

scan

Autumn 2025

The magazine of the

t**s****a**
tuberous sclerosis
association



Read our latest
annual report



Here for everyone in the TSC community

Registered charity 1039549 (England & Wales). Registered charity SC042780 (Scotland)

Help us to continue to be here: Give a regular donation to the TSA:
tuberous-sclerosis.org/donate

Scan Autumn 2025 highlights

NHS Ten Year Plan

The next ten years of the NHS have been set out. What changes can you expect, and what does it all mean for people with TSC?



Refreshing our research strategy

Find out the steps we took to refresh the TSA's research strategy, including how we made sure the TSC community is at its heart



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The **TSA Support Line** is
free and here for you:
0808 801 0700
support@tuberous-sclerosis.org
Webchat
(and WhatsApp coming soon!)



Luke Langlands

A word from your Joint CEO

"Our new annual report shows the progress that we're making"

"If you're on a winter walk and see a swan, it might seem like it's effortlessly gliding on the water. However, under the water it's paddling nonstop. This is like the TSA, with lots going on yet much of it below the surface. This is why our annual reports are vital.

Our annual report is a snapshot of how we're doing as a charity every year. It covers everything, from how we're meeting our strategic aims, and our overall impact, to how our finances are doing. It's a long read, but I hope as many people as possible will have a look. To do so, go here: bit.ly/4njyU4I or scan the QR code on the front cover.

Our annual report underlines the things going on across the charity's work, with the TSA team making great effort to ensure that the report is accessible and easier to read than previous iterations. You can also discuss and hear more about the annual report by virtually joining our AGM in November (more details on [page 16](#)).

Pooja (Joint Chief Executive) and I hope the report shows that your trust in us and the TSA team is being rewarded. We also hope it inspires people to continue to support us, or to begin to do so with a regular donation (tuberous-sclerosis.org/donate, **0300 222 5737**, fundraising@tuberous-sclerosis.org)."

Luke Langlands (TSA Joint Chief Executive)

New TSA annual report

Read our latest report to get an in-depth look at all-things TSA from the last 12 months

As a registered charity, the TSA must submit an annual report to regulators every year. However, this isn't just a 'box-ticking' exercise - it's an important opportunity for us to show things like what we've achieved over the year, that our governance and best practice is of a high standard, and how we take long-term financial stability seriously. Put together, this gives everyone an easy way to see that the TSA is in good hands.

This year, we've put a lot of effort in improving our annual report. Previously it was hard to read and not accessible. In some areas, it was very hard to understand. However, our new reporting template is much more transparent and clear - this was really important to us, because we want to make sure that everyone has the chance to stay updated with how the TSA is doing.

Read the report by going here: bit.ly/4njyU4I. Or, by visiting the Charity Commission or the Office of the Scottish Charity Regulator (OSCR) websites.

Welcome to Maisie!

Maisie is our new Support and Information Officer, joining us with lots of experience from different roles in supporting people

Maisie has worked in a variety of frontline supportive roles across charity and education settings, including co-ordinating food aid projects and providing a welcoming first point of contact in a wellbeing service. If you contact us on the TSA Support Line, it might be Maisie that you speak to! As well as taking support line enquiries, Maisie is also vital in all other aspects of our support and information work.



Maisie commented: "I'm so pleased to be part of the TSA team and look forward to working with the TSC community. I've already met some of you, as my first day was at a TSA event! I'm most looking forward to making a real difference in the lives of so many individuals and families."

Maisie has always been drawn to roles which involve supporting others and being there to listen. She also enjoys using her writing skills to create clear communications to help people access the information they need to move forwards.

NHS England's 10-Year Plan

NHS England shared what it'll focus on over the next 10 years. We looked into the plan and what might be most important to you

A neighbourhood health service. Support will shift from hospitals to places closer to home. This also means you'll get more personalised and accessible care, with appointments closer to where you live (such as a health centre). NHS England hopes this will lead to health issues being detected earlier, so they can be treated before they become bigger problems. It should also mean that different healthcare professionals work more closely with each other, so they understand your health needs more easily.

A greater focus on the NHS app. Currently, you might have lots of health records in lots of places. This can be hard to keep track of. The NHS app will undergo significant enhancements, allowing easier management of your appointments, prescriptions and other things around your health record. However, this will only work if the NHS app is accessible for everyone – there's question marks over how this will happen, like for those with learning disabilities or learning difficulties.

Improved access to specialist treatments. Innovation, especially in genomics and AI, will be used to personalise treatment and predict health risks more effectively. NHS England aims to become a global leader in genomics, offering universal newborn genomic testing by 2030. AI will be seen as the clinician's "trusted assistant", helping to make care more impactful and streamlined. This might mean earlier diagnosis and treatment of TSC, or new discoveries in TSC care.

More focus on prevention and early intervention. Currently, NHS England is very reactive, such as treating TSC tumours that are already causing problems. They want to move into a system focused on proactive prevention, including more use of wearables and technology to monitor people's health. It's hoped that this will allow NHS England to catch and address health problems before they escalate. This might mean treating new symptoms of TSC earlier than is currently possible.

Better mental health support. We know that TSC-Associated Neuropsychiatric Conditions (TAND) is a massive challenge for many people in the TSC community. However, it's often hard to get the specialist support needed for TAND. There's plans for more dedicated mental health emergency services, access to therapists available virtually 24/7, and more self-referrals. There'll also be expanded mental health teams in schools. It's hoped that this will mean faster specialist care access, while reducing strain on Accident and Emergency departments.

NHS England doesn't support everyone with TSC as well as it should. The 10-Year Health Plan is a big chance to change this. In particular, more integrated and local care, which could create a domino effect of better support. We'll do everything we can to make sure NHS England brings to life what they hope to achieve. We welcome these plans, but will be holding NHS England to account.

The TSA and TSC in the media

Recent features have included some of the most popular UK outlets

We've had some fantastic media coverage over the spring and summer, which is all very important in raising broader awareness of TSC as a condition and the TSA as a charity. We hope to get lots more coverage in the future, with some exciting plans in store!

BBC News discussed the special 'Room to Breathe' garden at the Chelsea Flower Show 2025, which was dedicated to the TSC community. The garden was inspired by designer Jenny Donnelly's hopes of creating a calming space for families in hospitals, following her experiences of ongoing hospital appointments for her son, who has TSC.

Other coverage came from direct stories of people experiencing the impact of TSC every day, including the ever-supportive acting great Sir David Suchet, who spoke to the Daily Mail about his grandson's TSC diagnosis. We were also equally delighted to get broader coverage, including in the national and regional press, all thanks to Philippa Ward who spoke to journalists about life as Mum to Thomas, who has TSC.

These stories truly make a big difference in getting more people to understand TSC and the impact that it has on so many people. We're very thankful to everyone willing to put their stories forward. **If you're happy to speak to local or national media about your experiences with TSC, please get in touch with Sophie Blyth (Comms and Events Manager): sophie.blyth@tuberous-sclerosis.org.**



Philippa Ward and one of her sons, Thomas



Strictly dancer Nadiya Bychkova, Sir David Suchet and Alexandra Burke visiting the 'Room to Breathe' garden

Volunteer spotlight: Philippa Ward and understanding TSC

As well as raising awareness of TSC in her local area, Philippa has been an inspiration in her work with our TSC Research Volunteer Network

Philippa is mum to two boys, including 13-year-old Thomas who has TSC. Philippa is one of the longest-standing members of the research volunteer network, having a pivotal role over the years in making sure that the voices and views of the TSC community are heard loud and clear by researchers and clinicians.

When a pharmaceutical company is conducting trials into potential TSC medicines, it's vital that they understand what the real-life impact of TSC is on individuals and families. Recently, Philippa spoke to a team of scientists hoping to make the next new big TSC discovery, giving them a first-hand account of what life with TSC actually means. Philippa's account helped strengthen the connection between TSC as a scientific challenge and the actual impact of the condition on real people.

After Philippa's talk, a director at the pharmaceutical company said: "Philippa was incredible. Thank you for being so generous with your time and for sharing the journey that you, your family, and your amazing son Thomas are on. We as a team now have

Thomas in our sight as we work on developing a potential new treatment option for refractory epilepsy."

On a different occasion, Philippa was asked to act as a public ambassador for an organisation researching TSC. This led to media appearances, and even a podcast, where Philippa flew the flag for the TSC community. All of this, alongside a busy family life and looking after two boys!

We're very thankful to Philippa and everyone who volunteers for us. Each conversation brings us closer to everyone understanding the impact of TSC.



Thank you Philippa and Thomas!

Bring hope to someone with TSC every month

A regular gift to the TSA does so much. You'll help people feel less alone. You'll help fund new research. You'll help make the future brighter

Even a small monthly donation could mean the world. Every minute of every day, an individual or family coping with TSC needs support and hope. A family like Ellen's.

"In early 2024, our world shifted when my daughter, Connie, was diagnosed with TSC at two and a half years old. No parent expects to hear that their child has a rare, incurable condition, and the emotional rollercoaster that followed has been overwhelming, frightening, and incredibly tough."

"The TSA has already been a huge source of comfort and support. They've made us feel less alone at a time when we could have felt completely lost. Whether it's the practical help, the emotional reassurance, the research they fund, or the advocacy they lead, the work they do is nothing short of inspiring. They are fighting for the future of people like Connie, and I want to stand beside them."

It takes just a few seconds to set up a regular gift, but can make a lifetime of difference. Please consider setting up a regular gift today. Thank you.



Ellen and her family

**Set up a
regular donation**



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tuberous-sclerosis.org/donate
0300 222 5737

TSA Grant Round 2025-2026

We're accepting new applications from researchers who want to research areas of TSC most important to you

We're excited to confirm that our new research grant round has launched! This is one of the key ways we invest in vital TSC research, helping to shape a better future for everyone affected by the condition.

A research grant round is when an organisation formally accepts applications for a set period of time from researchers to apply for funding. It's similar to a job application, with the researchers hoping that their idea and institution is picked so that they can bring to life their ideas in how to improve diagnosis, treatment or management of TSC.

At the TSA, we're proud of our extremely rigorous process of choosing the best applications in our grant rounds. The decision is made in partnership with the TSC community, as well as our research committee which comprises of TSC professional experts. We're directed by the views of the network and the committee as to which applications are chosen.

This year, we're offering two different opportunities for applications. The first focuses on developing a **TSC registry**. Medical registries are a central hub of information, allowing researchers and clinicians to better understand how TSC develops over time, how treatments affect people differently, and how care can be improved in the future. Creating a large and robust UK-based registry has been a major ambition of the TSC community and TSA for some time.

The second opportunity in our funding round is to **kickstart new ideas and collaborations in TSC** through 'seedcorn funding'. This is smaller grants for early-stage research projects that might one day grow into major studies or breakthroughs. Seedcorn funding allows researchers to get started on ambitious ideas that might snowball into future major discoveries. Other funders may not have the patience to provide these sort of grants, so this gives the TSA an opportunity to unlock the potential of new research that might make a huge difference in the future.

Our new research grant round reflects the aims of our latest strategic plan and our research strategy refresh (see next page). We previously made the very difficult decision to pause doing grant rounds like this, so restarting them is a huge boost to the TSA.

In 2026, we plan to launch a large appeal push to receive further donations that will go towards our work in research specifically. Be sure to keep an eye out on all of our channels to learn more about this.



Our research strategy refresh

We've given our research strategy a refresh. Instead of starting with a blank document, we started with the people who matter most

The TSA is a proud funder of TSC-related research. As part of this, it was recently time to look again at our priorities into what sort of TSC research we want to get behind. This is a mini-refresh before a future full update, so that we can be sure that we're still on track to achieve everything that we need to do. However, although it's a 'refresh' rather than a full update, there was still lots of work to make it happen.



Thanks to the research strategy refresh, we were reminded that knowing how TSC affects people and families across all ages and life milestones, rather than focusing on specific stages, is important to our overall knowledge and research goals in TSC. We also found that interest and uptake in AI and other technological breakthroughs is becoming an increasing focus for the TSC community and TSC professionals.

The research strategy refresh gives us a chance to take a step back and connect the dots once more in how and exactly why we fund TSC research. This was particularly important now more than ever, as we've now expanded the research that we fund with a brand new research grant round launching.

As an organisation, we consistently emphasise that the research we fund and focus on should be directed by the needs and experiences of the TSC community. This research strategy refresh was no different, with us keen to listen to what you thought that we should be funding and how it compares with the existing strategy.

These are steps we took in our research strategy refresh and how we uncovered the new conclusions in what sort of TSC research we should be funding:

Step 1: Listening without limits

We started with an open invitation to everyone in the TSC community – people with the condition, carers, loved ones and professionals – to share broad ideas and thoughts about TSC research. This was done online and in one-to-one conversations.

People spoke candidly about what daily life with TSC really looks like, the questions we still don't have answers to, and the moments where progress in TSC research would truly make a difference. Some talked about support during childhood. Others reflected on adulthood and ageing with TSC, an area rarely discussed.

A mum to a teenager with TSC said: “The thing that I find really hard as a parent is the uncertainty... it would be really lovely as a parent to have some type of levels of risk in terms of us understanding and accepting things.”

The feedback we received reminded us that TSC research isn't just about solving problems but can also provide information and insights into everyday challenges.

Step 2: Bringing it all together

We then gathered everything from step 1 and made more concrete questions around what research we should prioritise. We did this by working with our Research Committee (RESCOM), asking questions like: “What seems most urgent?” “What would make the biggest difference?” “What can't wait any longer?”

The step led to a more formal survey for the TSC community. Responses showed where people are in agreement and why. Responders spoke about wanting smoother care, clearer guidance, more effective treatments, and confidence that progress was possible at every life stage.

A TSC clinician answered the survey with: “Our treatments for TSC remain limited. We need more clinical trials, especially for TSC-Associated Neuropsychiatric Disorders (TAND), and to look for the potential for a cure.” With this stage wrapped up, we had a clearer understanding of what needs to change and how it should happen.

Step 3: Turning insight into action

The final step was to gather RESCOM once more and plan how the ideas and views from steps 1 and 2 can come to life as actual research projects. This step was really important, as it gave us the chance to really see what sort of research we could fund or advocate for in the future based on our existing strategy and the ongoing priorities of the TSC community.

This was also the stage at which we looked into how to get the most impact as quickly as possible in future research. This was done by leaning on the experiences of the TSC professionals that we work alongside, who have an inside-view into the world of TSC research labs and clinics.

The main conclusion from our research strategy refresh is that we must ensure that everyone in the TSC community can equally contribute to, and benefit from, TSC research. Often, new clinical trials and pieces of research focus only on specific age groups or different areas of TSC. However, in the future we'll look at how more people can get involved more often.

Together, we reached a final direction that balances real lived experience with scientific TSC knowledge.

Eye care and TSC

Did you know that TSC can have an impact on your eyes and sight? It's important to make sure that you get yours checked regularly

Around half of people with TSC show signs of the condition affecting their eyes. These issues are often mild and don't usually need treatment, but can lead to major problems. These issues can develop because of TSC-related growths in or around the eyes. Sometimes, facial angiofibromas (TSC bumps and marks on the skin) can also impact the eyelids, affecting vision. In other cases, sight changes might occur as a side-effect of epilepsy treatments.

The UK clinical guidelines for TSC recommend an ophthalmoscopy (eye examination) at each clinic visit. This is a special test that allows clinicians to see the back of the eye and spot any changes early. As well as this, everyone should have a routine eye test at least every two years, or more often if advised by a professional. It's helpful to think of an eye test as more than just checking how well you can see, as it also looks for signs of other health conditions and checks overall eye health. Regular appointments mean any problems can be picked up early, before they cause discomfort or affect vision.

Eye care is especially important for people with learning disabilities, who are at much higher risk of having a sight problem. In fact, adults with learning disabilities are 10 times more likely to have issues with their eyes, and children are 28 times more likely. There are optometrists who specialise in working with people with learning disabilities, making checkups more manageable. Check for one local to you at seeability.org.

If you're unsure about what type of eye care you should be receiving, or if it's been a while since your last check-up, speak to your TSC clinic or contact the TSA Support Line for information and signposting.



Our TSA Superhero Summer

We look back on a summer when the TSC community assembled for a bright and bold campaign. Together, we celebrated the everyday heroes living with TSC, while also raising awareness and vital funds

It kicked off with the **Heroes Among Us Award**, a chance to celebrate unsung heroes in the TSC community. What an incredible response, with over 30 nominations! This left us with an almost impossible task, with so many deeply moving stories. Special prizes went to: Daniel Marks, Chris Storey, Aaron Holt, Bee O'Shea, Kate Jennings, Laura Holt, Jessica Collins, Nara Sethi, Jonah Holt, Isabelle Robinson and Ella Rogers.

We'd love to share the photos and nominations of all of our brilliant winners, but we wanted to spotlight a very special young boy, Freddie Mantell, who received multiple nominations. Freddie, you and others are heroes in the lives of so many!

Next was the **Superhero Trio**, where heroic members of the TSC community came together at the beautiful Dorney Lake. With sunshine overhead and energy in the air, TeamTSA walked, cycled and swam their way through the inclusive course, showing what true strength and resilience looks like.



Well done Freddie!



The Phillips family, dressed for the Superhero Tri!

All across the UK, families, colleagues and friends took on our **Heroes Assemble** campaign, embracing their inner superhero by donning capes, hosting fundraising events and raising awareness in creative and heartfelt ways.

It's been wonderful to see all your photos, hear your inspiring stories, and witness your awesome fundraising events!



The Philips family with a familiar face The Robinson family showing they smashed it!

Thanks to your incredible energy and generosity, our Superhero Summer not only sparked important conversations, but also raised vital funds which will go towards support and information, research and advocacy for everyone in the community

Here's to a summer of impact, inspiration and unstoppable strength, and to every one of you who made it happen

Thank you, you are all heroes to us!



The Holts and (right of page) other Heroes Among Us award winners!



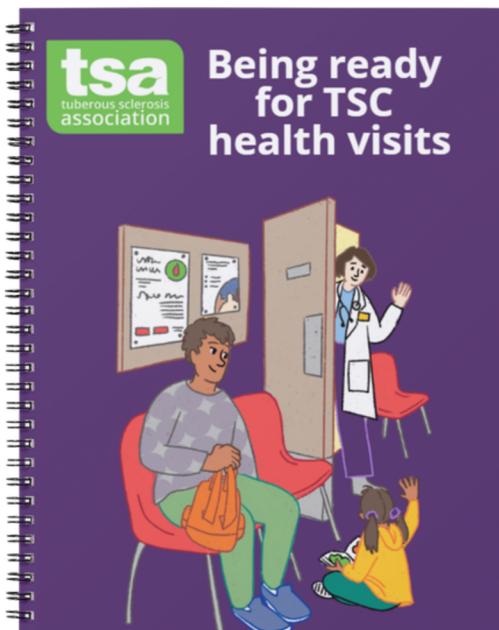
Updated TSA Welcome Pack

We're in the middle of updating the items offered to people new to either the TSC community or the work of the TSA

When individuals and loved ones are newly diagnosed with TSC, it can be an incredibly confusing, frustrating and difficult time. That's why we offer people a free TSA Welcome Pack. They're a vital reminder that you're never alone with the condition, with a few key materials to get you started on your TSC journey. This ensures a vital foothold into a new world, so people can navigate TSC more effectively and confidently.

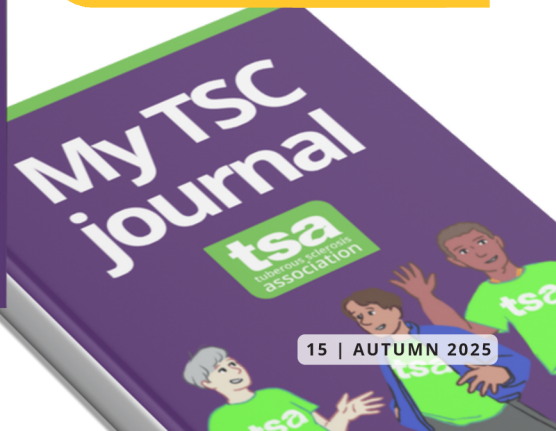
We know our welcome packs are really appreciated by those who receive them. It's a little while since we updated the pack, which is why we're now creating new materials to go into the pack, including:

- **'Being ready for TSC health visits' booklet.** Covering things like what to expect at medical appointments, how to get the most out of them, and things to do after you've had one
- **TSC appointments diary.** So you can track visits and meetings
- **'My TSC' journal.** Giving you a space to write down all your thoughts, feelings, experiences and 'Don't forget' notes on all-things TSC
- **Resources to help explain TSC to kids.** Making it easier for little ones to understand what the condition is and what it might mean for them or loved ones



Want a new TSA Welcome Pack of your own? They're completely free and we'd love to send you one! Even if you've already had one before

Just visit bit.ly/47IWc3H or contact the TSA Support Line





TSA Community Hub

You're never alone with TSC

Visit our TSA Community Hub page to discuss anything and everything

A big challenge of TSC is that it can often feel isolating. As well as the TSA Support Line, there's now also the TSA Community Hub, giving you a way to connect with others affected by TSC.

You can chat about anything at all - whether it's to ask a specific question, to share thoughts or feelings, or even talk about a new TV show you're loving. Register and get posting!

This is a new project, so we suggest that people post messages and regularly check back to see the hub slowly grow. **It will only be a success if the wonderful TSC community use it!**

The hub is available all day, every day. But, TSA staff will monitor posts only during working hours. Visit the hub at: **healthunlocked.com/tsa**.



TSA ANNUAL GENERAL MEETING 2025

The TSA's AGM for 2025 will take place virtually on **Thursday 27 November 18:00 - 19:30**. It **will include a 'TSC and genetics' Q&A, with a specialist TSC consultant geneticist**. Agenda items are:

- Discuss the Accounts of the Association for the year ended 31 December 2024 and the Reports of the Trustees and Auditors
- Election and re-election of Trustees
- Appoint an Independent Examiner until the conclusion of the next AGM in 2026
- To authorise the Trustees to determine the remuneration of the Independent Examiners

Notice given by the TSA Board of Trustees, courtesy of the TSA's Company Secretaries (Luke Langlands and Dr Pooja Takhar).

Register at: tuberous-sclerosis.org/agm2025

If you've ever been in touch with the TSA, you're a member, meaning you can attend and vote at AGMs. You may appoint one or more proxies to attend and vote for you. A proxy need not be a TSA member. There is no contract of service between any Trustee and the TSA. Interested in joining the TSA Board of Trustees, or would like to discuss any issues with the TSA Chair? Please contact: admin@tuberous-sclerosis.org / 0300 222 5737.

New horizons in epilepsy care

Tech developments and AI could revolutionise how epilepsy is studied, monitored, and treated in the near future

AI is the new hot topic across almost all areas of our lives. This is no different for TSC and how people with the condition are monitored and treated, especially in TSC-related epilepsy, where technological advancements could make life easier.

Wearables and implants have the potential to transform how seizures are detected and tracked. In one recent study by Kings College London and St George's Hospital London, a small device was placed just under the skin of participants. The implant recorded tens of thousands of hours of brainwave data over 15 months, accurately detecting hundreds of seizures. Participants found the device comfortable and easy to use, while it also gave doctors a clearer picture of how and when a person's seizures happened.



Prof Mark Richardson

Typically, people with epilepsy and their loved ones are expected to track seizures. A key benefit of the studied implant is that it allows more data and tiny changes in the body to be tracked, potentially leading to better overall care and management. Lead researcher Professor Mark Richardson commented: "It is vital that people with treatment resistant epilepsy are able to access the best possible care. This is made significantly more challenging by the fact that clinicians must rely on patient reporting to establish when episodes have taken place."

Multi-centre Epilepsy Lesion Detection (MELD) is an international collaboration using AI to improve care of people with drug-resistant epilepsy. Through things like MELD, AI could one day take all that we know about epilepsy and use it to create more personalised and impactful care. This is possible because AI takes massive amounts of data - in things like medical imaging, genetics and clinical information - and spots patterns and trends that would otherwise not be possible.

One of the biggest next steps in everyday TSC care has been more remote clinic meetings. Similar technology can now transmit seizure data, medication use, and other health information directly to healthcare teams. In practice, this might mean that a neurologist can respond to any changes in a person's epilepsy quicker.

Each new technological study brings us closer to a world where seizures are better and more consistently controlled. However, this can all work only if the needs of everyone are considered. The TSA will approach all new developments openly but also with a push that they're accessible for all.

Exploring the world through sensory play

There's lots of simple and creative activities that can bring you and loved ones together, all making use of the different ways that we experience the world around us

Sensory play can be a wonderful way to learn, have fun and feel connected. These activities focus on things like different textures, colours, smells, tastes and sounds to encourage curiosity and exploration. For those with TSC, this can feel even more meaningful, as senses can be often heightened.

Finding joy in senses might sound niche, but many of us do this without realising. Have you ever enjoyed the sound of birds singing, the smell of fresh tomatoes, the repetition of a pattern, or the feeling of a certain material? If so, then you've taken part in sensory play before!

As well as being possibly calming and enjoyable (but sometimes messy!), sensory play can have lasting benefits. It can support gross and fine motor skills, such as scooping, pouring or using play tools. It helps develop an understanding of cause and effect, and encourages communication through things like speech, vocalising, signs and pictures.

Importantly, sensory play can usually be enjoyed by everyone of all ages and abilities, giving the whole family opportunities to play together and be included in whatever way they feel most comfortable, as it's flexible and doesn't follow rigid rules.

You don't need special or expensive equipment to enjoy sensory play. Activities can be created with things you already have. Water play is always a favourite, such as freezing small toys in ice or adding food colouring to water and watching the patterns emerge. Sensory trays can also be effective, like a washing-up bowl filled with dried rice, shredded paper, or even edible sand made from crushed cereal. For something stickier, edible slime made from chia seeds, water, cornflour and food colouring can give hands plenty to explore. Painting is a classic option, whether using fingers, toes, sponges or natural items like leaves and sticks.

As fun as sensory play can be, it's important that exploration like this is monitored, as people might find certain sensory activities overwhelming, not enjoyable or suitable for them and their needs. For example, it might encourage people to try eating or drinking something that they shouldn't.

With a little imagination and everyday items, you can create activities that are safe and fun! These playful moments can make a real difference, helping people to develop important skills and understanding about how they and their loved ones experience and enjoy the world around them.

TSC Clinics Meeting 2025

A record number of medical professionals gathered at this year's meeting, all focused on improving TSC clinical care

One of the roles of the TSA is to act as secretariat to the TSC Rare Disease Collaborative Network (RDCN), a collective of NHS TSC Clinics all across the UK. Every year, we hold a special face-to-face meeting for the doctors and nurses that are part of the network. This gives clinicians a chance to discuss TSC in more depth, while setting out the key priorities and plans for the next 12 months.

The day had a packed agenda, and attendees created many new connections while improving their own understanding of TSC. Key discussion points included the upcoming new TSC clinical guidelines, ensuring that as many people as possible have access to approved TSC medicines, and the work so far in developing TSC registries. These meetings, and the work of the TSA to make them happen, are so important in ensuring that TSC care across the UK is as equal and impactful as possible.

The work doesn't stop there with the TSC RDCN, with more virtual events planned for the remainder of the year. Members of the network are also helping the TSA in a lot of our key future projects.

Despite the vital role of the TSC RDCN in ongoing care of people with TSC on the NHS, neither the network nor the TSA receives any funding from the NHS or the UK Government for all that it achieves. However, we and the clinicians who are part of the network recognise the importance of making sure that it continues.



Dr Jacqueline Eason (Consultant Clinical Geneticist, Nottingham TSC Clinic)

Fundraising thank yous

We celebrate some of the incredible fundraising taking place that means that we can continue to be here for the TSC community



Brilliant Nara and her friends!

Nara and her friends have so far raised a very impressive **£463** for the TSA! They design, make and sell beautiful colourful bracelets at their school. Nara was inspired to fundraise for the TSA by her Dad, Sanjay, who is one of our fantastic trustees. Thank you so much for your continued support!



Gordon's amazing birthday cake

Gordon Bull turned 70 and had a party to celebrate, requesting donations to the TSA rather than gifts, in memory of beloved daughter, **Zoë Bull**. Many in the TSC community remember Zoë, who did so much for TSC awareness and the TSA. Gordon's incredibly kind efforts raised **£1,250**. We're so thankful to you, Gordon.



L-R: Sam (TSA Community Fundraiser), Lucy, Claire, Claire's Mum - Mary - and her husband Bob. Thank you!

Grantham Rotary Club chose the TSA as their Charity for the Year, with motivation from club president Mary's granddaughter Lucy, who has TSC. Over the year, the club has held many fundraising events, with a brilliant total of **£3,500!**



Matt Dolan took on a bucket list challenge in July and jumped out of a plane at 12,000 feet, all in aid of the TSA! His sister Jenny who has TSC was his inspiration. Matt said after the feat: "Everyone should do this at least once in their life" - it's safe to say he thoroughly enjoyed it! Matt raised a fantastic **£1,185!**



Thank you Avril, Mal and Lana!

A cocktail evening by **Avril and Mal Greaves** with the help of friend **Lana Morris** was the toast of town, raising an amazing **£820**, along with a contribution from Booth Hall where the event was held of **£500!** Avril and Mal's motivation is inspirational daughter Jessica, aged 10, who has TSC.



Hattie's Leeds Half Marathon team

The fantastic family and friends of **Hattie Louise Storey** ran the Leeds Half Marathon, all in memory of Hattie. This included **Hattie's Dad, Chris, Uncle Oliver, her Godparents, and friend Ryan**. Between them they raised an absolutely astonishing **£13,350** for the TSA!

Hattie's Dad Chris had this to say: "Hattie was diagnosed at three weeks old with TSC. She suffered from seizures and learning difficulties every day. Hattie was a loving, cuddle giving girl, always exploring,

wanting to be on the move. She might not have said a word but love is the loudest presence in the room. Hattie is big sister to Elmer, Daphne and Felicity. Hattie will be missed every day, forever. Thank you to the team for running the Leeds Half Marathon and raising such a large amount of money for a charity close to our hearts. Thank you to every single person who made a donation, it means a lot to us." We're so thankful to Hattie's family and loved ones.



Much loved Hattie



Amazing work Miriam!

Miriam Bellamy raised a whopping **£1,288** for the TSA through the Swansea University Half Marathon 2025. Miriam has also fundraised for the TSA before as her sister has TSC. Thank you!



Well done and thank you Ross!

Ross Kemble and friend Steve took on the Stour Valley Path Ultra Marathon, covering a staggering 100k. Ross' motivation is daughter Sennen, who has TSC: "The TSA has been a lifeline for us, providing invaluable emotional and practical support as we navigate this challenging journey. While we don't know what the future holds for Sennen, we find immense comfort in the TSA's continued guidance, as do countless other families affected by this awful and rare condition." So far, Ross has raised a wonderful **£6,697!**

Robert Szalai, Oliver Biggs and Freddy Biggs took on the iconic Three Peaks Challenge, climbing the three highest peaks in England, Scotland and Wales in less than 24 hours. They achieved the incredible feat, with just 15 minutes to spare! Loved ones and colleagues all donated, with the trio raising a fantastic **£3,455!** With donations still coming in!



The Holts en route!



The Three Peaks Trio!

Aaron, Laura and Ruby Holt, along with 32 loved ones, took on an epic challenge and did the 'Pendle pub walk!' Taking in lots of lovely countryside and country pubs, all while raising vital awareness and funds. The Holt family are amazing ambassadors for the TSA, supporting their son, Jonah, who has TSC, as well as the wider TSC community. In total a brilliant **£860** was raised!



Thank you Luke and Hayley

Luke and Hayley James have done loads of fundraising events this year, including a recent football tournament. Their total is now over a staggering **£12,000** and still rising. The lovely couple do all this in memory of their daughter, Esme, who they lost at 35 weeks pregnant. Esme had TSC. Thank you so much to you both for all of your amazing fundraising efforts.

Stuart and Emma were joined by **Emma's cousin Lindsey, uncle Keir and stepdad Danny** as the family took on the Edinburgh Kiltwalk, all to raise funds for the TSC community. It was a long journey,

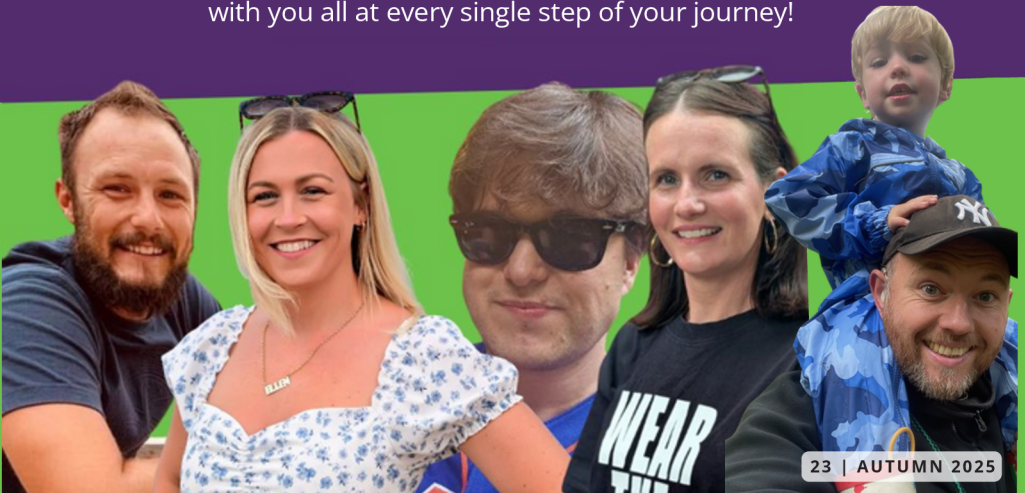
with the route crossing 33km and taking seven hours. However, it was all worth it, with a mammoth **£3,839** raised for the TSA! Motivation came from daughter Macie, who has TSC.



Top work all! Thank you!

Kenny Smith was inspired to give to the TSA after reading about a family with TSC in his company's newsletter. Since then, Kenny's been busy raising funds and also encouraging colleagues to get involved too! Kenny organised a 1% club team quiz and he also did a sponsored 'Walk to Work'. So far Kenny and his colleagues have raised a fabulous **£725!**

We're so excited to introduce the incredible #TeamTSA who'll be running the TCS London Marathon 2026! Our amazing runners are: **Ellen Richardson, Lee Phillips, Graham Ashbridge, Rebecca Cave-Brown and Aaron Holt!** We'll be with you all at every single step of your journey!





It was all systems go for Needham Market Co-op this summer, who took part in the TSA Superhero Summer by holding a range of fundraising events, all to help raise awareness and funds for the TSA. This included a sponsored walk, dress-up days and a bingo night. In total they raised a brilliant **£1,187**, a real superhero effort indeed! Thank you to all, and particularly **Jackie Mayer** and long-standing TSA supporter **Linda Smith** who helped organise these events.

When **Mel Charles** passed away suddenly last year, his daughter, **Laura**, wanted to do something to honour his memory. That's when the Mel Charles 2025 Trophy golf day started. Organised by **Kris Parker** and **Trevor Gowthorpe**, all funds were donated to the TSA as Laura's uncle, David, has TSC. The sun shone and everyone had a great time, raising an incredible **£5,485** for the TSA! Thank you to everyone involved!

Ellen Richardson and friends took part in the Born Survivor 10k, inspired by Ellen's daughter, Connie, who has TSC. Ellen said: "What an amazing experience! It was such a challenge and pushed me right out of my comfort zone, but our team absolutely smashed it! It was so amazing how everyone came together. The highlight was having Connie on the sidelines cheering us on."

The team have raised **£2,320** and vital awareness of the condition. Amazing effort all! Well done and thank you!



Top work Ellen and all!

The Mel Charles 2025 Trophy golf day!



The TSA at the Global TSC Research Conference

Dr Pooja Takhar (TSA Joint Chief Executive) went to Washington alongside 200 researchers, clinicians and advocates to attend the biggest TSC research conference of the year

Hosted by the TSC Alliance in the United States, the conference was held over three days, with participants sharing the latest developments in TSC. Pooja was invited to deliver a talk on behalf of the TSA and TSC International (TSCi).

In her presentation, Pooja focused on:

- How researchers, industry leaders and TSC groups across Europe are helping to accelerate TSC clinical trials
- Efforts to improve global access to clinical trials, especially in countries and communities that have historically been underrepresented
- Why research must consider real-life experiences of people affected by TSC

The conference underlined the progress made in TSC but also that there's lots of work still to do, including the need for more research into TSC issues that usually start in adults, such as kidney problems and LAM (problems with the lungs). TSC-Associated Neuropsychiatric Disorders (TAND) was also identified as a research area that's still a priority, with in-depth presentations exploring sleep, emotional regulation, and behavioural challenges.

Pooja commented: "It was another fantastic conference. In particular, it was wonderful to see early-career researchers receive mentorship and encouragement, ensuring the next generation of TSC scientists are equipped and inspired."



A session at the conference

Throughout the conference, voices of individuals and families affected by TSC had a key role. Powerful talks from community speakers reminded everyone that behind every research paper, idea and clinical trial is a real person or family with TSC.

For the TSA, taking part in these conferences ensures that the UK TSC community remains central to global TSC research.

What you're asking on the TSA Support Line

Recent key questions and answers between us and you



"I've never discussed my TSC diagnosis with my employer before. Do I have to? What are some things to consider?"

Sharing your diagnosis is a personal decision. Some people prefer to keep things private, while others find that being open helps them feel more supported and understood. However, letting your employer know can help you access something called 'reasonable adjustments'. If you have TSC-related epilepsy that isn't fully controlled, it's important to tell your employer because they have a legal duty to make sure you and others are safe.

Under the Equality Act 2010 (and the Disability Discrimination Act in Northern Ireland), an employer must consider reasonable adjustments for you, which are changes at work to make it easier and safer for you to do your job. It also means your employer can consider your health and wellbeing in a positive and proactive way. These changes make it easier for people with disabilities to work safely and effectively.

Adjustments vary depending on the individual, but could include flexible working hours, extra breaks for medical appointments, remote working options, or physical adaptations such as specialist equipment. The key is that adjustments should be practical for both you and your employer, helping you perform your role to the best of your ability.

If your employer is worried about potential costs because of reasonable adjustments that you might need, remind them about Access to Work, a government scheme that provides financial help for workplace adjustments such as equipment, support workers, or travel.

Depending on how TSC affects you, your employer can carry out a risk assessment and work with you to develop a care plan, which outlines what to do if you become unwell at work. This can include who to contact, what support you may need, and how colleagues can help. It's best to create this plan together, so it reflects your preferences and helps you feel confident and secure.



It can be hard to know how to begin with discussing TSC with an employer, but you're not alone. Start by thinking about what would make your workday easier. This might include shorter shifts, flexible hours for hospital visits, or time to take medicines.

Think about speaking with your HR team, a trusted manager or perhaps someone in a health and safety role about your needs. You could also ask this person, or someone in HR, to be present in any discussions with managers or bosses to discuss your needs and reasonable adjustments that could benefit you.

If you believe you've been treated unfairly at work because of TSC, you have legal protection. Keep a record of what's happened and speak with your HR team first if possible. If you need independent advice, you might want to contact ACAS (Advisory, Conciliation and Arbitration Service) or a local Citizens Advice office, both of which can guide you through the next steps.

Of course, the TSA is also here for you through all of this. We've got two handy resources that you might find useful:

- TSC and Employment: A Guide for Employers. This explains how TSC and workplaces can be more inclusive (available here: bit.ly/47Ecc2k)
- TSC and Employment: A Letter for Employers. A template letter you can edit to help start conversations about TSC (available here: bit.ly/4hrWRWf)

The TSA Support Line can also discuss all these things with you, as well as provide information and advocacy for your needs.

“An employer must consider reasonable adjustments for you, which are changes at work to make it easier and safer for you to do your job.”



We're here for everyone affected by TSC only
thanks to the **amazing people and groups**
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off donations**

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tuberous-sclerosis.org/donate

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