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## About the Tuberous Sclerosis Association

The Tuberous Sclerosis Association (TSA) was founded in 1977, and is the only UK charity focused on improving the lives of people affected by the rare genetic disorder Tuberous Sclerosis Complex (TSC).

The TSA's mission is to provide help for today and a cure for tomorrow. We do this by:

- Providing direction or a listening ear through our **support and information services** for the TSC community, including through our UK-wide TSA Support Line
- Organising **events and opportunities across the UK and virtually for those affected by TSC**, allowing the TSC community to come together and feel less alone
- **Funding internationally-significant research into the causes, diagnosis, management and treatment of TSC** that has the greatest impact on those affected by TSC
- **Campaigning on behalf of the TSC community** to ensure consistent and meaningful access to health and social care provision

## About Tuberous Sclerosis Complex

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 grow and cause problems, it is mainly because of their size and where they are growing in the body.





# A look back at 2020

**In 2020, the TSA faced some of the biggest challenges that it has ever come up against, right at a time when many people in the TSC community needed us more than ever before.**

Despite the disruption and confusion of covid-19, the global collapse of charitable giving, and the increased demands on resources at the TSA, our charity was able to push through one of its busiest ever years while succeeding in our strategic aims and objectives across support, research and income generation.

In 2020, the TSA urgently reviewed our business plan after the covid-19 pandemic caused extraordinary changes to the world around us all. Our Trustees were worried about the impact of the pandemic on people living with TSC and their families, many of whom were already isolated and living in difficult circumstances. We wanted to make sure that the TSA could meet their needs now and in the future.

During 2020, we continued our focus on the priorities set out in the TSA's five-year strategy, delivering them in innovative new ways to meet the challenge of the pandemic:

- **Reaching more people.** Through the new TSA Support Line, which launched in January 2020, we provided emotional support and tailored information about TSC by email and telephone. We organised monthly virtual events and get-togethers to bring people together, and remind people affected by TSC that they are not alone, especially while shielding or self-isolating
- **Driving more research.** We delivered a virtual International TSC Research Symposium, bringing together over **140 clinicians and researchers** from across the globe. We were determined to strengthen links across the global scientific community and ensure that the pandemic did not disrupt progress with research that brings hope for the future to individuals and families living with TSC

- **Balancing the books.** We continued to make the difficult decisions needed to manage our finances, with the view of balancing our books by 2022 or 2023. We carried on addressing our structural deficit by significantly reducing both expenditure (from **£1,000,461** in 2019 to **£614,314** in 2020) and headcount (from **13 posts** at the start of 2020 to **nine posts** by the end of 2020). These staff cuts were the second round of redundancies needed to make the charity the right size for the future

This booklet discusses these significant moments, as well as others, for the TSA in 2020. The Impact Report 2020 is a reminder of our key victories across our small team, giving us a chance to reflect on what we achieved during an incredibly turbulent year. In the Strategic Report 2020, readers can look into our work in greater detail, to better understand our strategy and planning for 2020 and beyond.

## TSC in numbers

- Every month around 10 babies are born with TSC in the UK
- Eight in 10 people with TSC have epilepsy that typically starts in infancy and is difficult to control using epilepsy medication
- One in two people with TSC have learning disabilities. Three in 10 people have profound learning disabilities and need lifelong support from their families, or live in residential care
- Nine in 10 people with TSC develop TSC-Associated Neuropsychiatric Disorders (TAND), which includes a range of conditions including autism spectrum disorder, attention deficit hyperactivity disorder, aggression, depression, anxiety, and sleep disorders, all of which can have a serious impact on family life

# How the TSA helps to improve lives

**As with every year, in 2020 the TSA worked hard across support and information, research and fundraising to improve lives in the TSC community. Here, TSC community members share how they worked with the TSA in 2020, and how the charity helped them.**

## Alex (age 11) and Evie (age 8) Donnelly, Community fundraisers



"We decided to run 2.6 miles (with our parents) for the 2.6 Challenge, which was organised by the London Marathon team as the 2020 marathon was cancelled because of covid-19. Our dad has ran the marathon before and is doing it again, and he is always talking about running which inspired us. We wanted to support the TSA as Alex has TSC, and we raised £3,609 which will fund work by doctors looking at new medicines. We are thankful for the TSA and the work they do to help people like Alex."

## Jonathan and Matthew Plant, Community Fundraisers



"Matthew and I took part in the first ever virtual Prudential Ride London to Surrey cycle challenge for the TSA, in honour of my nephew Greg Morris who has TSC. We cycled 53 miles around a course consisting of quiet rural roads in South Lanarkshire. The weather stayed fine and we had welcome support including drinks and cakes at the halfway point. Training for the virtual event gave us a real incentive to keep active, and we raised over £800 for the TSA who provide support to Greg's family. The TSA is an invaluable source of information about medical and behavioural issues encountered by people with TSC. The TSA also allows problems to

be shared, with helpful advice from those who have 'been there, done that'. We are thankful that the TSA ensures those with TSC and their carers are not alone.





# Support and information

Providing support and information to the TSC community is at the heart of the TSA. In 2020 this work continued, with milestone updates to our support services alongside other vital work to keep the TSC community informed and supported through the covid-19 pandemic and all TSC-related issues.

## TSA Support Line launch

In March 2020 we launched the TSA Support Line, a national service that TSC community can contact Monday – Friday 9am – 5pm. The TSA Support Line is here for everyone in the TSC community, with our small team of friendly advisers offering practical and emotional support.

In 2020, we received **384** support and information enquiries on a range of TSC-related topics. Around **25%** of enquiries were about covid-19. **Fifty-one** enquiries included signposting to other specialist organisations, including: Mencap, Contact, Epilepsy Action and Sibs.

The people who contacted the TSA Support Line in 2020 were most commonly:

- **Parents/Carers of a child living with TSC**
- **Parents/Carers of an adult living with TSC**
- **Adults living with TSC**
- **Siblings of someone living with TSC**
- **TSC professionals (such as a doctor, social worker or teacher)**

The most common reasons people contacted the TSA Support Line in 2020 were:

- **Financial enquiries, including the TSA Support Fund**
- **TSC health-related issues**
- **TSC and covid-19**
- **Accessing support materials**
- **Health and social referrals, including to NHS TSC Clinics**
- **Emotional support (such as following a new diagnosis)**

## Keeping you updated about covid-19

As well as the TSA Support Line, in 2020 our team focused on providing support and information across our website, e-newsletters, Scan magazine and social media platforms.

We developed a joined-up strategy, so every platform shared the same helpful information and resources as others. This included a focus on covid-19, by taking government updates and other news and giving it a TSC focus, so that the community felt more equipped and confident in getting through the pandemic.

We knew the huge impact that covid-19 would be having on individuals and families in 2020. This is why we also took the step of sending out special postcards, reminding people that they were not alone, and that the TSA was there for them (and continues to be).



The TSA Support Fund can offer a lifeline to individuals and families affected by TSC when the financial implications of the condition become too much to carry.

In 2020, we awarded the TSA Support Fund to **14 TSC community members or families**, with a total of **£3,329** being awarded to the TSC community.

## Working with and supporting NHS TSC Clinics

Throughout 2020, the TSA continued to work closely with NHS TSC Clinics across the UK. This helped to ensure a joined-up path of care and support for people affected by TSC, from initial diagnosis to across all life stages. In 2020, our work with TSC professionals had a particular focus on covid-19, ensuring that any medical covid-19 information we signposted was correct, reliable and up-to-date.



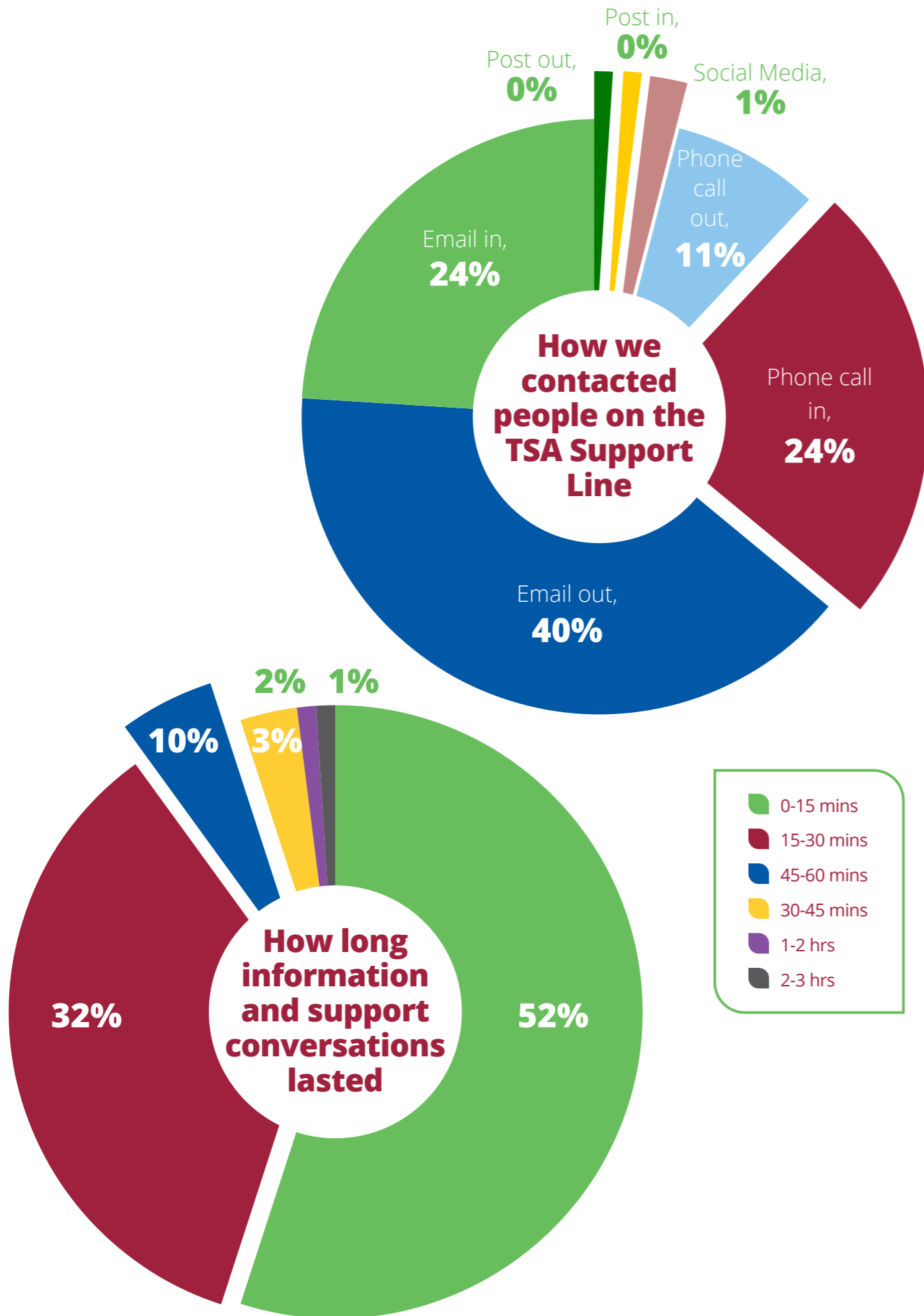
The TSA Support Line is here for everyone in the TSC community, whether you have a specific TSC question or would just like a listening ear.

You can speak to our small team of TSA Support Line Advisers over the phone, email, post and we launched webchat:

📞 **0808 801 0700**

@ **support@tuberous-sclerosis.org**

✉️ **Freepost TSA**



## Bringing people together

The global covid-19 pandemic meant that our typical events calendar was put on hold. However, this wasn't going to stop the TSA from bringing together the TSC community, especially at a time when so many individuals and families would be feeling isolated and alone during the pandemic.

By embracing online meetings, the TSA was able to host a record-breaking number of events in 2020. Over **578 users** registered to attend **16 virtual events**. In many cases, families joined events through a single device, with everyone gathered around one screen.

took place virtually, including Outlook (for adults mildly affected by TSC), the Scottish Get Together, the Welsh Get Together and the Northern Irish Get Together.

**Although we were almost completely virtual in 2020, we did host a face-to-face Family Fun Day in February, before the impact of covid-19 took a hold in the UK. 13 families signed up to come along to Portsmouth's Blue Reef Aquarium, for a fun day out!**

**TSA virtual events in 2020 covered a wide range of TSC-related topics and issues, including:**

- Covid-19 support and information, including vaccines
- TSC and epilepsy
- TSC-Associated Neuropsychiatric Disorders (TAND)
- Mental health and wellbeing
- Managing challenging behaviours
- Support and information for TSC carers

Christmas 2020 was a difficult time for everyone, with many festive gatherings around the UK cancelled or put on hold at short notice. The TSA worked hard to bring everyone together virtually, with a lovely online reading of 'The Night Before Christmas' by Sir David Suchet CBE, a Christmas singalong led by families and individuals living with TSC, and a virtual Outlook festive quiz to bring people mildly affected by TSC together during the festive season.

- “ The TSA has done all that can be done at the present time to reach out ”
- “ Brilliant, really helpful. I'll look forward to attending more ”
- “ Thank you for tonight's session, great to see so many join what was a superb and interesting presentation ”
- “ Thank you for your enthusiasm and commitment in organising and managing all the online sessions ”

Another major benefit of going virtual for our events was sharing event recordings across the TSC community. Embracing more video content at the TSA in 2020 has resulted in **17,576 views** of TSA recordings from 2020 so far.

Our popular range of TSA annual events also



# Driving more research

The TSA is the only UK charity with a major focus on supporting TSC research. We aim to drive research that gives individuals and families affected by TSC hope for the future.

## TSA-funded grant awards

In 2020, the TSA's research portfolio of previously committed grants consisted of **12** live grants, three of which were jointly funded. Our portfolio of ongoing projects is worth **£1,227,576**.

Investigator	Institution	Title and purpose of grant	Co-funder
Professor Patrick Bolton and Dr Charlotte Tye	Kings College London	Autism Spectrum and Attention Deficit Hyperactivity Disorder in the Tuberous Sclerosis 2000 Cohort Study	
Dr Charlotte Tye	Kings College London	Designing a protocol to measure the developmental trajectory of infants with Tuberous Sclerosis	
Dr Martin Baron	University of Manchester	Exploiting Notch regulation to probe alternative mechanisms of TSC signalling	
Dr Mark Nellist	Erasmus MC	Functional and structural characterisation of the TSC complex; improved function assessment of TSC1 and TSC2 variants associated with tuberous sclerosis complex	
Dr Rosemary Ekong and Dr Mark Thomas	University College London	The TSC1 and TSC2 variation databases	
Dr Kacper Rogala	Whitehead Institute – MIT	Identifying and creating more specific medicines for TSC	
Dr Elaine Dunlop	Cardiff University	Characterising the role of exosomes in TSC	
Professor Andrew Tee	Cardiff University	Understanding the limits of everolimus and rapamycin	
Dr Elaine Dunlop	Cardiff University	A model of cell invasion in TSC-LAM	US Ministry of Defence
Dr Sam Amin and Dr Ingram Wright	University of Bristol	Better understanding the accessibility of mental health services for children and young people with TSC	Anonymous major donor
Professor Petrus de Vries and Professor Anna Jansen	University of Cape Town and UZ Brussels	The TANDem Project	King Baudouin Foundation

You can find out more about all of these projects on page 12.

In 2020, we collected annual research data from 10 TSA-funded grants. Of these, three grants reported six publications in six different academic journals. Five grants reported seven other forms of engagement, such as oral and poster presentations at academic conferences or professional meetings. These figures are lower than in previous years as some of our researchers were unable to carry out lab work, which impacted on data generation and delayed publication and presentation of the data. The grant-holders have been given extra time to complete their projects and report their findings to us.

## International TSC Research Conference postponed to 2021

The three-day International TSC Research Conference is held each year to bring together academics, healthcare professionals, industry professionals and the TSC community. The 2020 conference was due to take place in London, hosted by the TSA. However, covid-19 led to us postponing the event and hosting it virtually in 2021 (to great success!)

## International TSC Research Symposium 2020 delivers!

We were determined to still bring the international research community together in 2020, despite covid-19. We hosted a half-day virtual research symposium in November 2020, working with USA charity TSC Alliance and USA organisation The LAM Foundation. Attendees were able to access recordings from the event for one month after it took place. Over **140 delegates** from **14 different countries** registered to attend the symposium. The symposium was sponsored by GW Pharmaceuticals and PlusUltra Pharma.

*"I thought the symposium was wonderful. It was amazing to see so much engagement and discussion from the audience. The talks were easy to follow, had novel data encompassing different facets of TSC, and garnered lots of very good discussion. In this covid world where we are unable to meet in person, these virtual gatherings are very important to keep the enthusiasm and momentum in the field intact, and I applaud and congratulate you in pulling this all together."*

Dr Nishant Gupta, University of Cincinnati

## Support and information for professionals

Regular contact between the TSA and NHS TSC Clinics helps to facilitate improvements in care through sharing best practice.

We were able to host our annual NHS TSC Clinics Day in March 2020, just a couple of weeks before the country went into lockdown. The day 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.

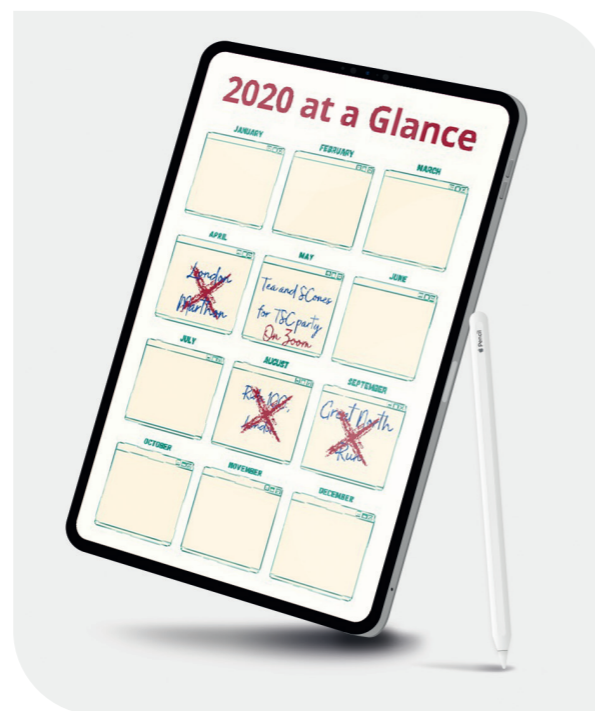
# Income generation and fundraising

**The pandemic didn't stop, us and it didn't stop you either!**

**In 2020, covid-19 meant that many of our annual fundraising events had to be cancelled or rearranged to being virtual. But, this didn't stop our amazing community fundraisers, who got creative!**

TSA fundraisers and donors achieved incredible things, all within shielding and social distancing guidelines. Personal challenges and donations included everything from cutting off lockdown hair to leaving large legacies. This incredible effort safeguarded the future of the TSA, for today and also for tomorrow.

To everyone who donated, ran, climbed, cycled, swam, hopped, skipped (and even climbed Everest from home) for our shared cause: Thank you!



## Coronavirus emergency Appeal

The TSA works hard to improve lives in the TSC community, and 2020 was no different. However, 2020 was also the year that the charity turned to the community to ask for help.

Covid-19 devastated the TSA's income, putting the future of the charity at risk. We appealed to the TSC community through

our **Coronavirus Emergency Appeal**, which asked community members to kindly give to the TSA so that we could continue our work to improve lives in the TSC community.

Your generosity was incredible, with a jaw-dropping **£21,695** donated by the TSC community to the appeal in 2020.

### We can only be here thanks to our committed and remarkable supporters:

Equistone Partners Europe Ltd	Charitable Trust	The Douglas Heath Eves Charitable Trust
GW Pharmaceuticals	Daytrippers	The Hamer Charitable Trust
PlusUltra Pharma	Dunn Family Trust	The Michael and Anna Wix Charitable Trust
John Lewis - Logic Park	Esher House Charitable Trust	Coronavirus Community Support Fund, distributed by The National Lottery Community Fund
Legal & General Group PLC	Joseph Strong Frazer Trust	The Rest-Harrow Trust
Lendlease UK Ltd	JTH Charitable Trust	The Tregelles Trust
Lomax DIY	Lorimer Trust	Thomas Sivewright Catto Charitable Settlement
Stokenchurch Lodge - Freemasons Lodge	Meikle foundation	Tower Hamlets Council
<b>Trusts:</b>		
Adint Charitable Trust	Sir James Knott Trust	
Anglo American Foundation	Sir Samuel Scott of Yews Trust	
Bank of Scotland Foundation	Swann Morton Foundation	
Charles & Elsie Sykes	The Bartlett Taylor Charitable Trust	

## Corporate support during the time of Covid: EQUISTONE

Private equity firm Equistone had selected the TSA as their Charity of the Year for 2020 before the pandemic struck. The decision was quickly and unanimously agreed by Equistone's Charity Committee after a colleague (CJ) had been informed that her child has TSC.

*"We are a close-knit team, so we've all been keen to support CJ and her family," says Annette Ratcliffe from Equistone's Charity Committee: "The personal element aside, we liked the fact that TSA is small, so our donations can make a big difference."*



The national lockdowns and restrictions on people meeting in 2020 meant that some of Equistone's planned activities were unable to go ahead.

However, Equistone seized the opportunity to make a huge difference to the lives of people affected by TSC, coming together as a team and shifting to online and at-home activities.

Equistone's UK team had to be creative to replace the events that would have taken place. They hosted lots of online events, and even decided to climb the equivalent of Mount Everest's elevation (8,846 metres) on their stairs at home, all while in fancy dress!

Over the course of an extraordinary year, Equistone raised an incredible **£45,000**. This figure is testimony to their determination, imagination and desire to support the TSA and the TSC community through a very challenging year.



## 2020 fundraising in numbers



**£418,746**  
Total income

the  
**2.6**  
challenge

**£3,800**  
Raised though the  
2.6 Challenge



**£42,750**  
Awarded from Trusts



**£85,000**  
Provided from gifts in wills

**Coronavirus  
emergency  
Appeal**

**£21,695**  
Donated to our Coronavirus  
Emergency Appeal



**£45,000**  
Generated by our corporate  
partner, Equistone

## Income and expenditure

Of every £1 we spent:

42p goes into  
Research

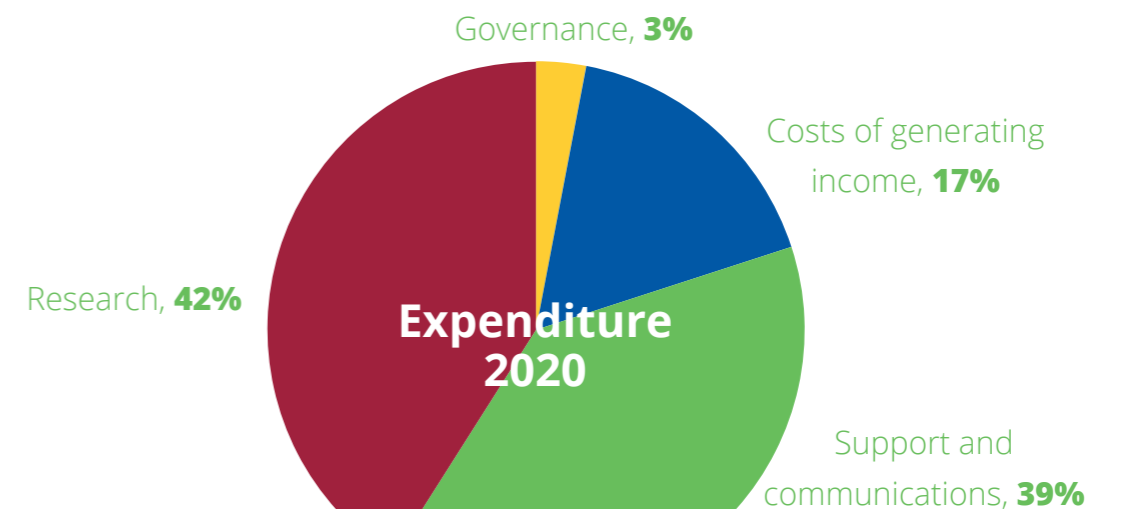
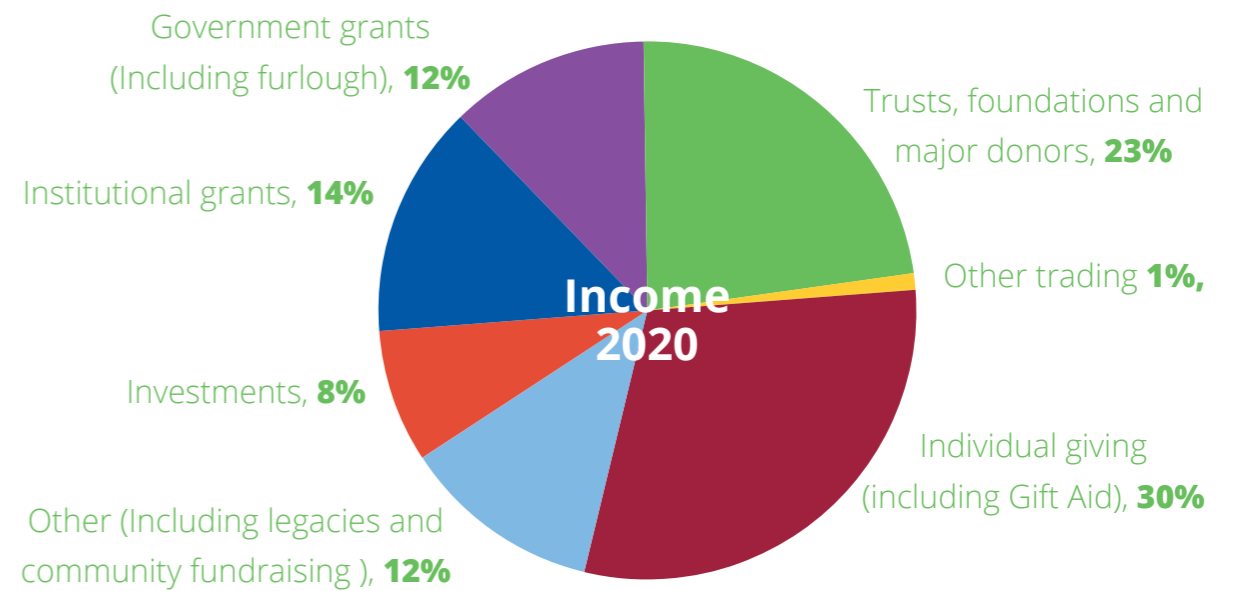
For every £1 invested  
in Fundraising the  
TSA generates £3



2p goes to  
Governance

17p is invested in  
Fundraising

39p goes to  
Support and  
Communications



# The Tuberos Sclerosis Association Trustees' Report 2020

## Strategic Report with Supplementary Information

The attached Strategic Report is reproduced in full form, and forms part of, the Report of the Trustees for the year ended 31 December 2020.

We have also attached the Summary Statement of Financial Activities (SOFA) for the year ended 2020 and the Summary Balance Sheet as of 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](mailto:admin@tuberous-sclerosis.org). In addition, the full report and accounts will be available via the TSA website ([www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)), Companies House ([www.find-and-update.company-information.service.gov.uk](http://www.find-and-update.company-information.service.gov.uk)) or from the Charity Commission ([www.gov.uk/governmentorganisations/charity-commission](http://www.gov.uk/governmentorganisations/charity-commission)).

This year we have moved from a full audit to an independent examination to make sure that we invest as much of our income as possible in activities that support the charity's beneficiaries. The Independent Examiner's report does not identify any areas of concern where accounting rules were not followed, disclosures not fully made or accounting records were incomplete.

On behalf of the Trustees  
Sanjay Sethi, Chair  
Tuberous Sclerosis Association



## STRATEGIC REPORT 2020

**tssa**  
tuberous sclerosis  
association



# 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 TSC-associated Neuropsychiatric Disorders (TAND), which includes 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

## 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 a 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 the 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

## 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

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
- Launching 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 International Research Conference 2020 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.

### 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 TSC 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 2020 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.

## 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 TSA 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)
- Welsh Get Together with the Cardiff NHS TSC Clinic (**28 people registered**)
- Scottish Get Together with the Glasgow Clinic (**7 people registered**)
- Northern Ireland Get Together 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
- 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 TSA 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 listen 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.	



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 mTOR 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	<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	<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>	
Dr Elaine Dunlop	Cardiff University	<p><b>A model of cell invasion in TSC-LAM</b></p> <p>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.</p>	US Ministry of Defence
Dr Sam Amin and Dr Ingram Wright	University of Bristol	<p><b>Better understanding the accessibility of mental health services for children and young people with TSC</b></p> <p>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.</p>	Anonymous major donor

<p>Professor Petrus de Vries and Professor Anna Jansen</p>	<p>University of Cape Town and UZ Brussels</p>	<p><b>The TANDem Project</b></p> <p>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.</p>	<p>King Baudouin Foundation</p>
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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 with TSC Alliance and the LAM Foundation. **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:

- 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.

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.

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 outperformed 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 Communications and Support, 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 costs 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).



# 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 TSC 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 living 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
- 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 2021
- 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.

# The TSA Summary Statement of Financial Activities

For 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>		<b>392,746</b>	<b>26,000</b>	<b>418,746</b>	<b>302,816</b>
<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>		<b>583,614</b>	<b>30,700</b>	<b>614,314</b>	<b>1,000,461</b>
Net gains/(losses) on investments		(50,959)	-	(50,959)	208,190
<b>NET INCOME/(EXPENDITURE)</b>		<b>(241,827)</b>	<b>(4,700)</b>	<b>(246,527)</b>	<b>(489,455)</b>
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		<b>1,213,996</b>	<b>4,700</b>	<b>1,218,696</b>	<b>1,708,151</b>
TOTAL FUNDS CARRIED FORWARD		<u>972,169</u>	<u>-</u>	<u>972,169</u>	<u>1,218,696</u>

# The Tuberosus Sclerosis Association Summary 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	960,594	-	960,594	1,268,946
		<u>960,594</u>	<u>-</u>	<u>960,594</u>	<u>1,269,797</u>
<b>CURRENT ASSETS</b>					
Debtors	14	82,171	-	82,171	98,608
Cash at bank		251,432	-	251,432	264,938
		<u>333,603</u>	<u>-</u>	<u>333,603</u>	<u>363,546</u>
<b>CREDITORS</b>					
Amounts falling due within one year	15	(322,028)	-	(322,028)	(414,647)
		<u>11,575</u>	<u>-</u>	<u>11,575</u>	<u>(51,101)</u>
<b>NET CURRENT ASSETS</b>		<b>11,575</b>	<b>-</b>	<b>11,575</b>	<b>(51,101)</b>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<b>972,169</b>	<b>-</b>	<b>972,169</b>	<b>1,218,696</b>
		<u>972,169</u>	<u>-</u>	<u>972,169</u>	<u>1,218,696</u>
<b>NET ASSETS</b>					
<b>FUNDS</b>					
	16				
Unrestricted funds				972,169	1,213,996
Restricted funds				-	4,700
<b>TOTAL FUNDS</b>				<u>972,169</u>	<u>1,218,696</u>





# Everyone at the TSA would like to give thanks to our Board of Trustees for all of their work:

Sanjay Sethi – Chair

Martin Short – Deputy Chair

David Vaughan – Treasurer

Annemarie Cotton

Chris Kingswood

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