

CORPORATE PARTNERSHIPS

with the Tuberous Sclerosis Association



tsa
tuberous sclerosis
association

WELCOME

On behalf of the UK's Tuberos Sclerosis Complex (TSC) community, thank you for choosing to find out more about supporting the Tuberos Sclerosis Association (TSA). We want to ensure that, if you choose to work with us, the partnership is mutually beneficial.

The TSA is a small charity that is proud to never settle for 'good enough.' We recognise the importance of our work for the thousands of people in the UK affected by TSC, and we'll never stop pushing ourselves to produce the best outcomes possible for the TSC community. We could easily look at what we've achieved over the years and pat ourselves on the back, but we'll never stop asking ourselves "What's next?". We hope you will join us on this mission!



LOUISE FISH, MBA
CHIEF EXECUTIVE

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What is Tuberos Sclerosis Complex (TSC)?

Tuberos Sclerosis Complex (TSC) is a rare genetic condition. Nearly 1 million people worldwide live with TSC. Between 3,700 – 11,000 people live with TSC in the United Kingdom, which means that up to 44,000 family members in the UK are impacted by the condition. In real terms, this means that every month approximately 10 babies are born with TSC in the UK.

Many people can go undiagnosed with TSC for years because of how uncommon the disease is, and the variability of symptoms people can have.

TSC affects everyone who has the condition differently. 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.

• **Eight out of every 10 people with TSC have epilepsy.** This often starts in infancy and is hard to control using medicines. Some people with TSC have a secondary diagnosis of Lennox Gastaut Syndrome which is a severe form of childhood epilepsy that can lead to multiple types of seizures, learning difficulties and challenging behaviours

• **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. Around two in 10 people will have mild or moderate learning disabilities and need support from their family or carers to develop a positive daily routine and cope with changes and challenges in their lives

• **Nine out of every 10 people living with TSC develop TSC-associated neuropsychiatric disorders (TAND) at some point in their lives.** The TAND aspects of TSC can include autism spectrum disorders, attention deficit hyperactivity disorders, aggression, depression, anxiety and sleep disorders which have a serious impact on family life

A person is born with TSC, meaning that the condition is not something that a person can develop over time. However, problems from TSC might not be obvious until later in life. The impacts of TSC vary significantly for every person, and some individuals can be severely affected and need support throughout their lives from their family and carers.



Every new diagnosis of TSC and its associated suite of conditions marks the beginning of an unexplored and unexpected journey for individuals, families and even whole communities. Our understanding of TSC, its influence on the body and how to manage the condition has improved significantly in recent years. This has led to improved diagnosis, medical care and support structures for individuals and families affected by TSC. However, we still have a long way to go

Who are the Tuberous Sclerosis Association?

The Tuberous Sclerosis Association (TSA) is the only UK charity dedicated to supporting and representing people living with Tuberous Sclerosis Complex (TSC). The 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.



Our small professional team come from a wide-range of different disciplines, including medical, social care, advocacy, and research backgrounds. These different experiences help the TSA team to drive forward improvements in the lives of people affected by TSC.

The TSA is here for everyone in the TSC community, including individuals living with the condition, families and entire communities. We help through:

Support for the community
We support individuals and families affected by TSC, through our dedicated support team, up-to date information and annual flagship events



Research
We fund world-class research into the causes, management and treatment of TSC

Campaigns
We work to influence NHS policy to ensure that people affected by TSC get the treatment and care that they deserve



Support for professionals
We expand the knowledge and expertise of health, social care and education professionals who help people affected by TSC

The TSA has a five-year strategy to **REACH more people and drive more REseArCH**. The strategy covers the period 2019-2023.

Our vision is a world where TSC and its effects are conquered.

Our mission is to provide help for today and a cure for tomorrow.

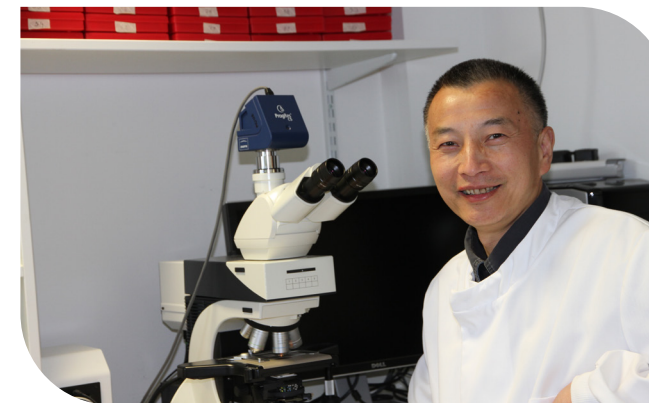
Our aims are to:

- Make a positive impact on the health and wellbeing of people living with TSC and their 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 services

The TSA receives no government funding and can support the TSC community only with your help.

Driving more research

Between 2019 – 2023 we are aiming to invest or directly stimulate £1.775m into TSC-focused research, meaning the TSA will continue to be at the forefront of TSC breakthroughs with the ultimate aim of finding a cure for TSC.



In 2019, we started to focus on co-funding as a useful way for the TSA to continue to push forward TSC research whilst getting other parties involved. The benefits of the TSA's new research strategy can be seen in pledged research funds for 2019.

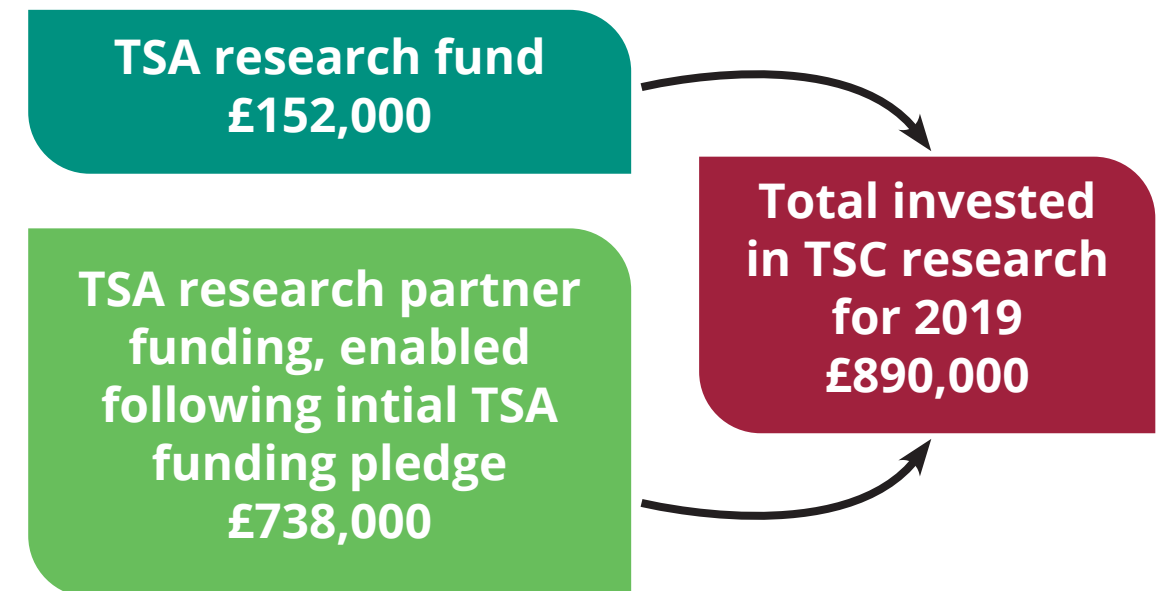
In 2019, we pledged £152,000 into three separate joint research projects. As a result of the TSA's commitment to co-funding, this initial £152,000 sparked a further investment into the same three research projects of £728,000 from other groups.

1. A model of cell invasion in TSC-LAM, co-funded with the US Department of Defence - Dr Elaine Dunlop, Cardiff University

2. The TANDem project, co-funded with the King Baudouin Foundation - Professor Petrus de Vries, University of Cape Town and Professor Anna Janssen, University of Brussels

3. Better understanding the accessibility of mental health services for children and young people with TSC, co-funded with an anonymous major donor - Dr Sam Amin and Dr Ingram Wright, University Hospitals Bristol

We also agreed to fund the Early Development in Tuberous Sclerosis (EDITS) study being carried out by the Institute of Psychiatry, Psychology and Neuroscience with a commitment of **£16,740**, taking our full portfolio to **12 live grants** (three of which are joint funded).



Our funded portfolio of ongoing projects is currently worth **£1,227,575**

What has the TSA achieved?

The Tuberous Sclerosis Association has a long and proud history of supporting the Tuberous Sclerosis Complex community in the UK.

Some of our key achievements



Towards the end of the 20th century, two of the most important breakthroughs in TSC research to date were made – the identification of TSC1 (in 1997) and TSC2 (1993), the genes responsible for the onset of TSC. The TSA is proud to have helped fund the work in identifying TSC1 and TSC2.

In 1998, the first international guidelines on the diagnosis, care, treatment and management of TSC are released. The international guidelines are a milestone to establishing more concrete, equal and efficient care for people living with TSC.

A landmark British Medical Journal education module for TSC was launched in 2014. The module remains very popular, having been completed by thousands of healthcare professionals.



Between 2016 and 2018, the TSA turns its focus towards advocating for access across the UK to a new treatment for TSC, everolimus. Following passionate campaigning and the support of the TSC community, everolimus is recommended by the NHS England and the Scottish Medicines Consortium as a treatment for TSC-related growths in the kidney and brain, and for TSC-related epilepsy.

In 2018, the first UK-specific guidelines on the diagnosis, care and management of people living with TSC were released. The guidelines enable UK clinicians to offer care that is more suitable to a UK-setting compared to the previous international guidelines. The TSA released a special summary of the guidelines, shared with the community and 18 NHS TSC Clinics across the UK.

Present – It is an exciting time for TSC research, with lots of potential treatments on the horizon including:

- New medicines to treat TSC-related epilepsy
- New topical creams to treat TSC-related growths around the nose and cheeks (facial angiofibromas)

There is also research taking place to see if existing medicines could be used in different ways to help with TSC, such as:

- Studying whether introducing vigabatrin earlier than we do at the moment can help to reduce the number of seizures in infants who live with TSC-related epilepsy
- Exploring whether metformin, a medicine used in type-2 diabetes, can reduce TSC-related seizure frequency and the size of TSC-related growths in the brain

Results of the clinical trials are submitted separately to the groups responsible for approving and funding the medicines in the UK nations. If approved by a group responsible for a UK nation, the medicine is made available for people to use in that UK nation only.

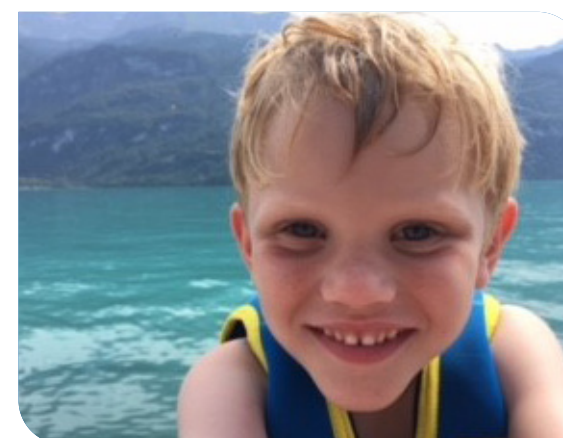
So, it is possible that one nation could approve its use, while others do not.

The TSA is always working to ensure equality and that the best treatments are available to everyone in the UK



Why support the TSA?

No one can be prepared for the overwhelming diagnosis of Tuberous Sclerosis Complex. By supporting the Tuberous Sclerosis Association, you are ensuring no one needs to go through it alone. Your support is vital in helping the TSA in our work to improve the lives of the hundreds of families in the UK living with the impact of TSC, but don't just take our word for it...



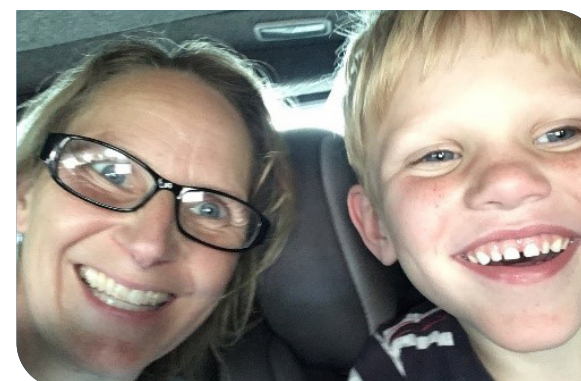
Hi, I'm George and I am 5 years old!

I was diagnosed with TSC when I was just nine weeks old. The first indication my family had that there was something not right was when I had some strange physical movements which my parents later discovered were seizure activated. We spent several days in hospital having lots of tests, I was too young to remember but my mum said it was very worrying! When we left we were given the diagnosis of TSC, something none of us had heard of, and anti-epilepsy medication. We were also given appointments to see a huge number of medical professionals including community paediatricians, occupational therapists, ophthalmologists, cardiologists and physiotherapists to name a few.

Thankfully we also had regular meetings with TSC experts and I had to have regular CT and MRI scans and have had my seizures monitored through telemetry ever since!

When I was 3 years old things got a bit worse. While on a trip with my family I had a seizure in the park we were visiting and had to be admitted to the local hospital – I was in the paediatric intensive care unit. At the time I was being monitored by the TSC experts for a brain tumour and the doctors decided the best course of action was for me to have it surgically removed. This was really hard for my family, but we knew there was no alternative - the surgery was long and deeply invasive apparently – I don't remember it!

Since then my TSC clinic team have kept a close watch on me, I still have seizures which, have become more serious and more frequent. I hope that, with the help of the TSA, new medicines can be found to control these!



Hi I am Claire, George's mother

This was an intensely difficult time, witnessing your child suffer. George was 3 when he went through this. He has had a great first year at his special school. But his seizures are now more serious and more frequent. This is hugely disruptive to our lives and as a result I cannot work.

I would urge you to get involved and fundraise for the Tuberous Sclerosis Association, this great charity. The vital funds raised each year are invested in research to find treatments to alleviate the terrible symptoms people must live with as well as paying for the support services that have helped my family and myself

get through this difficult time. We do what we can to fundraise each year as a family, from cycling 100 miles around London, running 5k to organising a dinner and raffle.

Please do support however you can, you can make a huge difference to families just like mine!

Partnerships with the TSA

As well as taking a leading role in the search for a cure for TSC, there are lots more reasons why a partnership with The TSA will be beneficial to your organisation. These include:

Empowering and engaging your employees

Our partnership will be a great way to engage employees. They'll be able to raise money for a vital charity, with the support of their organisation and colleagues. As well as this, we'll be raising awareness and improving understanding of TSC throughout the partnership, empowering your employees with the knowledge that, through research, we will make life-changing breakthroughs possible.

Emphasising your investment in Corporate Social Responsibility

By partnering with us, you'll be part of the TSC community, this will demonstrate your organisation's commitment to improving the lives of families across the UK.

Positive public relations

We'll work with you to highlight our partnership across the media and our different channels, so everyone outside of your organisation can also see the vital work that you are doing to support our cause.

What we can offer

- A dedicated partnership manager, with back-up from a dynamic support team, to work closely with you to achieve your partnership goals
- Your partnership manager will be on hand to help develop a charity committee and identify champions, organise regular meetings to review the partnership and provide ongoing stewardship
- A bespoke fundraising calendar, drawing on our extensive list of innovative and motivational ideas and packs
- Opportunities to enter the most prestigious sporting and challenge events for the TSA, and to arrange creative and exciting challenges that bring your team together when they're working remotely
- An adaptable learning and engagement plan to educate employees about TSC and the charity
- Chances to get involved with our awareness campaigns, giving your company recognition for your support

YOUR IMPACT

£500

You could provide a year's worth of 'welcome packs' for families that have received a new diagnosis of TSC to introduce them to the TSA's support services and make sure they are not alone on their TSC journey

£1,000

You could provide laboratory equipment for one month's research into the causes, symptoms, management or treatment of TSC

£5,000

You could provide online training materials and advice for social care professionals across the country to help them learn about the unique needs of individuals with TSC

£20,000

You could provide a listening ear for a newly diagnosed family by funding a professional support line advisor for the year

How you can get involved

We have found that corporate partnerships work best when we find ways that you can support us while fitting around your business objectives and skills. This can create a lasting partnership that you and your team can be proud of!

Below are some ideas of ways you can support the TSA, but we know every business is different so please do get in touch with any questions.



Charity of the Year

Create with us a long term, mutually beneficial partnership where your company or team adopts the TSA as its 'Charity of the Year' to maximise the benefits for both parties. This is a fantastic way to motivate and unite your employees while helping us raise vital funds and awareness for our cause.

Your TSA partnership manager will work with you to develop a strategy that will engage your employees and bring positive benefits for your organisation. The TSA will help you with ideas, publicity materials, merchandise and of course, dedicated support and advice.

Are you a team member who wants to nominate us for Charity of the Year? Please contact us and we can help you with the process!



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 the condition. The lockdown and restrictions on people meeting meant that some of their planned activities were unable to go ahead. Instead, Equistone's support of the TSA became focused on online activities and indoor challenges – it is fair to say they seized the opportunity to maintain camaraderie across the firm.

"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 so small, so our donations can make a big difference."

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 but with a twist: fancy dress. They also held online events such as quizzes.

Over the course of that extraordinary year, Equistone raised £45,000 – testimony to their determination, imagination and desire to support the TSA through a most challenging year.

EQUISTONE

Sponsorship

Sponsor one of our industry leading events, thought provoking awareness campaigns or an innovative initiative that will give us the best chance of making pioneering discoveries.

We'll find the right opportunity to suit your business needs.

We deliver the highest quality information for both individuals and families affected by TSA and social, medical and education professionals.

Plus, we regularly hold events such as our Welsh, Scottish and Northern Irish Get Togethers, family fun days, a national annual conference, and many virtual events that provide information and support, and connect people with TSC, such as the International TSC Research Conference 2021, which the TSA was proud to host.

Support on materials – Novartis

Novartis supported us with an unrestricted educational grant used to fund a study day for health, social care and education professionals who support those living with TSC and their families.

Based on conversations with professionals who attended the event, the TSA also produced a range of factsheets aimed at GPs, social workers, residential care workers and teachers to help them tailor their practice when working with those affected by TSC to learn about TSC and its symptoms.



There's plenty of opportunity to shape sponsorship packages for a specific part of our work from £1,000 for a virtual event, £4,000 to sponsor an issue of our bi-annual community magazine, and up to £20,000 for an international conference. If you are interested please contact our friendly and professional team at fundraising@tuberous-sclerosis.org or 0300 222 5737.

Cause-related partnerships

This is a fantastic way to align your products and services with our cause, drive sales, reach new audiences and help us spread our vital message.

A commercial partnership such as cause-related marketing will place your product in front of new audiences and tangibly demonstrate your commitment to your corporate social responsibility goals.

If your brand has a product or service that makes for a good fit with our cause, then a commercial agreement to donate a proportion of its profits to us could be a mutually beneficial partnership.

Digital supporters – Softcat

IT company Softcat selected the TSA to benefit from their Christmas '£1 per click' campaign. They asked everyone to click on their website and for every click they made a £1 donation.

The campaign raised over £10,000 while spreading a lot of good cheer and accessing new markets with the TSC community sharing far and wide!



Events

With skydives, cycle rides, treks and runs, there are plenty of opportunities to get involved with our general events series.

Fundraising for an event is a great way to get your whole team involved in fun activities whilst raising money to help people with TSC.

Why not take part in a local event, many events have corporate schemes such as marathon relays or a team triathlon, so you can share the challenge between your team members!

We can also help you to run bespoke events just for your company, what about virtual wine tasting or a cocktails night for colleagues and clients, or a cycle challenge where staff can work towards a collective distance target this summer?



Meet our challenge event champions: John Lewis, Logic Park (Leeds)

"This year myself and the Logic Park team have been fundraising for the TSA, a cause close to my heart as my daughter has the condition.



A 20 strong team of John Lewis partners took on the 12km total warrior obstacle run course. The event brought the whole team together – even those who decided to stay clean travelled to the event to cheer us on and bring snacks and drinks for the exhausted team. Bringing employees together around a single cause has been incredibly valuable and promoted a lot of cross-team working.

We have several more fundraising activities planned and collection tins across the site. Our target is to raise £10,000 for the TSA! We have

already signed up colleagues from the other stores in Yorkshire to take part in next year's Tough Mudder!

Our TSA partnership manager is always available to help us not only promote what we are doing via the TSA and John Lewis newsletters, but also to support us on event logistics and funding applications. She even came to our total warrior event but chose to stay clean!

Please do support the TSA and their amazing work today!"

Jamie (Fundraiser and dad)



Using your own event

If you already have your own event, such as an annual awards dinner, please consider us as your selected charity!

Just like the Lendlease Guvnors Club Ball did in 2019, raising an amazing £12,000 for the TSA and other staff nominated charities.



Other ways to give

Businesses can also help TSA in ways other than giving cash. Businesses can donate volunteers and expertise, equipment or event supplies.

Ideas include:

- Volunteering at our flagship fundraising events
- Support us with your expertise – do you have skills you could ‘donate’ to the charity?
- Printing our information leaflets, brochures or fundraising packs or other services
- Hosting a TSA collection tin in your business



Thames Security Shedding



Kindly offered their confidential waste disposal service for FREE to the TSA Office.

Skill Sharing - Steve at Moo Creative



Steve donates his time to the TSA to help with design projects such as our community magazine SCAN and support materials. His expertise helps our materials to stand out and be easy to understand for people living with TSC and their families.

Payroll giving

What is payroll giving?

Payroll giving (sometimes called ‘Give as you Earn’) is a really easy way for employees paid by PAYE to give regularly to a charity such as the TSA. Since donations are deducted before tax is calculated, it is one of the simplest and most tax-efficient ways of giving to us.

How does it work?

Every time you’re paid, a donation amount of your choice is taken from your pay before tax is deducted. This means, that if you pledge to donate £5 per month, it would only cost you £4 on basic tax rate or £3 on the higher rate.

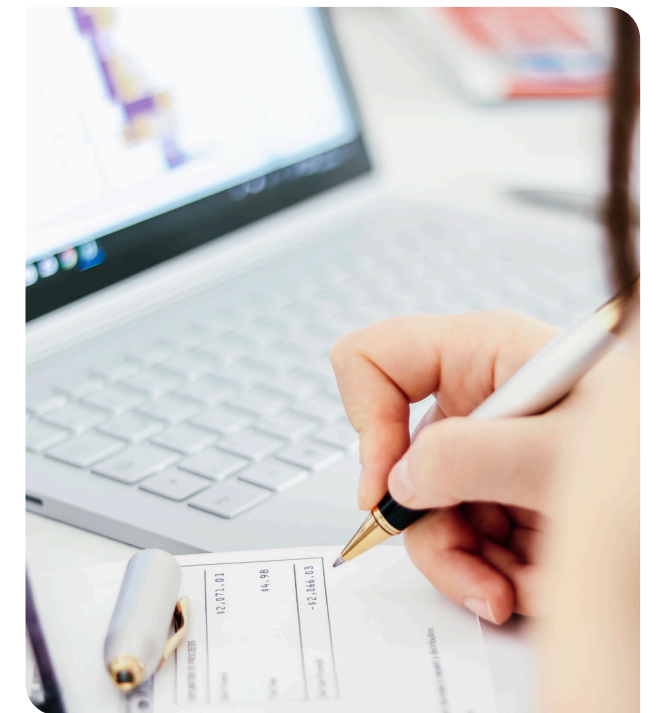
What are the benefits?

For employers

- Low cost to set up and maintain – potential to offset set up costs against tax
- One simple payment every pay run
- Engages employees in Charity of the Year (COTY) partnerships
- Positive publicity – demonstrates community involvement
- Boosts staff morale

For employees

- It’s tax-efficient so costs less to donate
- Quick, easy and convenient way to give
- It gives flexibility – donations can be stopped or changed at any time
- You don’t have to give bank details



“I give to the TSA in honour of my brother Harry who suffered from TSC. Donating via my payroll is such a simple way to do that.”
Mary, Payroll Donor

How do I get started?

As an employee (you must be a PAYE employee), you sign up to give to the TSA via your pay, so need to ask your payroll team if your company offers a scheme and they will explain the process and ask you to complete a form

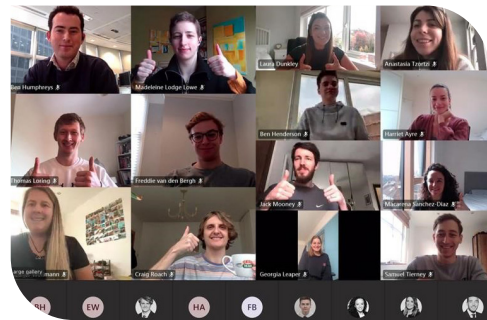
If your employer is not already part of a scheme, they can access the clear and simple information at www.gov.uk/payroll-giving on how to set up a scheme.

Your regular contribution will mean that we can plan well into the future and make sure we provide the best services for people affected by TSC.

Fundraising at work

There are lots of fantastic ways to fundraise for TSA and we're always coming up with innovative ways to get your employees motivated. Here are just a few of our ideas, but we have plenty more!

You don't need to commit to be a charity partner for a full year! By taking part and organising a day or even a lunch time fundraiser can not only get your team working together and away from their normal duties but can really help support the TSA in the process.



Whether it be a dress down day, Christmas jumper party or lunch time virtual talent show, what fantastic ways can you and everyone at work come together to make a difference to the lives of those with TSC?

Below are a few ideas that have been delivered by people like you, to get you on your way to achieving your fundraising target. Please do contact our friendly fundraising team to get advice, materials and support!

Get involved by picking your own personal challenge, an **office swear jar** or **Glitter Eyebrows** and **Glitter Beards** are always good ideas, right?

Start the working day by arranging tea, coffee and pastries at your breakfast meeting or take part in **Tea and SCones for TSC**.

Or if your employees are more long-distance runners, we may be able to offer you chances to run in sporting events as part of **#TeamTSA**.

Set your own challenge – you can make it competitive and set an **internal fundraising challenge** to see who will raise the most money, Finance or IT?

Take to the skies and sign up for a **Skydive!**

There's no right or wrong answer here – everyone loves a **good quiz** ...Get those thinking caps on!

Match Funding

Does your company run a Match Giving scheme which could boost the amount you raise, or does your company have its own charitable trust you can nominate the TSA to?

Always worth an ask!



We can also work with you to create exciting, bespoke fundraising events for your organisation. Tailored to your needs and with your employees' input, this will be sure to ignite their enthusiasm and make our partnership an even bigger success.

Communications

We love to shout about all the wonderful things our Corporate Partners do for the TSA!

Each partner benefits from a dedicated Partnership Manager, who will offer support for internal and external channels, as we know how important this is for a successful partnership.

You'll hear from us on a regular basis, this will keep your organisation up-to-date on the latest news from the charity and showcase all your fantastic fundraising efforts

We know that not all employees can be reached at their desks. A strength of ours is coming up with innovative communication ideas, tailored to your organisation, to reach and motivate as many people as possible

We'll generate positive coverage in the media about our partnership, showing how your organisation is at the forefront of TSC research

Your support will be vital for our awareness campaigns. We'll provide you with the content and support you need to help us spread the word even further

Our team will be making the most of our social media channels including LinkedIn, Twitter, and Facebook as well as the TSA website to promote our partnership



Acknowledging your effort

The TSA wants to make sure your hard work is recognised. We will:

Include your company logo is on our corporate supporter's page on our website, and we will promote your fundraising

Ensure Individuals, teams and departments are acknowledged in our community-wide SCAN magazine

Draft articles for your publications such as internal newsletters or website, or industry publications

Submit award nominations for partnership work where appropriate

How to get in touch

If you want to discuss anything in this pack or how we can kick start our partnership, please get in touch.

Contact us at fundraising@tuberous-sclerosis.org or call us on 0300 222 5737

Thank you





Registered with
**FUNDRAISING
REGULATOR**

This publication was developed by the Tuberosclerosis Association (TSA). We have made every effort to ensure that the enclosed information is correct at the time of its design, development and print. However, policy and/or practice may change, and the TSA does not accept liability for any errors or omissions in this publication.

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