

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

**THE TUBEROUS SCLEROSIS ASSOCIATION**

**Unaudited Financial Statements for the Year Ended 31 December 2020**

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# **THE TUBEROUS SCLEROSIS ASSOCIATION**

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**Report of the Trustees  
for the year ended 31 December 2020**

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 2020. 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 applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

**Report of the Trustees  
for the year ended 31 December 2020**

**OBJECTIVES AND ACTIVITIES**

**Objectives and aims, including public benefit**

The Tuberous Sclerosis Association (TSA) was launched in 1977 with a membership of 50 families and funds of just £25. We have grown from a round robin support letter to a professional organisation providing support to families affected by Tuberous Sclerosis Complex (TSC) across the UK.

Tuberous Sclerosis Complex (TSC) is a rare genetic condition. Every month around 10 babies are born with TSC in the UK. TSC causes growths to develop in different organs around the body, such as the brain, lungs, kidneys, eyes, heart and skin. These growths are sometimes referred to as benign (non-cancerous) tumours. When they cause problems, it is mainly because of their size and where they are growing in the body.

TSC in numbers:

- Every month around 10 babies are born with TSC in the UK
- 80% of people with TSC have epilepsy which typically starts in infancy and is difficult to control using epilepsy medication
- Five out of every 10 people with TSC have learning disabilities. Around three in 10 people have profound learning disabilities and need life-long support from their families or live in residential care
- 90% of people living with TSC develop associated neuropsychiatric disorders which can include autism spectrum disorders, attention deficit hyperactivity disorders, aggression, depression, anxiety and sleep disorders which have a serious impact on family life

Every new diagnosis of TSC marks the start of an unexpected journey for the individual and family affected. The TSA is here to provide support on every step of the way.

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.

**SUMMARY OF ANNUAL PERFORMANCE: 2020**

Despite an extraordinary year, the TSA proactively responded to the upheaval caused by the coronavirus pandemic and managed to deliver on its strategic priorities:

- Supporting the TSC community
- Being at the forefront of the research agenda
- Reducing its operating deficit

**OBJECTIVES AND ACTIVITIES**

The TSA has three main goals:

- Support individuals affected by TSC, together with their families or carers
- Encourage and support research into the causes and management of TSC
- Provide education, publicity and information to promote awareness of problems caused by TSC

The TSA is midway through its five-year strategy (2019-23) which sets out a clear vision of a world where TSC and its effects are conquered and continues the charity's mission to provide help for today and a cure for tomorrow. We plan to:

- REACH more people - significantly increase the number of people being supported by the TSA by 2023
- Drive more REseArCH - stimulate 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



**Report of the Trustees  
for the year ended 31 December 2020**

The aims, objectives, enablers and values that deliver the strategy

Our strategic aims are to:

- Positively impact on the health and wellbeing of people living with TSC, families and carers
- Lead research into tools, technologies and treatments which eliminate the effects of TSC
- Lead innovation in the integration of medical and social care

Our strategic objectives are to:

- Deliver quality, easily accessible and timely information about TSC and living with the condition
- Provide opportunities for people with TSC and their families to connect, support and learn together
- Build the knowledge and expertise of professionals working with people with TSC
- Drive the research agenda to improve outcomes and quality of life for people with TSC
- Expand our understanding of the condition to accelerate diagnosis, intervention and development of new treatments
- Disseminate and use evidence to influence NHS policy and practice
- Campaign for better access to treatments and care from the NHS
- Support the development of centres of excellence for supporting people with TSC and their families
- Pilot, then roll out, innovative approaches to whole person, family and carer support

Our strategic enablers that make it possible 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
- Having values that are inclusive, ambitious and effective

**2020 Business Plan**

The Business Plan for 2020 (approved in November 2019) reflected the second year of implementing our strategy to reach more people, drive more research and balance expenditure with income by prioritising the following actions:

**Providing access to good quality, accessible and timely information**

- Launch new free and confidential Support Line in January 2020 and make sure it meets people's needs for emotional and practical support
- Continue building high-quality website and social media channels to reach more people with online information

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

- Refresh Ambassadors role to welcome those with a new diagnosis to the TSA
- Introduce more regular Family Fun Days so people living with TSC and families can get together
- Hold a TSC Community Education Afternoon so that people living with TSC and their families see the latest research from international experts on TSC

**Building the knowledge and expertise of professionals working with people with TSC**

- Develop a new approach to working with NHS TSC clinics and publish online resources to help those living with TSC to prepare for clinic visits
- Introduce a training programme for health, social care and education professionals to help them provide the best possible care when working with people living with TSC and their families

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

- Implement new approach to driving investment in TSC research through joint working with partners and funders rather than using the TSA's Designated Endowment Fund
- Host the 2020 International TSC Research Conference in London

**Campaigning for better access to treatments and care**

- Contribute views of people living with TSC and their families to NICE and SMC decision-making on, for example, Epidiolex® (cannabidiol) for TSC-related epilepsy amongst other treatments.
- Support an NHS England Clinical Reference Group review of TSC service delivery

During 2020 we planned to continue reducing expenditure and increasing income with an ambitious goal of balancing the TSA's budget by 2021

**Report of the Trustees  
for the year ended 31 December 2020**

**Revisions to 2020 Business Plan as a result of Covid-19**

An urgent review was performed in April 2020 after the coronavirus pandemic caused extraordinary changes in the external environment.

The Trustees were concerned about the impact of the pandemic on our community (some of whom were already isolated and living in difficult circumstances) and wanted to ensure that the TSA could meet their needs now and in the future.

The TSA paused delivery on planned strategic objectives and agreed a revised plan that focused on:

**Supporting people living with TSC and their families during this difficult time by:**

- Sharing high quality, timely and accurate information about coronavirus and TSC developed by the TSA on our website, newsletter emails and social media channels as well as content developed by larger charities when relevant and helpful for the community
- Providing emotional support and tailored information for individuals and families who need help primarily through the new Support Line and those that contact us via social media and other means
- Developing regular, innovative ways for the TSC community to keep in touch with one-another through digital channels, including bringing people together virtually to reassure them that they are not alone while socially-isolating or shielding
- Developing regular and innovative ways for the TSA and TSC community to keep in touch through the post with individuals and families who are not active online while they are isolating or shielding

**Ensuring the survival of the charity by:**

It was recognised that our determination to balance the TSA's finances by 2021 was unlikely to be achieved due to the impact of coronavirus on the charity's ability to raise funds in the short term. Trustees took the difficult decisions needed to manage our finances proactively with actions that included:

- Asking senior staff to work reduced hours to save cost
- Furloughing six members of staff through the Government's Coronavirus Job Retention Scheme to safeguard future employment
- Pausing planned activities
- Launched emergency coronavirus fundraising appeal
- Providing dedicated supporters opportunities to continue to fundraise for the TSA through indoor activities and challenges that can still take place during the pandemic
- Rebuilding our trusts and foundations fundraising which is less likely to be affected even if the mechanisms for decision-making may cause some delays during this period

We moved the 2020 International Research Conference and the parallel TSC Community Education Afternoon to July 2021 and changed the format from an in-person to online event to minimise the likely impact of the pandemic on delegate numbers, delegate income and sponsorship.

In addition to reducing headcount and non-pay expenditure as set out on page 24, Trustees approved additional withdrawals from the Designated Fund (see page 28) during 2020 to top up income and meet our existing research funding obligations.

**STRATEGIC REPORT**

Despite the pandemic, the TSA's Trustees and staff remained ambitious about what we wanted to achieve for the TSC community. We remain determined to ensure that Coronavirus would not stop us being here for individuals living with TSC and their families.

Our mission remains unchanged: to provide help for today and a cure for tomorrow.

The Trustees monitor performance against three headline indicators and a broader set of key performance indicators to determine the progress of our new five year strategy.

**Report of the Trustees  
for the year ended 31 December 2020**

**Reaching more people**

We believe there are between 3,700 and 11,000 people living with TSC in the UK and we aim to significantly increase the number of people being supported by the TSA by 2023.

In 2018 there were 3,394 people in contact with the charity including people living with TSC, their families, carers and friends. By the end of 2020 the TSA had increased this number by 19 per cent with 4,187 people in contact with the charity.

The launch of our new Support Line in 2020 meant we were well positioned to provide advice by telephone and email to people living with TSC across the UK while they were self-isolating or shielding. 384 people contacted our Support Line for support in 2020, and 20,639 users visited our website for information.

**Driving more research**

The three-day International TSC Research Conference was moved from November 2020 to July 2021 to minimise the likely impact of the pandemic on the event.

In November 2020 we delivered a three-hour virtual 2020 International Research Symposium in place of an in-person event, bringing together 129 clinicians and researchers from across the globe. This event focused on emerging research around TSC and Covid-19 and was hosted jointly with the US TS Alliance and US LAM Foundation. We remained determined to strengthen links across the global scientific community and drive more research which brings hope for the future to individuals and families living with TSC.

**Balancing the books**

The Trustees are clear that for the TSA to be sustainable we need to raise sufficient funds to ensure that the charity is making a surplus before any further research commitments are made.

After considering significantly reduced income due to Covid-19, the Trustees made the difficult decision in June 2020 to make staffing cuts of 30% and to ask remaining staff to work reduced hours until 2022 to enable us to run sustainably at a projected much-reduced income level.

It was decided that the Designated Endowment Fund would be used to fund the already sunk costs of hosting the postponed International TSC Research Conference and cover the cost of our ongoing research grants programme in 2020-21.

The Trustees' goal is to retain our reserves at a sensible level to give us the best possible opportunity to grow the charity when a more normal life resumes and deliver the goals set out in the five-year strategy 2019-2023.

**Report of the Trustees  
for the year ended 31 December 2020**

**OBJECTIVES AND ACTIVITIES**

**PERFORMANCE:**

Support services and communications

The TSA remains focused on flexibly reaching more people impacted by TSC respecting geographical and cultural diversity.

The TSA joined the Helplines Partnership to access high quality advice and training and ensure the development of a service that is informed by best practice across the health and care charity sector.

We recruited two experienced helpline advisers in January 2020 as part of a Support Line formally launching in April 2020 that enables people across the UK to contact our small team of professional and friendly advisers confidentially by telephone, email and post (9am to 5pm on Monday to Friday each week).

We were contacted by around 43 people each month asking for help and support, and around 25% of the enquiries that we received related to the coronavirus. We supported the TSC community by responding to a variety of questions about issues including when people living with TSC needed to shield, how to support children living with TSC when schools were closed, and how to keep in touch with loved ones living in residential care for long periods without visits from family and friends. Some callers wanted practical advice and information, others needed a listening ear and emotional support. We also provided proactive information and resources through our website ([www.tuberous-sclerosis.org/news-coronavirus-tsc](http://www.tuberous-sclerosis.org/news-coronavirus-tsc)).

We worked with expert clinicians in the NHS TSC clinics to answer the questions that were being asked most by those contacting our Support Line (for example, are people with TSC more at risk from coronavirus? Should I stop taking immunosuppressive drugs to treat symptoms of my TSC?) and shared their responses on the TSC website, social media channels and at virtual events which were also recorded and shared online.

A Coronavirus and TSC insert was added to our Spring 2020 Scan magazine to ensure access for members of our community (some of whom who may be less comfortable with online communications). We also sent targeted postcards to the 200 members of the community who we only reach by post to remind them of our Support Line and encourage them to get in touch.

While we were able to deliver one community event before the pandemic (a day for children with TSC and their families at the Blue Reef Aquarium in Portsmouth), other events moved online as we found innovative ways for the TSC community to come together and reassure them that they were not alone.

We held two virtual Outlook events to bring together adults who are mildly affected by TSC and organised at least one virtual event every month focused on the concerns that people were expressing on the Support Line. These events were recorded and shared online so they were accessible for families with caring responsibilities. Events included:

- Managing aggressive and violent behaviours in TSC (expert speaker from the US with 103 people registered attendees and 369 views after the event).
- A virtual Welsh Get Together jointly with the Cardiff NHS TSC Clinic (28 people registered)
- Scottish Get Together with the Glasgow Clinic (7 people registered)
- and Northern Ireland Get Together jointly with the Belfast Clinic (8 people registered).

At the Welsh Get Together, both clinicians and members of the TSC community raised concerns about the sustainability of the Cardiff TSC Clinic and the lack of funding for Vortibia® (everolimus) for TSC-related epilepsy in Wales. In response the TSA wrote to the Welsh Health Minister and Chairs of relevant health committees to raise these concerns on behalf of the TSC community. We also developed template letters for members of the TSC community in Wales to use to directly raise their concerns with their elected representatives.

Christmas 2020 was a difficult time for everyone as festive gatherings were cancelled at short notice for many families. The TSA worked hard to bring the community together virtually with:

- A lovely online reading of 'The Night Before Christmas' by Sir David Suchet CBE who continued to support the charity throughout the year
- A Christmas Sing-a-Long led by families and individuals living with TSC

**Report of the Trustees  
for the year ended 31 December 2020**

**OBJECTIVES AND ACTIVITIES**

- A virtual Outlook festive quiz bringing mildly affected people living with TSC together

During 2020 we awarded £3,329 in grants from the TSA Support Fund to 14 individuals and families. The Support Fund provides small discretionary grants confidentially to our community, offering a lifeline to individuals and families when the financial implications of TSC overwhelm them. We prioritise community members in receipt of benefits or on low incomes who are unlikely to have savings.

We 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 2020 we continued to work closely with colleagues from the Specialised Healthcare Commissioning Alliance (SHCA) and Genetic Alliance to raise awareness of the need to the views of patients and families when making decisions about treatments for rare diseases. We continued our membership of the Embracing Complexity Coalition to raise awareness of the need for joined up support from health and social care for complex conditions, and the Council for Disabled Children to improve access to services for children living with TSC and their families.

Research

Our research team remain committed to driving more research to give people living with TSC and their families hope for the future. The TSA is the only UK charity dedicated to supporting TSC research, with an in-year research grant commitment of £147,224.

The charity's Trustees are determined to honour the research grant commitments that we made in 2018 and 2019, and Trustees decided that the Designated Endowment Fund would be used to cover the cost of our ongoing research grants programme over 2020-21.

The TSA's research portfolio of previously committed grants in 2020 consists of 12 live grants (three of which are jointly funded). Our portfolio of ongoing projects is worth £1,227,576, and we expect all of our previously committed research projects to be completed by 2023 at the latest.

Investigator	Institution	Title and purpose of grant	Co-Funder
Professor Patrick Bolton and Dr Charlotte Tye	Kings College London	<b>Autism Spectrum and Attention Deficit Hyperactivity Disorder in the Tuberous Sclerosis 2000 Cohort Study</b> The research is exploring links between the gene mutated (TSC1 or TSC2), the extent of brain abnormality (number of tubers), the severity of epilepsy in the early and later years and the neurodevelopmental outcome (Intellectual disability, Autism Spectrum Disorder, ADHD).	
Dr Charlotte Tye	Kings College London	<b>Designing a protocol to measure the developmental trajectory of infants with Tuberous Sclerosis</b> The EDiTS study team have developed a home-based assessment to better monitor and understand social and non-social attention in toddlers with TSC. This early intervention solution already indicated a dramatic improvement in social behaviour linked to autism spectrum disorder. The EDiTS study is ongoing and aims to pave the way for the design of more early interventions to improve the long-term quality of life for patients with TSC.	



**Report of the Trustees  
for the year ended 31 December 2020**

**OBJECTIVES AND ACTIVITIES**

Dr Martin Baron	University of Manchester	<p><b>Exploiting Notch regulation to probe alternative mechanisms of TSC signalling</b></p> <p>The research team is using the fruit fly model to uncover new mechanisms of action of TSC genes in the cell, which involve the control of the transport of key regulatory signalling components such, as the Notch receptor, around the cell to different locations where they are turned off or activated. By defining the components and links involved in this new pathway, they hope to identify candidates that will offer new targets to develop as TSC therapies that would augment Tor inhibitor strategies.</p>
Dr Mark Nellist	Erasmus MC	<p><b>Functional and structural characterisation of the TSC complex; improved function assessment of TSC1 and TSC2 variants associated with tuberous sclerosis complex</b></p> <p>The aim of this project is to assess the effects of TSC1 and TSC2 variants on TSC protein complex function using new, more sensitive assays. Comparing the biochemical effects of specific changes in TSC1 and TSC2 could help explain why some individuals have more or less severe TSC disease.</p>
Dr Rosemary Ekong and Dr Mark Thomas	University College London	<p><b>The TSC1 and TSC2 variation databases</b></p> <p>The two databases (<a href="http://www.LOVD.nl/TSC1">www.LOVD.nl/TSC1</a> and <a href="http://www.LOVD.nl/TSC2">www.LOVD.nl/TSC2</a>) list as far as possible all known changes in the TSC1 and TSC2 genes, together with evidence for which of them can cause Tuberous sclerosis Complex (TSC).</p>
Dr Kacper Rogala	Whitehead Institute - MIT	<p><b>Identifying and creating more specific medicines for TSC</b></p> <p>This project focuses on research into the structural biology of TSC and how this can help to identify and create new and more specific drugs to treat it. It is hoped that the research can contribute towards developing a treatment that would provide all the benefits of rapamycin, but without its unwanted long-term side-effects</p>
Dr Elaine Dunlop	Cardiff University Hospital	<p><b>Characterising the role of exosomes in TSC</b></p> <p>We know that TSC cysts surround and hijack healthy cells, in turn helping the cysts grow. This project plans to collaborate with world-leading TSC experts to help better understand exactly how TSC cysts communicate with healthy cells. It is hoped that this research could help to reveal new ways of preventing TSC cysts from growing, thereby helping to develop better strategies for treating and managing TSC.</p>
Professor Andrew Tee	Cardiff University Hospital	<p><b>Understanding the limits of everolimus and rapamycin</b></p> <p>This project is investigating the limits of everolimus and rapamycin, specifically, why these treatments are not 100% effective and why not all TSC tumours respond to treatment with them. The team are currently examining how TSC tumour cells in the lab respond to a series of new drugs in clinical development and will compare the effects with existing treatments. It is hoped that this research will help to find better and more effective treatments for TSC patients.</p>

**Report of the Trustees  
for the year ended 31 December 2020**

**OBJECTIVES AND ACTIVITIES**

Dr Elaine Dunlop	Cardiff University	<b>A model of cell invasion in TSC-LAM</b> One of the current priorities in TSC research is to develop a model of the human circulatory system using human cells, so that scientists can study LAM in more detail. LAM (or 'lymphangiomyomatosis') is a condition affecting around 35-40% of females who live with TSC. LAM is caused by TSC cells moving from different parts of the body to the lungs, causing cysts. This new project aims to create a LAM model. If the research is successful, it will give scientists a better understanding of why TSC LAM happens and why some cells invade the lungs whilst others do not.	US Ministry of Defence
Dr Sam Amin and Dr Ingram Wright	University of Bristol	<b>Better understanding the accessibility of mental health services for children and young people with TSC</b> This project aims to develop an understanding of appropriate and effective ways for children and young people with TSC to access available mental health services and psychological support in the UK. This research hopes to demonstrate a clear benefit of providing therapies to children and young people with TSC who are experiencing psychological or emotional distress.	Anonymous major donor
Professor Petrus de Vries and Professor Anna Janssen	University of Cape Town and UZ Brussels	<b>The TANDem Project</b> The TANDem Project brings together a worldwide team of families affected by TSC, researchers and clinicians to provide scientific evidence for greater intervention and treatment of TSC Associated Neuropsychiatric Disorders (such as anxiety, depression and aggressive behaviour). The two-part project will first focus on the development of a self-report TAND checklist and identification smartphone app, to measure how people are affected by TAND. The second part of the study will investigate the best ways to treat TAND, including agreement on suitable clinical guidelines for TAND. Following work in identifying and treating TAND, the TANDem Project will prepare a global team of TAND researchers to raise awareness and lead future research into TAND.	King Baudouin Foundation

The research portfolio continues to yield results and 2020 saw ten live grants submit data. Of these ten, three were published in six different academic journals while five reported seven other forms of engagement (for example, oral and poster presentations at academic conferences or professional meetings). These figures are lower than previous years as the pandemic meant that some researchers were unable to carry out lab work which impacted on data generation and delayed publication and presentation of the data.

The International TSC Research Symposium took place in November 2020 and was jointly hosted by TSA-UK with TS Alliance-US and the LAM Foundation-US. Over 140 people registered to attend with 129 delegates signing in on the day. Attendees were able to access recordings from the event a month after it took place, and feedback was sought to help us learn about the best approach to developing and delivering virtual research events. We charged a small fee for delegates to attend and raised just under £2,000 from ticket sales which was a welcome contribution to the charity's funds. The Symposium was also sponsored by GW Pharmaceuticals and Plusultra Pharma who each paid £2,000 to sponsor the event.

We continue to benefit from membership of the Association of Medical Research Charities (AMRC) and the UK Child Health Collaboration. The AMRC will audit our research grants programme in 2021 and we look forward to this opportunity to learn from their feedback and continually improve our work in this area.

We continue to build our relationship with NHS TSC clinics through our annual TSC Clinics Day which is organised by the TSA's research team. This year's TSC Clinics Day was held in March 2020 and brought together clinic leads (usually senior clinicians) and clinic coordinators (usually nurses) from the 15 clinics in England and one clinic each in Scotland, Wales and Northern Ireland. Regular contact with the staff leading and managing the clinics helps to facilitate:

**Report of the Trustees  
for the year ended 31 December 2020**

**OBJECTIVES AND ACTIVITIES**

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

**Income generation**

We noted that our ambition to balance the TSA's finances by 2021 was unlikely to be possible given the impact of coronavirus on the charity's ability to raise funds. The Trustees took the difficult decisions needed to manage our finances with a view to **balancing the books** by 2022 or 2023.

The coronavirus pandemic made for a daunting fundraising environment in 2020 and many of the activities we would traditionally use to raise income from our community were cancelled due to social distancing restrictions, such as:

- Tea and SCones for TSC coffee mornings (which raised £4,655 in 2019)
- the London Marathon (£15,473 in 2019)
- Great North Run (£10,133 in 2019)
- Ride100 (£10,583 in 2019).

This unprecedented environment encouraged us to seek innovative ways to generate income for the TSA. We assessed and utilised opportunities available from national and local government to support charities through the pandemic which included:

- the Government's Coronavirus Job Retention Scheme which we used to furlough six out of thirteen members of staff on 80% of their usual salaries in an effort to safeguard as many jobs at the charity as possible in the longer term, resulting in furlough income of £51,000 during 2020.
- A £10,000 grant from the Coronavirus Community Support Fund (distributed by The National Lottery Community Fund) which helped us through the pandemic
- A coronavirus-related grant of £2,000 from the London Borough of Tower Hamlets where the TSA's office is based

We sent out a direct mail Coronavirus Emergency Appeal to the TSC community to ask them to make one-off donations or sign up to give a regular direct debit to make sure that the charity continues to be here for everyone who needs us. We received an unprecedented response with 224 individuals contributing a total of £21,695 in response to the appeal.

We sent Coronavirus Emergency Appeal requests to seven pharmaceutical companies with an interest in TSC or epilepsy and received pledges of unrestricted grants from GW Pharmaceuticals and Plusultra Pharma which will be received by the charity early in 2021.

We developed ideas for coronavirus-proof fundraising which were shared with our community. This included encouraging more digital fundraising through online platforms such as Facebook and introducing the TSA Gaming Champion so that people could fundraise through a gaming challenge while staying at home. We encouraged our supporters to join the virtual 2.6 Challenge which was developed by the team who run the London Marathon and raised a welcome £3,800 for the charity.

Private equity firm Equistone had selected the TSA as their Charity of the Year for 2020 before the pandemic struck. The lockdown and restrictions on people meeting meant that some of their planned activities were unable to go ahead, and Equistone's UK team had to be creative to replace the events that would have taken place. They decided to climb the equivalent of Mount Everest's elevation (8,846 metres) on their stairs at home in fancy dress. They also held online events such as quizzes. Over the course of that extraordinary year, Equistone raised £45,000 which is testimony to their determination, imagination and desire to support the TSA through a most challenging year.

Other companies kindly supporting the charity during 2020 included Pearson who donated space at their head office and a facilitator for our senior management team away day, and Moo Creative who donated their time and expertise to deliver the design of our publications.

We received several amazing individual gifts and legacies from supporters of the TSA during 2020, which would be greatly appreciated at any time but were particularly timely given the challenging year facing the TSA.



**Report of the Trustees  
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**OBJECTIVES AND ACTIVITIES**

We received an incredible gift of £35,000 from a member of the TSC community who had been left the money by a relative to donate to a charity of her choice. We also received a generous legacy of £40,000 and two generous legacies of £5,000 each which made a substantial difference to the charity during this difficult year. We would like to formally record a huge thank you to everyone who supported us in this way.

We received a grant of £5,000 from The Adint Charitable Trust, plus an additional grant of £5,000 to help charities that they support to survive the covid-19 outbreak. The Bank of Scotland Foundation awarded us £2,000 to help support virtual events and support line tasks focused on Scotland-based community members.

We also received support from: Charles & Elsie Sykes Charitable Trust, Esher House Charitable Trust, The Michael and Anna Wix Charitable Trust, Anglo American Foundation and the Dunn Family Trust. We invested in Trusts and Foundations support to draft additional bids for support which were sent to trusts and foundations during a challenging period for charities.

We are profoundly grateful to all the trusts and foundations who helped us in 2020.

Organisation development and people

We noted that our ambition to balance the TSA's finances by 2021 was unlikely to be met given the impact of coronavirus on the charity's ability to raise funds. The Trustees took the steps needed to manage our finances with a view to balancing the books by 2022 or 2023.

In June 2020, the Trustees made the difficult decision to right size the charity and approve a proposal for restructuring. Following a two-week period of formal consultation, the Board reviewed and approved four redundancies: Head of Support and Information Services, Information Officer, Trusts and Foundations Manager, and Communications and Events Assistant. We would like to thank the staff who worked in these posts for their hard work and commitment during their time with the TSA, and wish them the very best for the future.

These staff cuts were the second round of redundancies that have needed to be made in order to make the charity the right size for the future.

In addition we asked all four members of the senior management team at the charity to voluntarily reduce their salaries to 80% of their usual hours and pay to support the charity during 2020. We are grateful for this much-needed support.

A new structure for the Support Line team was implemented. The Head of Communications and Support is responsible for leading the team, alongside two Support Line Managers. This team continued working hours and pay at 100% due to a business need for the Support Line to be available from 9am to 5pm from Monday to Friday.

We recruited a part time Joint Chief Executive for a twelve-month period to support the charity alongside our long-standing Chief Executive (who temporarily reduced her working hours to manage home-schooling and work) whilst the Head of Income Generation was on maternity leave. The Joint Chief Executive brought expertise in finance and fundraising to upskill colleagues and provide additional capacity for the charity during the pandemic.

Investment policy

The Trustees have appointed investment managers to manage the TSA'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 ARC steady growth benchmark.

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**OBJECTIVES AND ACTIVITIES**

In the year ended 31 December 2020, the total return on the portfolio was -1.4% as against the benchmark of 3.5%. Over the longer term, our investment managers have consistently out-performed the benchmark. Their performance continues to be kept under review and Trustees have an annual review meeting with them. The Trustees have agreed a formal investment policy reflecting the investment objective stated above. Part of the reason for the underperformance of the portfolio is that in 2020 £391k was held in cash which was generated in late September 2020 to ensure the charity held the cash it needed in 2020 and 2021. This prudent decision was taken in an uncertain market, but taken ahead of the significant recovery of markets in Q4 it resulted in the underperformance of the portfolio against the benchmark over the year.

**FINANCIAL REVIEW**

**Financial position**

**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.

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 Chief Executive or the Head of Support Services and Communications 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 and review of financial position**

At the end of the year the Association has total funds of **£972,169**. This included designated funds of **£851,483**, further details of which are given below. The designated funds are anticipated to reduce to approximately £300,000 by the end of 2022.

The reserves of the Association amounted to **£120,686** at 31 December 2020, representing three months of expenditure excluding any research commitments entered into.

**Designated Fund**

The funds of the Association include a Designated Fund which largely arises from a bequest in 1993 by the late Mr H I Leech. This does not form part of the Association's reserves.

This Fund has been broadly treated as an "endowment" and invested with professional advisers to provide 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
- Help fund the charitable activities from investment income, thereby helping to secure the future of the charity and provide continuing support to future and current sufferers of TSC

In recent years, the balance on the Designated Fund has reduced significantly as a result of both additional research commitments and the provision of additional services, the cost of which have not been covered by the income of the Association.

The commitments that the Association intends to make in the forthcoming years (including Research that has already commenced and is renewed on an annual basis, subject to a satisfactory review) are such that the trustees expect the Designated Fund to reduce to approximately £300,000 by the end of 2022. The trustees are of the opinion that this £300,000 designated fund should be retained so that the TSA has sufficient funds to instigate major medical research projects, co-funded by third parties, at short notice if necessary.

**Result for the year**

The Association's total income for the year was **£418,746** (2019 £303,000).

Our total investment gains/(losses) were **(£50,959)** (2019 £208,000). 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/(loss), the overall deficit for the year was **£247,000** (2019 £489,000).

**Report of the Trustees  
for the year ended 31 December 2020**

**FUTURE PLANS**

**Strategic objectives**

The first two years of our 2019-2023 strategy has seen the TSA significantly reduce expenditure (from £974,646 in 2018 to £614,314 in 2020) and headcount (from 18 posts in 2018 to nine posts by the end of 2020) to address the charity's structural deficit, while simultaneously improving the quality of our services and increasing our reach into the TSC community.

However, as a result of the pandemic and working with a smaller team than originally envisaged in 2021 and beyond, we have agreed to concentrate resource on a smaller number of strategic objectives to help the TSA community and the professionals who work with them.

We will focus on:

**Providing access to good quality, accessible and timely information**

- Embed the new Support Line (including introducing LanguageLine for users with English as a second language and regular supervision for advisers) and introduce the new web chat function to drive better access for family carers and young people with TSC.

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

- Make sure that no-one with TSC feels alone as the pandemic continues by bringing together individuals living with TSC, families and professionals at regular virtual events that focus on the topics that matter most to our community.

**Capacity building the knowledge of professionals supporting people living with TSC**

- Develop an income-generating training offer for generalist healthcare professionals, social workers and teachers combining online training modules and webinars to improve their understanding of TSC, ready for launch in 2022.

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

- Host the 2021 International TSC Research Conference in June, keeping the option of moving to a virtual event under review as the pandemic continues.

- Host a Community Education Afternoon to share this research with the TSC community, again keeping the option of this being a virtual event under review.

**Campaigning for better access to treatments and care**

- Work with pharmaceutical companies developing new treatments for TSC related epilepsy and facial angiofibromas to ensure that they understand the impact of TSC on individuals living with the condition and their families and the most important outcomes of their work for patients and carers.

Strategic enablers

We will focus on:

**High-quality, integrated financial management**

- Work with our external finance provider to move the TSA onto the Xero accounting system which will reduce the senior capacity needed to run parallel management accounts.

**Digital transformation and smart working to reach more people**

- Maximise the impact of our information by continuing our journey to regular and timely 'digital first' communications across the website and social media.

- Move our mailings to two Scan magazines each year (Spring, Summer) and a refreshed Impact Report/Annual General Meeting mailing (Autumn).

**An enterprising approach to income generation to drive more research**

- Develop new approaches to supporting major donors and potential major donors, encouraging legacies and working with corporates to generate income

- Develop general cases for support to generate unrestricted donations from trusts and foundations (for example, drafting separate cases of support targeting trusts who fund projects for young people, mental health, learning disabilities and elderly carers)

- Increase the number of individuals on the database, segment them, and develop bespoke stewardship journeys with the aim of making them into regular donors to the TSA

**Report of the Trustees  
for the year ended 31 December 2020**

- Maximise income generation from every touch point (for example, using the Impact Report and AGM mailing to steward donors and funders)
- Maximise income from delegates and sponsors at International TSC Research Conference
- Identify opportunities to bring in funding for Scan and virtual events

Trustees are keen to ensure that the TSA operates as efficiently as possible, so we can invest more of our income in driving improvements in services and research for our beneficiaries.

In 2021 we will put our accounting and audit services out to tender and move from an annual audit to an independent examination. We will close our small office and switch to being an entirely home-based organisation, sadly resulting in a decision by Trustees to make the post of Office Manager redundant when the office closes in October 2021.

The TSA's Trustees and staff continue to be ambitious about what we want to achieve for individuals living with TSC and their families.

Our mission remains unchanged: to provide help for today and a cure for tomorrow.

**Report of the Trustees  
for the year ended 31 December 2020**

**STRUCTURE, GOVERNANCE AND MANAGEMENT**

**Structure, governance and management**

**Constitution**

The Association was incorporated under the Companies Act 1985 as a company limited by guarantee, registered in England, No 02900107, and is governed by its Memorandum and Articles of Association. It is also registered as a charity in England and Wales (No 1039549) and in Scotland (No SC042780).

**Recruitment and appointment of new trustees**

The Association considers the skill sets of existing trustees, and prospective trustees are considered for appointment, based on the additional skills they can bring to the Association. Candidates arise as a result of recruitment campaigns.

**Organisational structure**

A list of the Offices and other Trustees who served for all or part of the year, or who have been appointed before the date of this report, appears in 'Reference and administrative information' below.

At each Annual General Meeting, one-third of the Trustees retire by choice or rotation. In 2020, these are Chris Kingswood, Martin Short, Lisa Suchet and Rob Vaughan. Chris Kingswood, Martin Short and Lisa Suchet offer themselves for re-election; after an appraisal process, the Board recommends their re-election. Rob Vaughan who has served as both Trustee and Treasurer will retire by choice at the 2021 AGM, and the Board is most grateful to him for all of his work and commitment to the TSA. Martin Short will remain as a trustee but relinquish his role as Vice Chair after holding the role for two years. From the 2021 AGM Rajan Khullar will take on the role of Treasurer and Robert Woodthorpe Browne will take on the role of Vice Chair.

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 Rescom Chair and a minimum of two professional and two lay members. Rescom meets to advise on strategic prioritisation of funding for research grant rounds. The TSA is a member of the Association of Medical Research Charities and we are committed to following the principles and practices of effective grant management including the AMRC's five principles of peer review.

**Risk management**

The Trustees meet as a Board four times each year.

The Trustee's policies ensure that strategic planning and risk management processes become part of the operating processes of the Association. The Trustees have identified the major risks to which the Association is exposed, determined the relevant significance of those risks, and regularly review the adequacy of the systems that have been established to mitigate those risks.

The Trustees's are also responsible for monitoring and overseeing the financial performance of the Association, which includes:

- Reviewing and approving a business plan and accompanying budget each year;
- Monitoring financial performance against the planned budget through quarterly finance reports which are scrutinised at each Board meeting;
- Approving unbudgeted expenditure in line with the Board-approved scheme of delegation;
- Regularly reviewing a three-year forecast to ensure that they are aware of the longer term financial outlook for the charity;
- Overseeing the preparation of the statutory Annual Report and Accounts, ensuring compliance with accounting standards the legal requirements;
- Having responsibility for appointing and overseeing the external finance provider, independent examination and audit function;
- Monitoring and reviewing the performance of the investment portfolio and reviewing and reappointing investment managers as appropriate.

Report of the Trustees  
for the year ended 31 December 2020

**REFERENCE AND ADMINISTRATIVE DETAILS**

**Registered Company number**

02900107 (England and Wales)

**Registered Charity number**

1039549

**Registered office**

Unit 56

Emma Street

Tower Hamlets

London

E2 9FP

**Trustees**

P F Bolton Doctor

T E Carter Company Director

Ms A Cotton Iass Adviser

Dr F V Elmslie Doctor

R Khullar Chartered Management Accountant (appointed 26.11.20)

Dr J C Kingswood Hospital Physician

J Rogers Nurse

S Sethi Fund Manager

Rev M P Short Clerk In Holy Orders

Ms L A C P Suchet Company Director

D R Vaughan Chartered Accountant

R Woodthorpe Browne Company Director

**Company Secretary**

Ms L Fish

**Independent Examiner**

Tudor John Limited

Nightingale House

46-48 East Street

Epsom

Surrey

KT17 1HQ

Approved by order of the board of trustees on .....28/09/2021..... and signed on its behalf by:



.....  
S Sethi - Trustee



**Independent Examiner's Report to the Trustees of  
The Tuberous Sclerosis Association (Registered number: 02900107)**

**Independent examiner's report to the trustees of The Tuberous Sclerosis Association ('the Company')**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 December 2020.

**Responsibilities and basis of report**

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

**Independent examiner's statement**

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of ICAEW which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Hazel Day  
ICAEW  
Tudor John Limited  
Nightingale House  
46-48 East Street  
Epsom  
Surrey  
KT17 1HQ

Date: 29th September 2021

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Statement of Financial Activities for the year ended 31 December 2020

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies		304,058	26,000	330,058	234,374
<b>Charitable activities</b>					
Family Care & Support		-	-	-	1,510
Other trading activities	2	2,884	-	2,884	1,756
Investment income	3	34,308	-	34,308	65,176
Other income		51,496	-	51,496	-
<b>Total</b>		392,746	26,000	418,746	302,816
<b>EXPENDITURE ON</b>					
Raising funds	4	110,927	-	110,927	157,232
<b>Charitable activities</b>					
Family Care & Support		246,864	-	246,864	457,658
Research		225,823	30,700	256,523	385,571
<b>Total</b>		583,614	30,700	614,314	1,000,461
Net gains/(losses) on investments		(50,959)	-	(50,959)	208,190
<b>NET INCOME/(EXPENDITURE)</b>		(241,827)	(4,700)	(246,527)	(489,455)
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		1,213,996	4,700	1,218,696	1,708,151
<b>TOTAL FUNDS CARRIED FORWARD</b>		972,169	-	972,169	1,218,696

The notes form part of these financial statements



**THE TUBEROUS SCLEROSIS ASSOCIATION (REGISTERED NUMBER: 02900107)**

**Balance Sheet  
31 December 2020**

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
<b>FIXED ASSETS</b>					
Tangible assets	12	-	-	-	851
Investments	13	<u>960,594</u>	<u>-</u>	<u>960,594</u>	<u>1,268,946</u>
		960,594	-	960,594	1,269,797
<b>CURRENT ASSETS</b>					
Debtors	14	82,171	-	82,171	98,608
Cash at bank		<u>251,432</u>	<u>-</u>	<u>251,432</u>	<u>264,938</u>
		333,603	-	333,603	363,546
<b>CREDITORS</b>					
Amounts falling due within one year	15	<u>(322,028)</u>	<u>-</u>	<u>(322,028)</u>	<u>(414,647)</u>
<b>NET CURRENT ASSETS</b>		<u>11,575</u>	<u>-</u>	<u>11,575</u>	<u>(51,101)</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<u>972,169</u>	<u>-</u>	<u>972,169</u>	<u>1,218,696</u>
<b>NET ASSETS</b>		<u>972,169</u>	<u>-</u>	<u>972,169</u>	<u>1,218,696</u>
<b>FUNDS</b>	16				
Unrestricted funds				972,169	1,213,996
Restricted funds				<u>-</u>	<u>4,700</u>
<b>TOTAL FUNDS</b>				<u>972,169</u>	<u>1,218,696</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2020.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 December 2020 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The notes form part of these financial statements

Balance Sheet - continued  
31 December 2020

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on .....28/09/2021..... and were signed on its behalf by:



.....  
S Sethi - Trustee

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements for the year ended 31 December 2020

### 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 2019)', 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.

#### **INCOME**

All income is recognised in the Statement of Financial Activities once the charity 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 which 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.

#### **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.

#### **TANGIBLE FIXED ASSETS**

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Fixtures and fittings                      - 25% on reducing balance

#### **TAXATION**

The charity is exempt from corporation tax on its charitable activities.

#### **FUND ACCOUNTING**

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2020

### 1. ACCOUNTING POLICIES - continued

#### FUND ACCOUNTING

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

#### PENSION COSTS AND OTHER POST-RETIREMENT BENEFITS

The charitable company operates a defined contribution pension scheme. Contributions payable to the charitable company's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

#### 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.

#### 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 and in hand

Cash at bank and 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 any trade discounts due.

### 2. OTHER TRADING ACTIVITIES

	2020	2019
	£	£
Christmas cards & other sales	<u>2,884</u>	<u>1,756</u>

### 3. INVESTMENT INCOME

	2020	2019
	£	£
Deposit account interest	141	201
Income from managed portfolio	<u>34,167</u>	<u>64,975</u>
	<u>34,308</u>	<u>65,176</u>

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2020

### 4. RAISING FUNDS

#### INVESTMENT MANAGEMENT COSTS

	2020	2019
	£	£
Portfolio management charges	<u>8,496</u>	<u>11,795</u>

### 5. GRANTS PAYABLE

	2020	2019
	£	£
Family Care & Support	-	(13,053)
Research	<u>147,224</u>	<u>265,618</u>
	<u>147,224</u>	<u>252,565</u>

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

	2020	2019
	£	£
* Addenbrookes Hospital - TSC Psychology	-	(13,053)
* Brighton TS Registry	-	(101)
* Whitehead Institute - Towards Specific Mtor Inhibitors Capable of Rescuing Tuberous Sclerosis Complex Loss-of-function	51,000	51,000
* Cardiff University - Targeting the Ref1/STAT3 axis to treat Tuberous Sclerosis Complex	32,719	61,744
* Cardiff University - Characterising the Role of Exosomes in Tuberous Sclerosis	32,712	32,537
* Cardiff University - An innovative model system of cell invasion in TSC/LAM to uncover new drug targets and therapies	30,793	-
* Institute of Psychiatry Psychology and Neuroscience - Neurocognitive predictors of neurodevelopmental impairment in infants and toddlers with TSC	-	16,740
* University of Cape Town - Empowering Families through Technology: a mobile-health project to reduce the TAND identification and treatment gap	-	41,697
* University of Bristol NHS Foundation Trust - Randomised Controlled Trial of Acceptance and Commitment Therapy in the Tuberous Sclerosis Complex	<u>-</u>	<u>62,000</u>
	<u>147,224</u>	<u>252,564</u>

Research Grants are awarded 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.

Negative balances represent the unclaimed elements of grants previously awarded, which have now expired.

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2020

### 6. SUPPORT COSTS

	Management	Finance	Other	Governance costs	Totals
	£	£	£	£	£
Family Care & Support	127	1,004	22,796	8,088	32,015
Research	<u>77</u>	<u>833</u>	<u>9,593</u>	<u>8,087</u>	<u>18,590</u>
	<u>204</u>	<u>1,837</u>	<u>32,389</u>	<u>16,175</u>	<u>50,605</u>

Support costs have been allocated between Raising donations and Legacies and the Activities of the Association by reviewing each cost type and identifying what drives the cost and splitting based on those cost drivers.

### 7. NET INCOME/(EXPENDITURE)

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

	2020	2019
	£	£
Auditors' remuneration	-	6,357
Depreciation - owned assets	851	284
Surplus on disposal of fixed assets	<u>(75)</u>	<u>-</u>

### 8. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2020 nor for the year ended 31 December 2019.

#### TRUSTEES' EXPENSES

	2020	2019
	£	£
Trustees' expenses	<u>-</u>	<u>3,036</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. No (2019 - 5) Trustees received payments for reimbursement of expenses during the year.

### 9. STAFF COSTS

	2020	2019
	£	£
Wages and salaries	298,750	397,223
Social security costs	26,928	35,294
Other pension costs	<u>16,743</u>	<u>21,705</u>
	<u>342,421</u>	<u>454,222</u>

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

	2020	2019
Fundraising	2	3
Family Support and Communications	8	10
Research	<u>3</u>	<u>3</u>
	<u>13</u>	<u>16</u>

**THE TUBEROUS SCLEROSIS ASSOCIATION**

**Notes to the Financial Statements - continued  
for the year ended 31 December 2020**

**9. STAFF COSTS - continued**

No employees received emoluments in excess of £60,000.

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

	Unrestricted funds £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	229,674	4,700	234,374
<b>Charitable activities</b>			
Family Care & Support	1,510	-	1,510
Other trading activities	1,756	-	1,756
Investment income	<u>65,176</u>	<u>-</u>	<u>65,176</u>
<b>Total</b>	298,116	4,700	302,816
 <b>EXPENDITURE ON</b>			
Raising funds	157,232	-	157,232
<b>Charitable activities</b>			
Family Care & Support	452,237	5,421	457,658
Research	<u>385,571</u>	<u>-</u>	<u>385,571</u>
<b>Total</b>	995,040	5,421	1,000,461
Net gains on investments	<u>208,190</u>	<u>-</u>	<u>208,190</u>
<b>NET INCOME/(EXPENDITURE)</b>	(488,734)	(721)	(489,455)
 <b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	<u>1,702,730</u>	<u>5,421</u>	<u>1,708,151</u>
<b>TOTAL FUNDS CARRIED FORWARD</b>	<u><u>1,213,996</u></u>	<u><u>4,700</u></u>	<u><u>1,218,696</u></u>

**11. INTANGIBLE FIXED ASSETS**

	Database costs £
<b>COST</b>	
At 1 January 2020 and 31 December 2020	<u>19,624</u>
<b>AMORTISATION</b>	
At 1 January 2020 and 31 December 2020	<u>19,624</u>
<b>NET BOOK VALUE</b>	
At 31 December 2020	<u>-</u>
At 31 December 2019	<u>-</u>

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2020

### 12. TANGIBLE FIXED ASSETS

	Fixtures and fittings £
<b>COST</b>	
At 1 January 2020 and 31 December 2020	<u>1,135</u>
<b>DEPRECIATION</b>	
At 1 January 2020	284
Charge for year	<u>851</u>
At 31 December 2020	<u>1,135</u>
<b>NET BOOK VALUE</b>	
At 31 December 2020	<u>-</u>
At 31 December 2019	<u>851</u>

### 13. FIXED ASSET INVESTMENTS

	2020 £	2019 £
Shares	570,319	1,259,896
Brewin Dolphin capital account	<u>390,275</u>	<u>9,050</u>
	<u>960,594</u>	<u>1,268,946</u>

Additional information as follows:

	Listed investments £
<b>MARKET VALUE</b>	
At 1 January 2020	1,259,896
Additions	36,726
Disposals	(675,344)
Revaluations	<u>(50,959)</u>
At 31 December 2020	<u>570,319</u>
<b>NET BOOK VALUE</b>	
At 31 December 2020	<u>570,319</u>
At 31 December 2019	<u>1,259,896</u>

There were no investment assets outside the UK.

Investments (neither listed nor unlisted) were as follows:

	2020 £	2019 £
Brewin Dolphin capital account	<u>390,275</u>	<u>9,050</u>

The historical cost of the investments at the year end is £324,612 (2019 £721,783).



# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2020

### 14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020 £	2019 £
Other debtors	<u>82,171</u>	<u>98,608</u>

### 15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020 £	2019 £
Trade creditors	13,354	36,410
Social security and other taxes	5,413	8,892
Other creditors	296,858	358,888
Accrued expenses	<u>6,403</u>	<u>10,457</u>
	<u>322,028</u>	<u>414,647</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 5.

	At 1.1.20 £	SOFA £	Paid £	At 31.12.20 £
* University of Birmingham	3,499	-	-	3,499
* Institute of Psychiatry, Kings College London - Designing a Protocol to Measure the Development Trajectory of Infants with Tuberous Sclerosis	24,607	-	-	24,607
* Institute of Medical Genetics, Cardiff	1,371	-	-	1,371
* Centre for Integrative Physiology, University of Edinburgh	335	-	-	335
* Institute of Psychiatry, Kings College London	14,153	-	-	14,153
* Cardiff University	618	-	-	618
* Research Department of Genetics, University College, London	513	-	-	513
* University of Manchester, Faculty of Life Sciences	24,679	-	(8,981)	15,698
* Erasmus MC, Department of Clinical Genetics	180	-	-	180
* University College London - The TSC1 and TSC2 Variation Databases	29,945	-	(21,064)	8,881
* Whitehead Institute - Towards specific Motor Inhibitors capable of rescuing Tuberous Sclerosis Complex loss-of-function	35,321	51,000	(61,985)	24,336
* Cardiff University - Targeting the Ref1/STAT3 axis to treat Tuberous Sclerosis Complex	36,659	32,719	(31,954)	37,424
* Cardiff University - Characterising the roles of exosomes in Tuberous Sclerosis Complex	36,273	32,712	(27,634)	41,351
* University of Bristol NHS Foundation Trust - Randomised Controlled Trial of Acceptance and Commitment Therapy in Tuberous Sclerosis Complex	62,000	-	-	62,000

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2020

### 15. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR - continued

* Institute of Psychiatry Psychology and Neuroscience - Neurocognitive predictors of neurodevelopmental impairment in infants and toddlers with TSC	16,740	-	(5,191)	11,549
* University of Cape Town - Empowering Families through technology: a mobilehealth project to reduce the TAND identification and treatment gap	41,697	-	(41,697)	-
* Cardiff University - An innovative model system to cell invasion in TSC/LAM to uncover new drug targets and therapies	28,353	30,793	(12,146)	47,000
	<u>356,942</u>	<u>147,224</u>	<u>(210,652)</u>	<u>293,515</u>

### 16. MOVEMENT IN FUNDS

	At 1.1.20 £	Net movement in funds £	At 31.12.20 £
<b>Unrestricted funds</b>			
General fund	190,000	(69,314)	120,686
Designated Endowment Fund	<u>1,023,996</u>	<u>(172,513)</u>	<u>851,483</u>
	1,213,996	(241,827)	972,169
<b>Restricted funds</b>			
Research	4,700	(4,700)	-
	<u>4,700</u>	<u>(4,700)</u>	<u>-</u>
<b>TOTAL FUNDS</b>	<u>1,218,696</u>	<u>(246,527)</u>	<u>972,169</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
<b>Unrestricted funds</b>				
General fund	358,580	(427,894)	-	(69,314)
Designated Endowment Fund	<u>34,166</u>	<u>(155,720)</u>	<u>(50,959)</u>	<u>(172,513)</u>
	392,746	(583,614)	(50,959)	(241,827)
<b>Restricted funds</b>				
Research	22,000	(26,700)	-	(4,700)
Scotland	<u>4,000</u>	<u>(4,000)</u>	-	-
	<u>26,000</u>	<u>(30,700)</u>	-	<u>(4,700)</u>
<b>TOTAL FUNDS</b>	<u>418,746</u>	<u>(614,314)</u>	<u>(50,959)</u>	<u>(246,527)</u>

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Notes to the Financial Statements - continued for the year ended 31 December 2020

### 16. MOVEMENT IN FUNDS - continued

#### Comparatives for movement in funds

	At 1.1.19 £	Net movement in funds £	Transfers between funds £	At 31.12.19 £
<b>Unrestricted funds</b>				
General fund	-	(496,057)	686,057	190,000
Designated Endowment Fund	1,473,818	236,235	(686,057)	1,023,996
Kilmain Family Research Fellowship	228,912	(228,912)	-	-
	1,702,730	(488,734)	-	1,213,996
<b>Restricted funds</b>				
Research	-	4,700	-	4,700
Education	5,421	(5,421)	-	-
	5,421	(721)	-	4,700
<b>TOTAL FUNDS</b>	<u>1,708,151</u>	<u>(489,455)</u>	<u>-</u>	<u>1,218,696</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
<b>Unrestricted funds</b>				
General fund	233,141	(729,198)	-	(496,057)
Designated Endowment Fund	64,975	(36,930)	208,190	236,235
Kilmain Family Research Fellowship	-	(228,912)	-	(228,912)
	298,116	(995,040)	208,190	(488,734)
<b>Restricted funds</b>				
Research	4,700	-	-	4,700
Education	-	(5,421)	-	(5,421)
	4,700	(5,421)	-	(721)
<b>TOTAL FUNDS</b>	<u>302,816</u>	<u>(1,000,461)</u>	<u>208,190</u>	<u>(489,455)</u>

### 17. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 December 2020.

# THE TUBEROUS SCLEROSIS ASSOCIATION

## Detailed Statement of Financial Activities for the year ended 31 December 2020

	2020 £	2019 £
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and legacies</b>		
Donations and subscription	327,058	230,180
Grants	<u>3,000</u>	<u>4,194</u>
	330,058	234,374
<b>Other trading activities</b>		
Christmas cards & other sales	2,884	1,756
<b>Investment income</b>		
Deposit account interest	141	201
Income from managed portfolio	<u>34,167</u>	<u>64,975</u>
	34,308	65,176
<b>Charitable activities</b>		
Family days and weekends	-	1,510
<b>Other income</b>		
Government grants - CJRS	<u>51,496</u>	<u>-</u>
<b>Total incoming resources</b>	418,746	302,816
<b>EXPENDITURE</b>		
<b>Raising donations and legacies</b>		
Wages	68,133	82,081
Social security	4,521	7,310
Pensions	2,769	4,611
Events fees	280	11,823
Sundries	2,391	26,514
Travel & Communications	1,884	7,458
Bid writing	2,800	-
Staff training	-	3,325
Marketing & Media	2,622	-
Insurance	1,337	-
Office costs	4,452	-
Professional fees	687	-
Accountancy & legal fees	5,317	-
AGM, Big Day and Annual Report costs	2,770	-
Fixtures and fittings	<u>88</u>	<u>-</u>
	100,051	143,122
<b>Other trading activities</b>		
Christmas card sales	2,380	2,315
<b>Investment management costs</b>		
Portfolio management charges	8,496	11,795

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# THE TUBEROUS SCLEROSIS ASSOCIATION

## Detailed Statement of Financial Activities for the year ended 31 December 2020

	2020 £	2019 £
<b>Charitable activities</b>		
Wages	230,617	271,142
Social security	22,407	22,955
Pensions	13,974	14,454
Sundries	1	-
Staff training	3,714	-
No description	-	22,577
Accommodation and room hire	4,532	-
Publications	7,409	18,704
Travel & Communications	4,750	-
Benevolent grants	3,070	5,700
Family days and weekends	314	1,175
Subscriptions	2,041	-
Postage and Stationery	2,751	-
Sundries	5,054	2,237
Insurance	758	-
IT and GDPR services	540	-
Marketing & Media	2,610	-
Professional fees	1,016	-
Grants to institutions	147,224	252,565
	<u>452,782</u>	<u>611,509</u>
<b>Support costs (see page 24 no. 6)</b>		
<b>Management</b>		
Chief executive salary	-	44,000
Social security	-	5,029
Pensions	-	2,640
Chief executive expenses	154	1,375
Recruitment costs	50	1,028
	<u>204</u>	<u>54,072</u>
<b>Finance</b>		
Postage and stationery	358	3,386
Bank charges	716	2,173
Amortisation of intangible fixed assets	-	333
Depreciation of tangible fixed assets	763	250
	<u>1,837</u>	<u>6,142</u>
<b>Other</b>		
Trustees' expenses	-	3,036
IT & GDPR Services	15,113	15,375
Insurance	2,674	3,551
Office costs	10,386	11,564
Sundries	723	4,677
Professional fees	3,441	7,053
Marketing	-	24,420
Travel	127	608
Carried forward	32,464	70,284

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# THE TUBEROUS SCLEROSIS ASSOCIATION

## Detailed Statement of Financial Activities for the year ended 31 December 2020

	2020 £	2019 £
<b>Other</b>		
Brought forward	32,464	70,284
Loss on sale of tangible fixed assets	(75)	-
Redundancy costs	<u>-</u>	<u>52,333</u>
	32,389	122,617
<b>Governance costs</b>		
Auditors' remuneration	-	6,357
Sundries	-	13,926
Accountancy and legal fees	10,634	10,264
AGM expenditure	<u>5,541</u>	<u>18,342</u>
	<u>16,175</u>	<u>48,889</u>
Total resources expended	<u>614,314</u>	<u>1,000,461</u>
<b>Net expenditure</b>	<u>(195,568)</u>	<u>(697,645)</u>

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