TSA Year in Review: 2021
Key projects and milestones
Welcome

The TSA’s Year in Review 2021 looks back at the work of the TSA during what was a year of great transition and change. The document gives the TSC community, our supporters and the TSA itself a chance to reflect on the key victories of our small team in 2021.

In this booklet, you’ll find:

• TSA Impact Report 2021. An at-a-glance look at the work of the TSA in 2021 and just some of the major milestones that we achieved for the TSC community
• TSA Strategic Report 2021. A more in-depth look at the TSA and what we achieved in 2021, looking at the inner-workings of our strategy and key enables. The report also looks at the present day and beyond

We welcome comments and questions from anyone about the work and strategy of the TSA for the TSC community. If you’ve got a question for us about the impact report or strategic report for 2021, or about anything else, be sure to get in touch: admin@tuberous-sclerosis.org.

About Tuberous Sclerosis Complex

• Rare genetic condition, often inherited
• Every month around 10 babies are born with TSC in the UK
• Causes growths to develop in different organs around the body, such as the brain, lungs, kidneys, eyes, heart and skin
• Common problems with TSC include epilepsy, autism, learning difficulties and kidney problems. However, the way that TSC impacts on a person’s life can vary considerably

About the Tuberous Sclerosis Association

The Tuberous Sclerosis Association (TSA) is the only UK charity focused on improving the lives of people affected by the rare genetic disorder Tuberous Sclerosis Complex (TSC). Founded in 1977, the TSA’s mission is ‘To provide help for today and a cure for tomorrow’. We do this by:

• Providing support and information to the TSC community, including the UK-wide TSA Support Line
• Organising events and opportunities for the TSC community, allowing people affected by TSC to come together, learn and feel less alone
• Funding internationally-significant research into all aspects of TSC, with research focused on what will have the greatest impact on life with TSC
• Working closely with clinicians and other professionals focused on improving the lives of people affected by TSC
• Campaigning on behalf of the TSC community to ensure consistent and meaningful access to health and social care provision
“We think you are an amazing light in a stormy sea. I don’t know how we would have started to navigate TSC without the TSA.”

“TSA are always on the end of the phone or e-mail. They are very helpful and finding information very promptly. They go out of their way to answer questions. It is nice to know that we can contact TSA if we have any concerns or problems.”

“We think you are an amazing light in a stormy sea. I don’t know how we would have started to navigate TSC without the TSA.”

“The help and advice that TSA Support Line Advisers have provided by phone and email over the years has been absolutely invaluable. Please continue this service.”

“The level of support for families living with TSC is invaluable, it helps bring people together who feel isolated, it increased knowledge - families and professionals and it gives hope, guidance and comfort.”

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A look back at 2021

**2021 was a time of transition for the TSA and the world as a whole, with everyone continuing to feel the impact of covid-19 while slowly entering the ‘new normal’**

Moments of great difficulties are often also the time when ingenuity and creativity are called upon. In the TSC community throughout 2021, this was evident through the uptake of more at-home consultations, remote professional events, and the continuation of virtual TSA events for the TSC community. Things that had been previously thought of as too difficult or technical were suddenly at the heart of everyday life.

Just like in 2020, we paused the strategic aims of our five-year plan for 2019 – 2023. This allowed us to concentrate on what would best help the TSC community and the TSA itself to get through the challenges of 2021. Our primary objectives were:

- **Provide access to good quality, accessible and timely information.** The TSA Support Line continued to develop. There were key improvements in ways to access and engage with the service, including the free installation of translation services.

- **Provide the opportunity for people with TSC to connect, support and learn together.** Our popular virtual events started in 2020 and continued throughout 2021, giving the TSC community the chance to be together. Topics were focused on areas that matter most to the TSC community.

- **Build the knowledge of professionals supporting people living with TSC.** Working closely with NHS TSC Clinics and the amazing clinicians who operate them, the TSA was able to continue to forge important links with TSC specialist and non-specialist healthcare professionals.

- **Drive the research agenda with the aim of improving outcomes and quality of life for people living with TSC.** Despite the disruption of covid-19, we were able to still fulfil all of our vital research funding obligations, ensuring that future breakthroughs in the diagnosis, treatment and management of TSC continue. We were proud that this was possible.

- **Campaign for better access to treatments and care.** The TSC treatment pipeline remains positive and optimistic. In 2021, this included us working hard to campaign for access to key medicines in the UK. We were delighted when this led to cannabidiol (brand name Epidyolex) being approved and funded for use in Wales for those with TSC-related epilepsy.

A further milestone that was also hit in 2021 was that the TSA was able to balance the books – bringing in as much as we spend.

At the dawn of 2022, we entered a new world were the innovations pushed onto us by the pandemic could lead to better lives in the TSC community. The hard work of the small TSA team has continued into 2022, made possible thanks to the breakthroughs across support and information, research, fundraising and advocacy in 2021.
A snapshot of our work in 2021

- Successful NHS TSC Clinics Education Meeting, with record-breaking attendance from TSC specialist clinicians
- Successful campaigning for access to cannabidiol (Epidyolex) in Wales for TSC-related epilepsy
- Successful funding of research, covering a wide range of TSC topics
- New and exciting ways to fundraise for the TSA, including the very first NHS TSC Clinics Virtual Challenge
- Reaching many more people, using different methods of communications
- Building on the TSA Support Line, making the service even better
- Bringing the TSC community together, at a time when many were alone
Support and information

The TSA’s support services team worked flat-out during 2021 – mostly in providing information, signposting and a listening ear to the TSC community during the covid-19 pandemic. But, the team also achieved a number of key milestones in our work for the TSC community.

Reaching more people

Launch of the TSA Monthly Roundup

• A snapshot of all-things TSA and TSC every month, straight to four email inbox
• Sent to around 3,000 people every month
• Part of the TSA’s efforts to be more focused on digital communications

More people on the TSA database

• 940 new individuals added
• Now over 5,000 people on the TSA database

Our aim was to be in contact with 3,700 people with TSC between 2019 – 2023. This means that we’ve already exceeded this target!

Some people new to us in 2021 told us about their TSC connection. This was most commonly:
1. TSC professional (researcher, clinician, social worker etc.)
2. Parent or guardian
3. Wider family member (auntie, cousin etc.)
4. The person living with TSC themselves
5. Sibling

20% * increase in the number of people we’re in contact with

16% more followers on social media (Facebook)

PLUS 23,458 visits to the TSA website

*Individuals registered on our database
TSC connections on the TSA database (when known)

- Individual with TSC: 48%
- Parent of TSC Individual: 22%
- TSC researcher: 13%
- TSC specialist and non-specialist clinician: 10%
- Other family member: 6%
- Other professional: 1%

Scan to your doorstep and inboxes

Our monthly magazine, Scan, continued to be produced and enjoyed in 2021 by everyone in the TSC community. We made the difficult decision to reduce Scan to two issues a year. This means that we can spend more time on making sure that the remaining two Scan include the most useful and impactful content possible.

If you enjoy reading Scan, consider reading it online rather than getting it through the post – you’ll be saving the TSA a lot of costs, but still receiving great content!

TSA Support Line

The TSA Support Line was open for its first full year in 2021, with our small and dedicated support team speaking to many different people about a wide range of TSC-related topics. We also received full accreditation for the TSA Support Line by helplines body Helplines Partnership. The accreditation demonstrates the high quality and professionalism of the service.

Improvements to the service

• Launch of webchat, allowing people to contact us through our website
• Installed translation service LanguageLine – people can talk to us in their chosen language, at no added cost

In numbers

• 406 enquiries by 277 different individuals
• Roughly 7 enquiries fielded by the TSA support team every week, alongside other projects and duties.

Common reasons we spoke to people on the TSA Support Line included (in no specific order):

1. Questions about the health of someone living with TSC
2. Engagement with TSC professionals, including clinicians and social care teams
3. Information and support following a new diagnosis
4. TSA Support Fund applications
5. Questions about TSC and covid-19
6. A listening ear and emotional support for people, focused on TSC
The TSA Support Fund

The TSA Support Fund is a small grant-giving scheme by the TSA, to give a helping hand to the TSC community when the costs of living with the condition become too much.

In 2021, the TSA Support Fund provided £3,379 directly to individuals and families affected by TSC.

Working with NHS TSC clinics

The TSA works very closely with NHS TSC clinics across every UK nation, and 2021 was no different. Notably, we were delighted to host the annual NHS TSC Clinics Education Meeting. The event was held virtually for the first time, allowing for a record-breaking attendance.

The NHS TSC Clinics Education Meeting had 82 registrations from TSC clinical professionals.

TSA events

- 13 virtual events throughout 2021
- 282 live attendees – around 21 per session
- Event recordings viewed 3,674 times

Virtual events in 2021 included:

- Practical aspects of TSC, such as better sleep for children with the condition
- Clinical talks focused on specific medical aspects of TSC
- Separate get together events for those in Scotland, Wales and Northern Ireland
- Virtual Outlook events, for adults mildly affected by TSC.
Fundraising and income generation

The need to ensure the long-term survival of the TSA was even more important than ever during 2021. We were still feeling the full impact of covid-19 (which continues to today), but received incredible support from individual donors, corporate supporters, trusts and foundations.

Balancing the books

An important part of our current five-year strategy was to balance finances at the TSA – we wanted to make sure that the income we brought in was the same as the money we spend.

The team agreed that balancing the books in 2021 would likely be a step too far for us, as a result of covid-19. However, we were remarkably able to not only break even but to also increase income.

Community Fundraising

**London Marathon 2021**

Five runners

£20,500 raised

**Great North Run 2021**

Six runners

£3,013 raised

Sir David Suchet CBE generously supported the TSA throughout 2021. This included ‘In Conversation with Sir David Suchet CBE’, a virtual event where Sir David discussed his incredible career across stage, television and film. Sir David raised an incredible **£16,667** for the TSA during 2021, for which we are all incredibly grateful.

**TSA Christmas Appeal 2021**

£5,475 raised by the TSC community, through purchases of festive cards and other goodies.

**NHS TSC Clinics Virtual Challenge**

2021 was the first year of the NHS TSC Clinics Virtual challenge, where we asked you to target an equivalent distance between two NHS TSC Clinics and to cover that distance over one month. Your efforts in walking, running, jogging, swimming (and more!) raised a wonderful **£3,806**.

**The Big Give Challenge 2021**

In December 2021, we asked you to help us to raise vital funds for the TSA Support Fund through national project The Big Give Challenge. Our target was £3,000, which we hit in just one day! This figure was doubled by The Big Give, with the final amount being a brilliant **£8,674**.

• A J & K M Barnett Charitable Trust
• Ardwick Trust
• Arnold Clark Community Fund
• Bailey Thomas Charitable Foundation
• Bartlett Taylor Charitable Trust
• Beechwood Trust
• Dunn Charitable Trust
• Esher House Charitable Trust
• Gosling Foundation
• Hamilton Wallace Charitable Trust
• Hospital Saturday Fund
• Ian Fleming Charitable Trust
• Jeans for Genes
• Joseph Strong Frazer Trust
• Leach Fourteenth Trust
• Marsh Charitable Trust
• Meikle Foundation
• Michael and Anna Wix Charitable Trust
• Moo Creative
• PF Charitable Trust
• R S Brownless Charitable Trust
• Rainford Trust
• Rest-Harrow Trust
• Sir James Roll Charitable Trust
• Softcat PLC
• St James Place Charitable Foundation
• Swann-Morton Foundation
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Income and expenditure

Of every £1 we spent:

- 3p goes to Governance
- 27p is invested in Fundraising
- 32p goes to Support and Communications
- 38p goes into Research

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

Income 2021:
- Trusts, foundations and major donors, 22%
- Other trading, 1%
- Individual giving (including Gift Aid), 37%
- International TSC Research Conference, 18%
- Institutional grants, 19%
- Investments, 8%

Expenditure 2021:
- Costs of generating income, 27%
- Support and communications, 32%
- Research, 38%
- Governance, 3%
Driving more research in 2021

During 2021, our research team continued to drive and support more research to give people living with TSC and their families hope for the future.

TSA-funded grant awards

The TSA is the only UK charity dedicated to supporting TSC research with a forward commitment / liability of research funding at 01Jan21 of £268,981 with an in-year research grant commitment in 2021 of £130,290. The TSA's research portfolio of committed grants at 31Dec2021 consists of eight live grants (three of which are jointly funded). Our portfolio of ongoing projects has a combined funding commitment of £138,691.

The charity's Trustees remain determined to honour the research grant commitments that we have made despite the pandemic and decided that the Designated Endowment Fund would be used to cover the cost of our ongoing research grants programme through 2022.

The research portfolio continues to yield results and 2021 saw 11 grants submit data. Of these 11 grants, nine grants reported 10 publications, and eight grants reported 36 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 has meant that some researchers have been unable to carry out lab work which has impacted on data generation and resulted in delayed publication and presentation of the data.

We continue to benefit from various memberships, including the Association of Medical Research Charities (AMRC), the UK Child Health Collaboration, and Charities Research Involvement Group – part of the Shared Learning Group on Involvement.

The TSA passed AMRC’s latest peer review audit

Every five years, the AMRC holds an audit of each of its members, which ensures that each member is upholding research governance processes of the highest quality. The AMRC audited the TSA's research grants programme in 2020-21 and we are grateful for the opportunity to learn from their feedback and continually improve our work in this area. Not only did we successfully pass our audit, but the AMRC also commented that the TSA's processes are "a great example of how a smaller charity can still meet the requirements." The audit helps us to make sure that every pound the TSA invests in research is spent on high quality research that is peer reviewed to world-class standards.
International TSC Research Conference 2021

The International TSC Research Conference 2021 was originally planned to take place face-to-face at the Royal College of Physicians in London, in November 2020. Due to the covid-19 pandemic, we were forced to postpone the meeting. The TSA and the international TSC research committee were determined to drive research forward despite covid-19, and we agreed to host the event virtually through Royal College of Physicians’ virtual conference platform from Thursday 17 – Saturday 19 June 2021.

TSC research we funded in 2021

• Exploiting Notch regulation to probe alternative mechanisms of TSC signalling
  (Dr Martin Baron, University of Manchester)

• Identifying and creating more specific medicines for TSC
  (Dr Kacper Rogala, Massachusetts Institute of Technology)

• Characterising the role of exosomes in TSC
  (Dr Elaine Dunlop, Cardiff University Hospital)

• Understanding the limits of everolimus and rapamycin
  (Prof. Andrew Tee, Cardiff University Hospital)

• A model of cell invasion in TSC-LAM
  (Dr Elaine Dunlop, Cardiff University Hospital)

• Better understanding the accessibility of mental health services for children and young people with TSC
  (Dr Sam Amin and Dr Ingram Wright, University of Bristol)

• The TANDem Project
  (Prof. Petrus de Vries and Prof. Anna Janssen, University of Cape Town and UZ Brussels)

• Designing a protocol to measure the developmental trajectory of infants with Tuberous Sclerosis
  (Dr Charlotte Tye, King’s College London)
Around 250 TSC professional delegates joined the research conference from 22 different countries from across the globe. Attendees included healthcare professionals, academics, clinical and lab researchers, early career researchers, including PhD students and post-doctoral fellow students, and TSC-focused organisations including TS Alliance (USA) and e-TSC (Europe-wide).

We received 70 written summaries from attendees about significant TSC research projects they are undertaking and watched presentations from 12 keynote speakers and 42 presenters. The conference also included a virtual exhibition area for TSC-focused groups and industry bodies, a networking area for delegates, and two industry-sponsored events for healthcare professionals and prescribers to attend. Delegates were able to access recordings from the event through the online platform for one month afterwards, which gave them the opportunity to maximise their learning from the conference.

The research conference was sponsored by Jazz Pharmaceuticals (previously GW Pharma) and Plusultra Pharma. The Early Career Researcher Awards were sponsored by Noema Pharma. Novartis purchased a virtual exhibition stand at the event.

Decision-makers in Wales noted the “real difference” that the input of the TSA and the TSC community had on the approval process.

Access to new treatments

In December 2021, Welsh decision-makers approved funding of cannabidiol (Epidyolex®) for TSC-related refractory epilepsy, allowing access to the medicine in Wales. Approval by a UK nation of cannabidiol for the first time is a major milestone in the treatment and management of TSC, with the medicine offering an important option for TSC clinicians and the TSC community in managing TSC-related epilepsy that is ‘refractory’ (not well managed using other medicines). The TSA worked tirelessly with decision-makers in Wales during the decision-making process, to ensure that the potential benefits of cannabidiol to the TSC community in Wales was well understood.

Decision-makers in Wales noted the “real difference” that the input of the TSA and the TSC community had on the approval process. The TSA continues to work hard with decision-makers across the other UK nations to ensure that they hear the voices of people living with TSC and their families when making decisions about funding cannabidiol for TSC-related refractory epilepsy in the other UK nations.
The TSA launched its research volunteer network

The TSA launched the TSC Research Volunteer Network in early 2021. The aim of the network is to include people with TSC and their families in all aspects of TSC research, from identifying and evidencing research priorities that will have the greatest impact for people living with the condition, to participating in workshops and giving valuable input and feedback to decision-makers such as NICE and the NHS.

Since its launch, we have shared a number of exciting opportunities with the members of our network, including: an invitation to attend a half-day face-to-face conference organised by Epilepsy Research UK’s ‘Shape Network’ at the Frances Crick Institute in London; reviewing draft lay summaries and patient-facing documents for researchers; and giving input and feedback on patient information sheets (PIS) for pharmaceutical companies.

The TSA's work and impact in TSC research

"Patient and public involvement is vital for the EDiTS Study as our goal is to collaborate with individuals living with TSC to help shape the design, quality, and impact of our research. Listening to these voices provides a valuable insight into what matters most to those affected and ensures we prioritise these areas."

- Natasha, a researcher from the EDiTS study at Kings College London

"Knowing that you're helping to increase awareness and understanding of TSC, which will hopefully lead to improvements in available therapies and treatments for patients, is a really rewarding experience. There's so much variety in the research opportunities available - on a couple of occasions, I've helped researchers formulate questions and create information packs for studies they wanted to carry out, which will hopefully help improve outcomes and available care for patients in the future."

- Phillipa, TSC research volunteer and mum of a child with TSC
The TSA Strategic Report 2021 is a deeper look into the innerworkings of the TSA’s strategy and planning, not only for 2021 but also for 2022 and beyond. The strategic report includes reflections on how the TSA fulfilled its objectives for 2021, a financial review of the TSA, and a snapshot into future plans for the charity.

A message from our Chair

This report forms part of the TSA’s annual report and accounts, which are submitted to UK regulators. You can obtain a full copy of the report and accounts by emailing admin@tuberous-sclerosis.org.

The full report and accounts will also be available through the TSA website (www.tuberous-sclerosis.org), Companies House (www.gov.uk/government/organisations/companies-house) and the Charity Commission (www.gov.uk/government/organisations/charity-commission).

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
Best wishes,
Sanjay Sethi
TSA Chair
Objectives and activities

Purpose and Strategy
The TSA has 3 main charitable objectives:
• 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 5 year strategy (2019-23) which sets out a clear vision for 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 the TSA supports by 2023
• Drive more REseArCH - stimulate the same amount of investment in TSC research during 2019-2023 as was invested by the TSA over the previous five years
• Balance the TSA’s finances by 2021 - having invested in research in recent years, we need to reduce expenditure and grow 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 (how we will do it) 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

2021 Business Plan
The first 2 years of our 2019-2023 strategy saw the TSA significantly reduce expenditure to address the charity’s structural deficit while simultaneously maintaining the quality of our services and increasing our reach into the TSC community. However, as a result of the pandemic and working with a less resources than originally envisaged in 2021 and beyond, we agreed to concentrate resource on a smaller number of strategic objectives in 2021 to help the TSA community and the professionals who work with them. These were:

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, the new web chat function to drive better access for family carers and young people with TSC, and regular supervision for our Support Line advisers.

Providing the opportunity for people with TSC to connect, support and learn together
Make sure that no-one with TSC feels alone 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.

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.

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.** Working with our new finance provider to move the TSA onto the Xero accounting system reducing the senior capacity needed to run parallel management accounts

- **Digital transformation and smart working to reach more people.** Introducing a regular monthly e-newsletter and reducing our postal 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.** Maximising income from delegates and sponsors at the International TSC Research Conference and continuing to deliver incremental improvements across our support for major donors and potential major donors, encouraging legacies, working with corporates, trusts and foundations, and individual givers

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 reviewed our overhead costs resulting in the following changes:

- We tendered our accounting and audit services and moving to a new and more cost-effective finance provider

- We moved from an annual audit to an independent examination

- We closed our small office and switched to being an entirely home-based organisation

- We reduced headcount to eight members of staff, following the closure of the TSA's office

- We asked the majority of staff to voluntarily work at 90% of contracted hours, reducing salaries in 2021

**Strategic report**

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 is 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 current 5 year strategy.

**Reaching more people**

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 2021 the TSA had increased this number by 47 per cent with 5,009 people in contact with the charity.

Our Support Line continued to provide vital support and advice by telephone and email to people living with TSC across the UK. 406 people contacted our Support Line for support in 2021 (2020: 384 people), and 23,458 users (2020: 20,639 users) visited our website for information.

**Driving more research**

The TSA hosted the International TSC Research Conference from Thursday 17 to Saturday 19 June 2021 to encourage and support research into the causes and management of TSC. The event, which was planned to take place face-to-face in 2020 and postponed due to the pandemic, was delivered virtually in 2021 through the Royal College of Physicians online event platform

Around 250 TSC professional delegates joined the research conference from 22 countries, all of whom are dedicating their lives to improving the lives of people affected by TSC.

The theme of the research conference was ‘A Vision for the Future’ exploring how academics, researchers and clinicians from across the globe are ambitiously driving new opportunities in TSC to advance their understanding, deliver innovation in clinical practice, and transform the lives of people living with TSC and their families.

**Balancing the books**

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

During 2021 the Trustees took a number of steps to address the deficit:

- Moving to a new and more cost-effective finance provider

- Closing down the TSA head office and reducing the head count

- Working in partnership with other organisations and capitalising on the exceptional opportunity to raise funds through delegate fees, sponsorship and exhibition fees by hosting the 20201 International TSC research conference

The Trustees' goal is to retain our reserves at a sensible level to give us the best possible opportunity to grow the charity from 2022 and deliver the ambitions set out in the five-year strategy 2019-2023.

**Performance**

**Support services and communications**

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

We continue to provide a Support Line that enables people across the UK to contact our small team of professional advisers confidentially by telephone, email and post (9am to 5pm on Monday to Friday each week). We were contacted by around 34 people each month in 2021 asking for help and support. Some callers want practical advice and information, others need a listening ear and emotional support. We also provided proactive information and resources through our website (www.tuberous-sclerosis.org) and signpost to them through our popular social media channels (we use Facebook for people living with TSC and their families, Twitter for opinion formers in the media and Parliament, and LinkedIn for health, social care and education professionals).

The TSA is a proud member of the Helplines Partnership, a national body that represents and supports organisations that manage help and support lines. In 2021 we were delighted that the TSA Support Line achieved accreditation by Helplines Partnership, demonstrating the level of quality and service that the TSA's small, friendly and professional support team offers those who we support.
We’re proud to offer a service of a high quality and continue to work hard to make it even better. During 2021 we introduced LanguageLine to make it easier for users with English as a second language to speak to our Support Line advisers, and launched a new web chat function to drive better access for family carers and young people with TSC. We also introduced regular supervision for our Support Line advisers as part of our procedures to proactively manage the risk of vicarious trauma which can harm helpline workers and have negative implications for service users.

During 2021 we hosted regular virtual events to provide innovative ways for the TSC community to come together and reassure them that they were not alone as the pandemic continued.

We organised thirteen virtual events focused on the concerns that people were expressing on the Support Line, and 283 people attended live – an average of 20 people per session. These events were recorded and shared online so they were accessible for families with caring responsibilities, and the event recordings were viewed 3,674 times. Virtual events in 2021 included:

- Events focused on practical aspects of TSC such as better sleep for children with the condition
- Community get-togethers with NHS TSC Clinics across all UK nations

We also held a virtual Outlook event to bring together adults who are mildly affected by TSC, together with an Outlook Festive Special in the run-up to Christmas 2021.

During 2021 we awarded £3,379 in grants from the TSA Support Fund to 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.

In October 2021 everolimus was finally approved for use in TSC-related epilepsy in Wales after ongoing campaigning by the TSA and the Cardiff NHS TSC Clinic. In December 2021 the Welsh Government approved a recommendation from the All-Wales Medicines Strategy Group (AWMSG) that cannabidiol (brand name Epidyolex®) should be funded within Wales for managing TSC-related epilepsy that is ‘refractory’ (not well managed using other medicines). This means that people living with TSC in Wales can access this new medicine from early 2022. Decision-makers in Wales noted the "real difference" that the input of the TSA and the TSC community had on the approval process.

The TSA continues to work hard with decision-makers across the other UK nations to ensure that they hear the voices of people living with TSC and their families when making decisions about funding cannabidiol for TSC-related refractory epilepsy in the other UK nations. A decision is expected in Scotland in early 2022 and in England in late 2022.

We continue to build our relationship with NHS TSC clinics through our annual TSC Clinics Day. In 2021 the TSC Clinics Day was held virtually in partnership with St George’s University Hospitals NHS Foundation Trust and the Evelina Children’s Hospital. The day brought together clinic leads (usually senior clinicians), clinic coordinators (usually nurses) and specialist colleagues from 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.

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 2021 we continued to work closely with colleagues from Genetic Alliance UK and the Specialised Healthcare Commissioning Alliance (SHCA) 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 is committed to driving more research to give people living with TSC and their families hope for the future.

The International TSC Research Conference 2021 was originally planned to be face-to-face, and we were forced to postpone the meeting. The TSA and the international TSC research committee were determined to drive research forward despite covid-19, and we agreed to host the event virtually through an RCP platform Thursday 17 – Saturday 19 June 2021.

Around 250 TSA professional delegates joined the research conference from 22 countries. Attendees included healthcare professionals, academics, clinical and lab researchers, early career researchers including PhD students and post-doctoral fellows and TSC-focused organisations including TS Alliance (USA) and e-TSC (Europe-wide).

We received 70 written overviews from attendees about significant TSC research that they are undertaking and watched presentations from 12 keynote speakers and 42 presenters. The conference also included a virtual exhibition area for TSC-focused groups and industry bodies, a networking area for delegates, and two industry-sponsored events for healthcare professionals and prescribers to attend. Delegates were able to access recordings from the event through the online platform for one month afterwards so that they could maximise their learning from the conference.

We charged a fee for delegates to attend the research conference and raised £29,159 from ticket sales which was a welcome contribution to the charity's funds. The research conference was sponsored by GW Pharmaceuticals and Plusultra Pharma, and the Early Career Researcher Awards were sponsored by Noema Pharma. Novartis purchased a virtual exhibition stand at the event. In total £44,240 was generated through sponsorship and exhibition services at the conference.

The TSA is the only UK charity dedicated to supporting TSC research with a forward commitment / liability of research funding at 01Jan21 of £268,981 with an in-year research grant commitment in 2021 of £130,290. The TSA’s research portfolio of committed grants at 31Dec2021 consists of 8 live grants (three of which are jointly funded). Our portfolio of ongoing projects has a combined funding commitment of £138,691.

The charity's Trustees remain determined to honour the research grant commitments that we have made despite the pandemic and decided that the Designated Endowment Fund would be used to cover the cost of our ongoing research grants programme through 2022.

The research portfolio continues to yield results and 2021 saw 11 grants submit data. Of these 11 grants, nine grants reported 10 publications, and eight grants reported 36 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 has meant that some researchers have been unable to carry out lab work which has impacted on data generation and resulted in delayed publication and presentation of the data.
We continue to benefit from various memberships, including the Association of Medical Research Charities (AMRC), the UK Child Health Collaboration, and Charities Research Involvement Group – part of the Shared Learning Group on Involvement.

The AMRC audited our research grants programme in 2021 and we are grateful for the opportunity to learn from their feedback and continually improve our work in this area. Every five years, the AMRC holds an audit of each member, to ensure that members are upholding processes of the highest quality. Not only did we successfully pass our audit, but the AMRC also commented that the TSA's processes are "a great example of how a smaller charity can still meet the requirements." The audit helps us to make sure that every pound the TSA invests in research is spent on high quality research that is peer reviewed to world-class standards.

**Income Generation**

The coronavirus pandemic continued to make for a daunting fundraising environment in 2021, and we worked hard to maximise our income from every opportunity.

We welcomed the return of mass participation challenge events; in September our six strong team raised £3,013 at the rescheduled 40th Anniversary Great North Run and in October five runners took on the London Marathon and raised an incredible £20,500 for the charity. In addition, in April we launched our own virtual event the 'TSC Clinics Virtual Challenge', which saw our community covering an equivalent distance to travelling between two chosen NHS TSC clinics in their local area. In total we had eight individuals take part, raising £3,806. The ongoing challenging 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, and successfully applied for a grant of £74,527 from the UK Government COVID medical research charity support fund. This grant reimbursed the TSA for the research grant payments that the TSA paid out in 2021 for work delivered by eligible early career researchers.

We received unrestricted grants from GW Pharmaceuticals (£10,000) in response to our Coronavirus Emergency Appeal which was a welcome boost for the charity.

Sir David Suchet CBE continued to generously support the TSA throughout 2021 through a range of means including donating profits from his books and signing books and photographs. He also gave his time to the charity for 'In Conversation with Sir David Suchet CBE', a virtual evening event where Sir David discussed his incredible career across stage, television and film, as well as his passions and interests away from performing. Sir David raised an incredible £16,667 for the TSA during 2021.

Corporate support plays an increasingly important role in the work of the TSA, with organisations choosing to help us in lots of different ways. We would like to thank Hiscox London Market Operations team and Softcat PLC for their support in 2021. Other companies kindly supporting the charity during 2021 included Moo Creative who continue to donate a proportion of their time and expertise when delivering the design of our publications.

We received over £16,000 from supporters who chose to give to the TSA in memory of someone special during 2021. Honouring someone's life through a TSA donation is an incredibly kind offer and one that we do not take lightly. We would like to thank everyone who chose to celebrate the life of their loved one in this way.

We received generous grants for the TSA's Support Line from the Ian Fleming Charitable Trust (£1,000), St James Place Charitable Foundation (£1,000) and Ardwick Trust (£500), together with grants from the Bailey Thomas Charitable Foundation (£2,000), PF Charitable Trust (£4,000) and Swann-Morton Foundation (£1,000) to fund the introduction of Web Chat.

The Meikle Foundation awarded the TSA £2,000 to help support virtual events and support line tasks focused on Scotland-based community members.

The Leach Fourteenth Trust (£1,000) and Hospital Saturday Fund (£2,000) awarded grants to our vital research project on better understanding the accessibility of mental health services for children and young people with TSC.

The Gosling Foundation awarded us a grant (£5,200) toward the creation of a training program for Social Care professionals on TSC. We received unrestricted grants from GW Pharmaceuticals (£10,000) in response to our Coronavirus Emergency Appeal which was a welcome boost for the charity.

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The Gosling Foundation awarded us a grant (£5,200) toward the creation of a training program for Social Care professionals on TSC. We also received support from:

- A J & K M Barnett Charitable Trust (£3,000)
- Arnold Clark Community Fund (£1,000)
- Beechwood Trust (£500)
- Dunn Charitable Trust (£3,000)
- Esher House Charitable Trust (£2,500)
- Hamilton Wallace Charitable Trust (£2,000)
- Jeans for Genes (£3,417)
- Joseph Strong Frazer Trust (£2,000)
- Marsh Charitable Trust (£350)
- R S Brownless Charitable Trust (£200)
- Rainford Trust (£2,000)
- Sir James Roll Charitable Trust (£1,000)
- Swann-Morton Foundation (£1,000)
- The Bartlett Taylor Charitable Trust (£750)
- The Michael and Anna Wix Charitable Trust (£1,000)
- The Rest-Harrow Trust (£1,500)
- The Rest-Harrow Trust (£1,500)
- The Rest-Harrow Trust (£1,500)
- The Rest-Harrow Trust (£1,500)
- The Rest-Harrow Trust (£1,500)
- The Rest-Harrow Trust (£1,500)
- The Rest-Harrow Trust (£1,500)

We are profoundly grateful to all the trusts and foundations who helped us in 2021.

In December 2021 TSA's Big Give Challenge raised vital funds for our TSA Support Fund. The fund offers a lifeline to individuals and families affected by TSC when the financial implications of the condition become too much to carry, and they need financial assistance. We smashed our target to raise £3,000 for the TSA Support Fund through the Big Give Christmas Challenge in seven hours – which was be doubled by the Big Give to £6,000 providing us with funding for the TSA Support Fund for the whole of 2022! Our generous supporters continued to give after the target was reached donating a total of £4,650 to the 2021 TSA’s Big Give Challenge, and including gift aid a total of £8,674 was raised for the charity.

Finally, the response to our 2021 Festive season was fantastic raising £5,475 for the TSA. The Christmas cards sold this year included a lovely 'robin in the snow' design from our festive card competition winner 10-year-old Jasmine Ferguson whose 7-year-old brother Leo lives with TSC. Not only was it a bumper year for card sales, but the TSA also received fantastic support through additional donations such as swapping Christmas card giving to provide a gift to the TSA.
Organisation Development and People
In 2020 we noted that our ambition to balance the TSA's finances by 2021 was unlikely given the impact of coronavirus on the charity's ability to raise funds. In fact, in 2021 the charity ended the year in surplus for the first time since the start of the five-year strategy 2019-2023. We are delighted to have reached this milestone due to the Trustees' focus on reducing the charity's expenditure and increasing and diversifying our sources of income.

In 2021 the Trustees continued to take the difficult decisions needed to manage our finances with a view to giving us the best possible opportunity to grow the charity from 2022 and deliver the ambitions set out in the five-year strategy 2019-2023. Throughout 2021 most staff at the charity continued to voluntarily reduce their salaries to 80% of their usual hours and pay to support the charity. Trustees are grateful for this much-needed support, and glad that we have been able to keep our firm commitment that all staff at the TSA can return to their usual hours and pay from 1 January 2022.

In October 2021 the TSA closed our small office and switched to being an entirely home-based organisation which resulted in significant savings. The charity's registered address and postal address have moved to our new external finance provider. Sadly, the closure of our office resulted in the post of Office Manager at the charity being made redundant in October 2021.

During 2021 we tendered our accounting and audit services and moved to a new and more cost-effective finance provider, Tudor John. We moved from an annual audit to an independent examination to ensure we can spend more of the TSA's income on supporting our beneficiaries.

We continued to benefit from the expertise of a part-time joint Chief Executive from January to August 2021 to support the charity alongside our long-standing Chief Executive (who temporarily reduced her working hours to manage home-schooling and work). The Joint Chief Executive brought expertise in finance and fundraising to upskill colleagues and 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 2021, the total return on the portfolio was 6.71% as against the benchmark of 13.77%. 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. In 2021 £344,720 was held in cash due to continuing economic uncertainty because of the pandemic. The effect of this cash drag in rising markets resulted in the underperformance of the portfolio against the benchmark over the year.

In Q1 2022 Trustees will review how much cash the charity is holding and decide whether to reinvest the cash remaining with our investment managers, move it into an account to attracting a higher rate of interest, or divide this cash so that some can be reinvested and some can be moved into higher interest accounts.

Financial review
Grant making policy
Research grants are given for purposes directly concerned with furthering an understanding of TSC and its treatment. The TSA is a member of the Association of Medical Research Charities (AMRC) and follows AMRC policy in the conditions attached to awarding grants. All applications are peer reviewed.

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 as at 31st December 2021
At the end of the year the Association has total funds of £992,091. This included designated funds of £883,122, further details of which are given below.

The reserves of the Association at 31 December 2021 amounted to £108,969 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 because of additional research commitments and the provision of additional services, the cost of which have not been covered by the income of the Association.

The policy in place for 2022 onwards is that the Designated Fund can be drawn upon to help fund 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. However, there needs to be strong emphasis on securing new funding for future research with the aim of keeping the Designated Fund balance above £300,000 so that the Association 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 £443,454 (2020 £418,746). Total investment gain was £52,835 (2020 -£50,959 loss). To fund payments relating to research commitments entered into during the year, some investments needed to be sold to provide the Association with additional working capital.
Adjusting for the investment loss, the overall surplus for the year was £19,922. This represents a significant improvement on the deficit of (£246,527) in 2020.

Future plans
Strategic objectives
The 2022 Business Plan focuses on the following activities.

Providing access to good quality, accessible and timely information
- Developing an integrated package of support for individuals living with TSC and their families on TSC-Associated Neuropsychiatric Disorders (TAND) which can be delivered across our support line, website, social media, and regular monthly webinars
- Building and improving the TSA website and social media channels, working to achieve the Patient Information Forum accreditation as a kite-mark of service quality

Providing the opportunity for people with TSC to connect, support and learn together
- Carrying out a ‘TSC Census’ to better understand who the TSA is supporting, where there are gaps in the people we reach, and how we can reach them
- Delivering a face-to-face Big Day for people living with TSC and their families to come together for the first time since the pandemic, as well as continuing to bring people together through our monthly virtual events

Capacity build the knowledge and expertise of professionals working with people with TSC
- Supporting the NHS TSC Clinics Network through a range of activities including a virtual annual NHS TSC clinics day and a revival of the role of medical advisers
- Developing and launching virtual training for residential and home support workers which will help them to provide better support for individuals living with TSC and their families
- Developing and launching virtual training for special educational need (SEND) leads, teachers, and teaching assistants ready for launch in September 2022, helping those with a child who has TSC joining their new class to understand how to support them over the coming year

Driving the research agenda with the aim of improving outcomes and quality of life for people living with TSC
- Continuing to support the TSA’s current portfolio of funded grants, as some projects are continuing into 2022 due to delays in data gathering caused by the pandemic.
- Repurposing the money ring-fenced for a TANDem workshop to open a TAND-focused flexi-grant round for researchers across the globe
- Supporting a review of the UK guidelines on identifying and managing TSC so it is consistent with updated international guidelines and incorporates UK guidance on new treatments
- Developing and delivering the UK natural history database of epilepsy and standards of care in TSC, working closely with the Chief Investigator and Co-Investigators

Campaigning for better access to treatments and care
- Sharing the views of people living with TSC and their families on newly licensed treatments for TSC-related epilepsy (Epidyolex, cannabidiol) with UK decision-makers
- Making sure people living with TSC and their families are involved in research by manufacturers relating to topical sirolimus treatments for facial angiofibromas
- Continuing to grow TSA’s research volunteer network to drive patient-centric research and increase investment in TSA research through patient and public involvement and engagement

We will also invest time and energy in the strategic enablers that secure the long-term future of the charity including:

High-quality, integrated financial management. Working with our new finance provider to build the skills and confidence of senior managers using the Xero accounting system.

Digital transformation and smart working to reach more people. Tendering our IT provider in a more competitive market due to the increase in home-workers following covid; reviewing our IT assets such as laptops and scanners which are rapidly depreciating and identifying funding for a rolling programme of replacements; invest in our website so we have the technical capability to support online fundraising.

An enterprising approach to income generation. Generating income by delivering patient and public involvement activities across both academic and industry research projects; developing a ‘medium gifts’ programme of donations up to £3k per annum; reviewing the relative merits of our own community fundraising campaigns (such as Tea and SCones) compared to external community fundraising campaigns (such as the Big Give).

The Board has discussed the 2019-2023 Strategy and the need to refresh it in view of the coronavirus pandemic’s impact on the charity’s operating environment, income and staffing levels. Trustees agreed that we should discuss what we can achieve as a smaller charity and how we will fund it; with a focus on the fast-changing world of genomics; the potential for a UK TSC registry or database; and the need to improve the support provided for families affected by TSC through social care.

Our mission remains unchanged:
To provide help for today and a cure for tomorrow
<table>
<thead>
<tr>
<th>Reference</th>
<th>Investigator</th>
<th>Institution</th>
<th>Title and purpose of grant</th>
<th>Co-funder</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016-P01</td>
<td>Dr Martin Baron</td>
<td>University of Manchester</td>
<td>Exploiting Notch regulation to probe alternative mechanisms of TSC signalling</td>
<td></td>
</tr>
<tr>
<td>2018-F01</td>
<td>Dr Kacper Rogala</td>
<td>Whitehead Institute – MIT</td>
<td>Identifying and creating more specific medicines for TSC</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>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.</td>
<td></td>
</tr>
<tr>
<td>2018-S02</td>
<td>Dr Elaine Dunlop</td>
<td>Cardiff University Hospital</td>
<td>Characterising the role of exosomes in TSC</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>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.</td>
<td></td>
</tr>
<tr>
<td>2018-S04</td>
<td>Professor Andrew Tee</td>
<td>Cardiff University Hospital</td>
<td>Understanding the limits of everolimus and rapamycin</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>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.</td>
<td></td>
</tr>
<tr>
<td>2019-P01</td>
<td>Dr Elaine Dunlop</td>
<td>Cardiff University</td>
<td>A model of cell invasion in TSC-LAM</td>
<td>US Ministry of Defence</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>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 lymphangioleiomyomatosis) 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.</td>
<td></td>
</tr>
<tr>
<td>Reference</td>
<td>Investigator</td>
<td>Institution</td>
<td>Title and purpose of grant</td>
<td>Co-funder</td>
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<tr>
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<tr>
<td>2019-P02</td>
<td>Dr Sam Amin and Dr Ingram Wright</td>
<td>University of Bristol</td>
<td>Better understanding the accessibility of mental health services for children and young people with TSC. 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.</td>
<td>Anonymous major donor</td>
</tr>
<tr>
<td>2019-P03</td>
<td>Professor Petrus de Vries and Professor Anna Janssen</td>
<td>University of Cape Town and UZ Brussels</td>
<td>The TANDem Project</td>
<td>King Baudouin Foundation</td>
</tr>
<tr>
<td>2019-F01</td>
<td>Dr Charlotte Tye</td>
<td>King’s College London</td>
<td>Designing a protocol to measure the developmental trajectory of infants with Tuberous Sclerosis</td>
<td></td>
</tr>
</tbody>
</table>
# The TSA Summary Statement of Financial Activities

## For year ended 31 December 2021

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted funds £</th>
<th>Restricted funds £</th>
<th>2021 Total funds £</th>
<th>2020 Total funds £</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INCOME AND ENDOWMENTS FROM</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donations and legacies</td>
<td>344,236</td>
<td>-</td>
<td>344,236</td>
<td>330,058</td>
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<tr>
<td><strong>Charitable activities</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research</td>
<td>77,969</td>
<td>-</td>
<td>77,969</td>
<td>-</td>
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<tr>
<td>Other trading activities</td>
<td>6,290</td>
<td>-</td>
<td>6,290</td>
<td>2,884</td>
</tr>
<tr>
<td>Investment income</td>
<td>14,959</td>
<td>-</td>
<td>14,959</td>
<td>34,308</td>
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<tr>
<td>Other income</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>51,496</td>
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<tr>
<td><strong>Total</strong></td>
<td>443,454</td>
<td>-</td>
<td>443,454</td>
<td>418,746</td>
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<tr>
<td><strong>EXPENDITURE ON</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Raising funds</td>
<td>127,006</td>
<td>-</td>
<td>127,006</td>
<td>110,927</td>
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<tr>
<td><strong>Charitable activities</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Care &amp; Support</td>
<td>162,472</td>
<td>-</td>
<td>162,472</td>
<td>246,864</td>
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<tr>
<td>Research</td>
<td>186,889</td>
<td>-</td>
<td>186,889</td>
<td>256,523</td>
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<tr>
<td><strong>Total</strong></td>
<td>476,367</td>
<td>-</td>
<td>476,367</td>
<td>614,314</td>
</tr>
<tr>
<td>Net gains/(losses) on investments</td>
<td>52,835</td>
<td>-</td>
<td>52,835</td>
<td>(50,959)</td>
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<tr>
<td><strong>NET INCOME/(EXPENDITURE)</strong></td>
<td>19,922</td>
<td>-</td>
<td>19,922</td>
<td>(246,527)</td>
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<tr>
<td><strong>RECONCILIATION OF FUNDS</strong></td>
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<tr>
<td>Total funds brought forward</td>
<td>972,169</td>
<td>-</td>
<td>972,169</td>
<td>1,218,696</td>
</tr>
<tr>
<td><strong>TOTAL FUNDS CARRIED FORWARD</strong></td>
<td>992,091</td>
<td>-</td>
<td>992,091</td>
<td>972,169</td>
</tr>
</tbody>
</table>
# The Tuberous Sclerosis Association
## Summary Balance Sheet
### 31 December 2021

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted funds</th>
<th>Restricted funds</th>
<th>2021 Total funds</th>
<th>2020 Total funds</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FIXED ASSETS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investments</td>
<td>906,723</td>
<td>-</td>
<td>906,723</td>
<td>960,594</td>
</tr>
<tr>
<td><strong>CURRENT ASSETS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Debtors</td>
<td>90,740</td>
<td>-</td>
<td>90,740</td>
<td>82,171</td>
</tr>
<tr>
<td>Cash at bank</td>
<td>202,171</td>
<td>-</td>
<td>202,171</td>
<td>251,433</td>
</tr>
<tr>
<td></td>
<td>292,911</td>
<td>-</td>
<td>292,911</td>
<td>333,604</td>
</tr>
<tr>
<td><strong>CREDITORS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amounts falling due within one year</td>
<td>(207,543)</td>
<td>-</td>
<td>(207,543)</td>
<td>(322,029)</td>
</tr>
<tr>
<td><strong>NET CURRENT ASSETS</strong></td>
<td>85,368</td>
<td>-</td>
<td>85,368</td>
<td>11,575</td>
</tr>
<tr>
<td><strong>TOTAL ASSETS LESS CURRENT LIABILITIES</strong></td>
<td>992,091</td>
<td>-</td>
<td>992,091</td>
<td>972,169</td>
</tr>
<tr>
<td><strong>NET ASSETS</strong></td>
<td>992,091</td>
<td>-</td>
<td>992,091</td>
<td>972,169</td>
</tr>
<tr>
<td><strong>FUNDS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unrestricted funds</td>
<td></td>
<td></td>
<td>992,091</td>
<td>972,169</td>
</tr>
<tr>
<td><strong>TOTAL FUNDS</strong></td>
<td>992,091</td>
<td></td>
<td>992,091</td>
<td>972,169</td>
</tr>
</tbody>
</table>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 December 2021. The members have not required the company to obtain an audit of its financial statements for the year ended 31 December 2021 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.
Everyone at the TSA would like to give thanks to our Board of Trustees for all of their work:

Sanjay Sethi – Chair
Robert Woodthorpe Browne - Vice Chair
Rajan Khullar – Treasurer
Annemarie Cotton
Chris Kingswood
Frances Elmslie
Jane Rogers
Lisa Suchet
Martin Short
Patrick Bolton
Thomas Carter