award round received 9 applications	
Investigator	**Institution**	**Title**	**Project type**
Kacper Rogala	Cambridge Institute, USA	Towards specific mTORC1 inhibitors capable of rescuing TSC loss-of-function	Fellowship
Elaine Dunlop	Cardiff University	Characterising the role of exosomes in Tuberous Sclerosis Complex	PhD Student
Andrew Tee	Cardiff University	Targeting the Ref1/STAT3 axis to treat Tuberous Sclerosis	PhD student

3 awards completed in 2018

£277,713 in-year commitment of research funding.

The 2018 research award round received **9** applications ... **3** were funded from 2018.

11 oral presentations at academic conferences or professional meetings

TS Cure

Our commitment to research into Tuberous Sclerosis Complex

Membership of amrc ASSOCIATION OF MEDICAL RESEARCH CHARITIES & The UK Child Health Research Collaboration

IMPACT REPORT 2018

TS Campaign

Our commitment to improving NHS services for people with TSC

READY... STEADY... WRITE!

The TSA successfully campaigned for NHS England to fund everolimus for TSC-related refractory epilepsy from April 2019.

6,737 people signed our petition to get NHS England to reconsider its decision to not fund everolimus for TSC-related refractory epilepsy

30 people let us know they had contacted their MPs

15 MP's supported our campaign

The Everolimus for Epilepsy campaign resulted in **22** pieces of coverage in local/regional media (including television and radio)

7 pieces of coverage in specialist or medical media

5 pieces of coverage in national media

Volunteering

£3,261! was raised by Tea & SCones for TSC get togethers

52 fundraising pages created with **1,850** gifts given to them

Fundraisers covered **11,397** miles for the TSA – the same distance as London to Auckland!

£143,192! raised by community fundraisers

5 people ran the London Marathon raising **£15,438!**

Communications

9 Facebook Live streams with different TSC experts

5,937 times TSA videos were viewed

14 press articles

4 featured on radio programmes

2 TV features

IMPACT REPORT 2018

TS Events

Our commitment to bringing people living with TSC together

TSA BIGDAY 2018 Family Conference

179 people attended

13 experts shared their work

6 experts held 1-2-1 sessions

5 specialist workshops delivered

15 children with TSC and siblings enjoyed the creche

Outlook weekend for adults with TSC

40 people with TSC attended the event

Scottish Get Together

37 attendees in Glasgow

4 specialist workshops delivered

Tuberous Sclerosis Study Day, Cardiff

58 education, health and social care professionals attend

THE TUBEROUS SCLEROSIS ASSOCIATION
Thanks to our supporters

We would like to give enormous thanks our corporate supporters

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We would like to give thanks to our Trustees:

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