

scan

SPRING 2026

The magazine of the TSA



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 Spring 2026 highlights

We're funding new TSC research

The TSA has awarded funding to new TSC research. Read all about the studies that we've chosen to fund and support



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We hear about Logan, an amazing young man who has TSC with a passion for BMX and motorsport



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TSA Support Line:
0808 801 0700
(freephone and WhatsApp)
support@tuberous-sclerosis.org
Webchat



Dr Frances Elmslie

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A word from your Chair

“Our new annual report shows the progress that we’re making”

“This issue shows how progress in TSC happens when we keep two things moving forward together: Ambitious research and practical support for everyday life.

There’s real momentum in TSC research. MiTS2 is exploring a potential TSC treatment ([see page 7](#)), while new TSA-funded projects range from a national TSC registry to studies exploring inflammation, lung repair and the blood-brain barrier ([see page 12](#)). Each step adds to the evidence and moves us forward.

Of course, support is equally important to us. The TSA Support Line is now available through WhatsApp, making it even easier to ask our support team questions or to have a listening ear. This Scan issue also covers developments in changes to Special Educational Needs and Disabilities (SEND) support ([see page 18](#)) and our views on unacceptable inequalities in healthcare for people with additional needs ([see page 21](#)).

What matters most continues to be people in the TSC community itself. Logan’s story reminds me of the many different and diverse lives experiencing TSC ([see page 10](#)), as does our recent campaign ‘TSC and Me’ ([see page 26](#)).

It’s only through your support that we can continue to be here. Thank you.”

Dr Frances Elmslie (Chair, TSA Board of Trustees)

TSC Teens Art Club

Join our monthly virtual get-together for teenagers in the TSC community

Being a teenager can come with lots of pressure. Add in TSC and things get even more complex. The TSC Teens Art Club is a monthly online meeting focused on creativity, connection and doing things at your own pace.

The club is led by a brilliant professional artist, Sarah Goy, who also has TSC herself. Sessions are on Zoom and have a playful, low-pressure approach to art. You don't need to be "good" at drawing or painting, and you don't need to talk if you don't want to. Some teens come ready to chat, others prefer to listen while they create. That's all absolutely fine, and it's part of what makes the club welcoming and non-judgemental.



Sarah Goy, professional artist

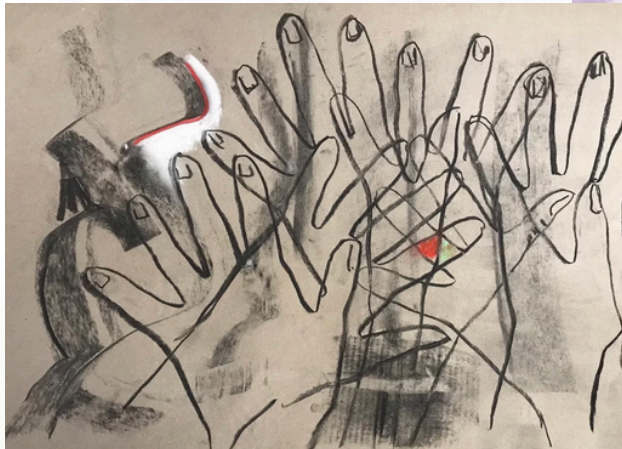
Art supplies can be costly, which is why **all sign ups receive an art kit completely free of charge!** This means you can just sign up, get your kit, log on and join in!

People are already loving the club:

"My daughter is 13 and until this group had never met anyone else with TSC. That alone meant so much to her. The art sessions give her a way to express herself creatively, build confidence, and feel understood."

If you're a teen who might enjoy the TSC Teens Art Club, we hope you'll come along! Teen siblings, family members and friends of people with TSC are also very much encouraged to join.

Sign up for the TSC Teens Art Club here or scan the QR code:
<https://bit.ly/3MAKOUE>



Sign up to the club!

Join us at Outlook and Big Day

Two key dates for your diary, both focused on connecting with others, practical support and the latest TSC research

Many readers might be familiar with Big Day and Outlook. Big Day is for EVERYONE in the TSC community, while Outlook is for adults with TSC. Both feature full agendas based around what the TSC community tells us matters most.

Big Day 2026
Leonardo Hotel Milton Keynes
Saturday 6 June
www.bit.ly/bigday26

Outlook 2026
Holiday Inn Portsmouth
Saturday 25 April
www.bit.ly/Outlook26

Big Day 2026 has parallel sessions on different aspects of living with TSC. These include discussions on early years with TSC, music therapy and a special research Q&A session. **Big Day also features a creche run by SEN-specialised nannies.**

Outlook 2026 begins with a gentle icebreaker, discussions on practical wellbeing and support and special moments to mark 30 years of Outlook. This year, Outlook also features a special buddy system, to help people new to the event to feel more at ease.

If cost is a barrier to attending either event, please **contact the TSA Support Line** to discuss travel bursaries.

Head to our website, scan the QR codes or contact the TSA Support Line to join us at Big Day and Outlook!



Get your Big Day tickets



Get your Outlook tickets



TSA Support Line on WhatsApp

It's now even easier to get in touch with our friendly support team

The TSA Support Line can help with everything related to TSC. Whether you just want a listening ear or have a specific question or challenge, we're here for you and your loved ones. However, with life only getting busier, it can be difficult to find the time to speak to our support team. That's why we've made it possible to contact us through WhatsApp!

WhatsApp is monitored Monday to Friday, 9am–5pm (excluding bank holidays and training days). We'll reply as soon as we can during working hours. If you've not heard back within 24 hours, please resend your message, as WhatsApp restricts replies after this window.

Contact the TSA Support Line

0808 801 0700 (WhatsApp and Freephone)
support@tuberous-sclerosis.org
Webchat (tuberous-sclerosis.org)



Scan this QR code or
message 0808 801 0700

A new way to update your information with us

Staying connected with the TSA and keeping us updated is now easier

TSA Portal gives you more control over your information and helps us ensure we're providing the right support, information and opportunities to you. It's a single place to see and update:

- Contact details
- Preferences for keeping in touch
- TSA donations and Gift Aid declarations
- TSA event sign up details (like dietary or allergy information)



TSA Portal QR code

Thanks to TSA Portal, you also shouldn't miss any issues of Scan or things like our newsletters. You also have more control of your data.

If you're having any issues logging in or you have any queries about TSA Portal please visit: tuberous-sclerosis.org/tsaportal

Major new investment in TSC epilepsy research

Over £2.5m has been awarded from a national programme for the new MiTS2 clinical trial. We're proud to have an important role in the study

MiTS2 is a clinical trial looking at whether a medicine called metformin, which is widely used to treat other conditions, is effective in TSC-related refractory epilepsy (this means epilepsy that doesn't respond to two or more standard existing treatments). Metformin has a strong safety record, has relatively mild side effects and is inexpensive. If shown to be effective, metformin could represent a promising and highly accessible new treatment option for people whose TSC-related seizures are difficult to control.

The trial, whose Chief Investigators are Prof Finbar O'Callaghan and Dr Sam Amin, is the next step following the previous MiTS trial, which suggested that metformin might be effective for TSC-related refractory epilepsy. MiTS2 involves more participants than the first MiTS trial and will be a 'double-blind, placebo-controlled randomised trial', which is considered the gold standard in clinical research.

The trial is funded by the National Institute for Health and Care Research (NIHR), the UK Government's way of driving new health and social research. As well as seizure frequency, MiTS2 researchers will assess the impact of metformin on the size of SEGAs and AMLs (tumours in the brain and kidneys) in participants under 25, and will also examine quality of life, sleep and behaviour.

The TSA has an important role in MiTS2. We're helping clinicians, researchers and the NIHR understand what's most important to the TSC community through our TSC Research Volunteer Network. This research is vital not only because it might lead to a new TSC-related epilepsy treatment option, but it also shows the power of repurposing existing medicines for new uses. Rather than developing a completely new drug, which is incredibly expensive and usually takes 10–15 years, researchers in MiTS2 will see if metformin can be used in a new way. If the results are positive, this should mean that people get access to metformin for TSC-related refractory epilepsy quicker than if it were a brand new medicine.

In the coming months, the MiTS2 researchers will recruit 136 children and adults aged 6–65 with refractory TSC epilepsy. We'll keep everyone updated on when recruitment starts. In the meantime, you can register your interest at: mits2@exeter.ac.uk.

This study/project is funded by the NIHR [Efficacy and Mechanism Evaluation (EME) programme (NIHR159386)].





Join us in funding transformational research that will make a real impact in the lives affected by TSC

From Research to Real Life is our new fundraising campaign aimed at strengthening our capabilities to fund new and impactful research projects. As we launch our new three-year research strategy alongside this campaign, we want you to be part of this journey.

Our strategy has been built with the input of people in the TSC community to ensure that every pound invested goes to the areas that matter most. Dr Pooja Takhar, Joint Chief Executive, comments: "We're accelerating the path between the lab and life-saving treatments. By backing the most promising projects and global collaborations we can make cures come faster".

When we talk about medical research, it can often sound like a very dry topic. It's understandable to visualise a cold and sterile lab, with obscure findings that don't translate to the real world. This isn't what medical research means to us at the TSA. To us, medical research is hope for real people and real lives, with discoveries that make a real difference.

Our research priorities for the next three years are to:

- **Better understand the lifelong impact of TSC**
- **Bring about effective medical treatments**
- **Optimise TSC care, with a focus on early diagnosis and monitoring**

With your support, we're funding projects that could lead to earlier diagnosis, more effective treatments and a greater understanding of how TSC will play out over a person's lifetime.

If it's going to work, we need your support!

“By backing the most promising projects and global collaborations we can make cures come faster”

- Dr Pooja Takhar, Joint Chief Executive

Research in detail

Some of the research we want to fund through From Research to Real Life includes:



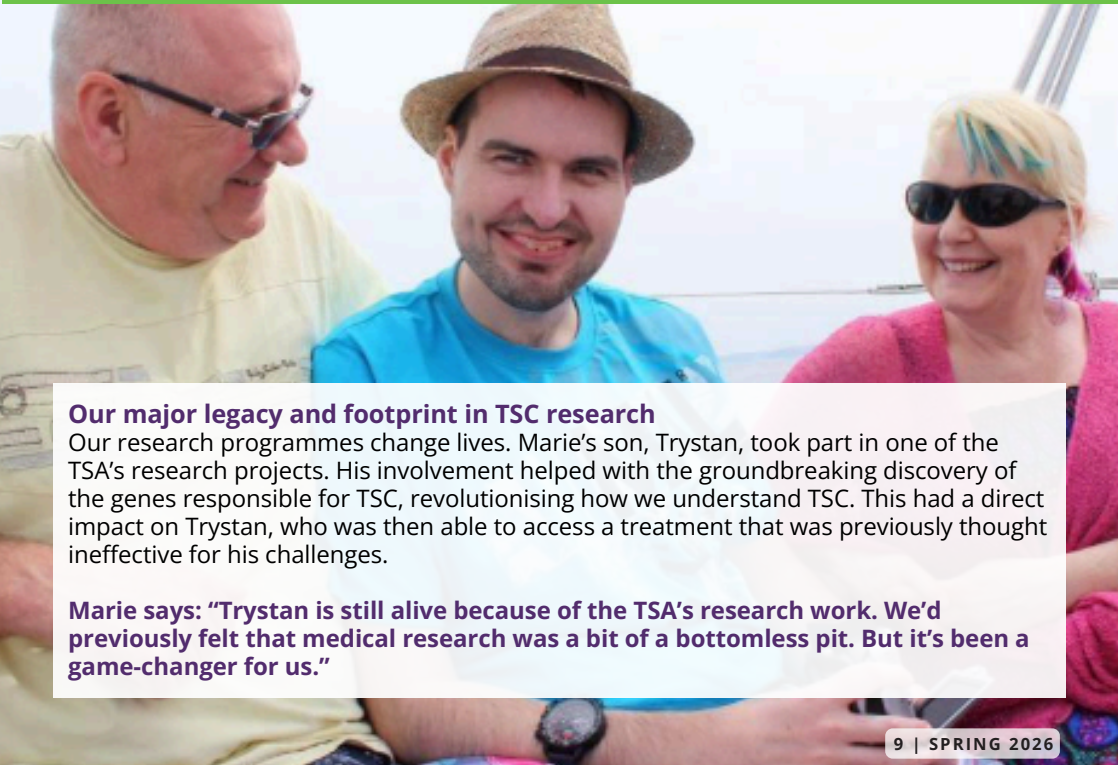
Four awards to support early-stage or exploratory projects. This can generate preliminary data, build collaborations, or strengthen applications for larger funding.



Match funding to initiate the development of a TSC registry. A registry could have massive implications for our understanding of how to treat and manage TSC.

Every penny donated to From Research to Real Life will go directly towards the aims of our Research Strategy

To donate to From Research to Real Life, visit:
tuberous-sclerosis.org/research-donate
 Read more about the campaign at: bit.ly/research2rl



Our major legacy and footprint in TSC research

Our research programmes change lives. Marie's son, Trystan, took part in one of the TSA's research projects. His involvement helped with the groundbreaking discovery of the genes responsible for TSC, revolutionising how we understand TSC. This had a direct impact on Trystan, who was then able to access a treatment that was previously thought ineffective for his challenges.

Marie says: "Trystan is still alive because of the TSA's research work. We'd previously felt that medical research was a bit of a bottomless pit. But it's been a game-changer for us."

Logan's TSC Story

Logan Ritchie was diagnosed with TSC as a baby. Despite ups and downs, he's a passionate young man going from strength to strength, alongside support from his brother Seth. Logan's Mum and Dad, Sophie and Paul, told us about Logan's life:

"Logan's story starts at age 9 months when he started having infantile spasms. We took him to the doctors and over a few days and various visits, which included a trip to A&E, we were told that he was just attention seeking and it was nothing to worry about. We were not happy with this, we knew there was something wrong. On our third or fourth visit to the doctors in as many days, we sat in the doctor's office and said we were not leaving until we saw a specialist. That day, we met a specialist and after they saw Logan and the videos we had of him Logan was diagnosed there and then with TSC. That's when the journey began. Scans showed two main growths, and multiple shaded areas, in his brain.

At 11 months old, during routine TSC scans, doctors noticed an abnormal growth on Logan's left kidney. We were sent to Nottingham Children's Hospital for a biopsy. We were then hit with the news he had cancer. It had taken hold of his left kidney and within a week or so Logan was in surgery having his left kidney removed. All we asked is that he made it to his first birthday which was the following month. This was nothing at all to do with the TSC, it was just an abnormality.

After years of scans and regular check-ups, Logan is a fighting fit 15-year-old boy. He has ADHD and some learning issues at school, but he doesn't let it get him down. Logan tries his hardest in everything he does and he really doesn't like to fail.

The only visual sign of TSC for Logan is a butterfly rash on his face and a few white patches on his skin. This has caused a few comments at school but he just shrugs it all off.



Logan is a passionate BMX and motorsport fan

Logan competes at a regional and national level in BMX racing, even racing for his club in Milton Keynes. He used to train and play tennis but he's stopped this to concentrate on the BMX racing and coaching. Logan aims to achieve his goal of racing in a BMX World Championship.

We know when Logan's struggling at an event as he wears his goggles and shuts out the world. He also enjoys some time down the driving range playing golf.

Logan aspires to work in motorsport in some capacity and even has an interview with a college in the coming month.

Logan never moans too much about all the hospital trips. This is just a small story about a boy who has had struggles with many things in his life, but just keeps smiling and moving forward."

Thank you to Logan, Sophie, Paul and Seth for sharing Logan's journey! If you'd like to share yours, get in touch with us: support@tuberous-sclerosis.org.

TSC STORIES



Logan at the driving range



Seth (left) and Logan (right)

Five new research projects funded by us

We've funded TSC research aligning to our latest research strategy, in order to help improve diagnosis, treatment and management of TSC

Building a national TSC registry

PhD student Leila Ben-Chaabane will help to create a sustainable national TSC registry. This will help answer key questions on UK prevalence, the impact of TSC-Associated Neuropsychiatric Conditions (TAND), and how diagnosis and care vary across regions. Ultimately, a national registry could have a positive impact on all aspects of service improvement and TSC research.



Leila Ben-Chaabane

Understanding lung repair in TSC-LAM

Women with TSC can develop lymphangioleiomyomatosis (LAM), which affects the lungs. Current treatments can slow LAM progression, but they don't repair existing damage. Dr Roya Babaei-Jadidi will investigate if raised levels of interleukin-6 (a chemical substance in the body) contribute to lung damage in LAM, and whether targeting IL-6 could open up new treatment possibilities.

Simpler tools for diagnosing and monitoring TSC

Diagnosis and monitoring of TSC can involve repeated scans over many years. Dr Elaine Dunlop is exploring whether measuring blood-based biomarkers could make this easier, including tiny things in the body called extracellular vesicles. If the research is successful, it could mean much simpler ways to diagnose and monitor TSC in the future.

Is TSC partly driven by inflammation?

Emerging evidence suggests body inflammation may contribute to TSC tumour growth. Professor Andrew Tee will investigate whether anti-inflammatory medicines can be a new treatment approach against TSC tumours, potentially alongside existing medicines like everolimus.

Exploring the blood-brain barrier in TSC

The blood-brain barrier controls what enters and exits the brain. Research suggests disruption of this barrier might contribute to TSC-related seizures. Dr Claire Behan will use advanced brain imaging to explore whether blood-brain barrier changes are in fact linked to seizure activity. This could help identify seizure-prone brain regions and guide future treatments.

Thanks to your ongoing support, we continue to progress TSC research!

The difference Charity of the Year can make

We're so thankful to organisations across the UK selecting us as their Charity of the Year, helping raise funds for the TSA and awareness for TSC

Coveris produce high-quality plastic food packaging and are equally committed to supporting meaningful causes. They chose the TSA because a member of their team has a child with TSC.

Throughout the year, they'll run a full calendar of fundraising and awareness activities. Alongside usual fundraisers such as bake sales, raffles, and "guess how many sweets in the jar" competitions, they're excited to be doing a charity walk in September. They're also planning some new initiatives, including a pumpkin carving competition later in the year. Their goal is to raise a significant amount, while encouraging all staff to get involved and feel connected to the cause.

Dunelm Lodge in Darlington kindly chose the TSA as their charity of the year due to a family's connection to the condition. Mal and Avril's granddaughter Jessica, aged ten, lives with TSC and is an inspiration to those around her.

Jessica's grandad, Mal, said this about Jessica: "Jessica was officially diagnosed with TSC alongside infantile spasms at six months old. She's now aged ten and has tubers in and around her brain, and both eyes, as well as learning delays, sensory issues and drug-resistant epilepsy. It has been a rollercoaster of highs and lows throughout her journey, but she remains to be the funniest, happiest and most caring child."

Victory Marine Lodge. W Bro Paul Beecham is the Worshipful Master of the Victory Marine Lodge which is a long-established Masonic lodge that meets at the Upminster Masonic Temple, known as The Square. Paul has chosen the TSA as their main charity for very personal reasons.

Paul's step-grandson lives with TSC, and his family has seen first-hand the impact the condition can have, not only on the individual but on the whole family. Paul said: "We greatly value the work that the TSA does in supporting families, raising awareness, and funding vital research into TSC. By choosing the TSA, our lodge hopes to contribute both financially and by helping to raise awareness of a condition that is still not widely understood."

Throughout the year, Victory Marine Lodge will be holding a series of fundraising events in support of the TSA, with events planned for April, June, and October. These will involve lodge members, their families, and the wider community, reflecting our shared commitment to making a positive difference.

A huge THANK YOU to everyone involved in Charity of the Year fundraising for the TSA!

Researcher in focus: Professor Andy Tee

Many people in the TSC community will be familiar with Prof Tee, thanks to his longstanding role in TSC research

From his lab at Cardiff University, Andy's work over the years has focused on understanding what goes wrong inside cells (the basic blocks of what our bodies are made of) in TSC. This has led to many milestones in TSC research. Andy aims to find out what actually leads to TSC growths and other complications in TSC.

One of Andy's most important contributions to TSC research has been helping to explain how changes in the genes responsible for TSC - called TSC1 and TSC2 - lead to TSC tumours developing. This discovery was a crucial step towards the development and use of a type of medicine called mTOR inhibitors, such as sirolimus and everolimus (Votubia).



Professor Andy Tee



Andy and his lab team are now asking an important further question in TSC research: "What comes next?" While current treatments can slow TSC progression, they don't fix damage that has already happened. Existing treatments also don't work for everyone and don't always reflect the full complexity of TSC. As a result, the research is exploring other processes involved in TSC. It's hoped that this will allow us to find new major discoveries and treatments.

One of these new pieces of research, which goes beyond mTOR alone, is focused on better understanding the TSC2 gene. Andy and his team have discovered that one part of the TSC2 protein acts a bit like a control switch, helping to control what other genes do. This affects how cells react to things like stress, inflammation and other signals in the body. By studying this newly discovered role of TSC2, the team hopes to better understand why TSC can affect so many different parts of the body, and why people's experiences of TSC vary so much.

What motivates you to continue working in TSC research?

"I've always thought a little differently and have a very strong drive to understand how complex systems work. I can become deeply focused on solving a scientific problem and find it hard to let go until I feel I truly understand it. That persistence has been a real strength in research.

On a more personal level, I also see how neurodiversity shapes learning and development within my own family. That gives me an added sense of perspective and empathy. TSC is not just a biological puzzle, it affects real children, real families, and real futures.

What keeps me going is the extraordinary TSC community. It is one of the most collaborative and supportive research communities I've encountered. There is a shared determination to work together and find better therapies and support for people living with TSC."

What could your research mean for people living with TSC?

With continued support from the TSC community, our research has uncovered a new function of the TSC genes that we believe plays an important role in how the disease develops. This gives us a deeper understanding of what may be driving tumour growth and some of the wider features of TSC.

With this new knowledge, we are now in a much stronger position to test potential new drugs in the laboratory. The goal is to identify treatments that target the disease more precisely and, ultimately, improve the quality of life for people living with TSC. While research takes time, every new discovery brings us closer to more effective and better-tolerated therapies."

What would you say to families affected by TSC who are reading this?

The work we do in the laboratory is driven by you. TSC is not just something we study; it represents real challenges faced by real families every day. That awareness shapes how we think about our research and the questions we choose to pursue.

Research can sometimes feel slow from the outside, but progress is being made. Our understanding of TSC biology is deeper than it has ever been, and that knowledge is guiding smarter and more targeted approaches to treatment.

Most importantly, you are not alone. The TSC community, including families, clinicians, researchers and charities, is united. There is a genuine shared commitment to improving care and finding better therapies. It is a privilege to contribute to this worldwide effort.

“What keeps me going is the extraordinary TSC community. It is one of the most collaborative and supportive research communities I've encountered” 

Fundraising thank yous

We're so thankful to all of our incredible community fundraisers



Richard took on a frosty walk!

Richard Baker took on another chilly 9 mile winter walk challenge along the Wolverhampton canal, fundraising for the TSA because a work colleague has a son with TSC. Richard's hard work was well worth it, raising a fantastic **£415!** Thank you for your efforts Richard!



Well done Alice and Katie!

Alice Titley smashed the Great North West Half Marathon, raising a brilliant **£280!** Alice, who has TSC alongside her brother, has received support from the TSA and wanted to give something back. Alice has even fundraised for us in the past and has plans for future events too, which we're so thankful for!

Alice said that the weather was "not on her side" and that Blackpool seafront was "brutal". Yet, Alice and her partner Katie completed it in 2 hours 30 mins!



Halstead Road Runners Club organises the Halstead and Essex Marathon every year. They've kindly included the TSA as one of their chosen charities for this year! **Ross Kemble**, a regular fundraiser for the TSA, is also a member of the running club.

Enter the Halstead & Essex Marathon by going here: bit.ly/4ub0cgq. Last year, a total of £5,000 was raised for worthy causes and local schools!

Find lots more fundraising and challenge events on our website or by talking to our fundraising team: bit.ly/tsa-fundraising



Emily and one of her friends who ran the Bedford Half - well done!

Emily Kruger laced up her trainers and took on the Bedford Half Marathon for her beautiful girl, Peggy. In doing so, she created a tidal wave of support and Peggy's Army was born.

At just 6 months old, Peggy had already been through more than most of us will ever face. After a difficult stay in Kettering General Hospital, undergoing a series of invasive and exhausting tests, she was diagnosed with TSC.

Emily gained so much support along the way and even had six people who ran with her. She's raised an astounding **£12,890** which is still rising! What an effort!



Thank you Emily!



Major SEND reforms in England

New proposals to reform special educational needs and disabilities (SEND) services in England, including Education, Health and Care Plans (EHCPs)

To be implemented from 2029 onwards, children with SEND will be categorised as needing either a 'Targeted' level of support (pupils in mainstream schools) or 'Specialist' level of support (children with the most complex needs, who may require EHCPs). This means that EHCPs may be available only to those with the most complex needs.

From summer 2029, most children with SEND will have an Individual Support Plan (ISP), rather than an EHCP, which will be digital information on needs that the school must produce for every SEND child. The new system is set to then start from September 2030.

What this might mean for you and your family

It's being reported that some children and young people with spectrum disorders, such as ADHD and autism, may not be eligible for future EHCPs. If someone has an EHCP, from 2030 onwards they might be re-assessed at an education milestone, such as going from primary to secondary school. We don't have enough information yet to understand what dispute and resolution steps may be in place for families and caregivers who might disagree with a decision.

It's important to note that **nothing is going to change soon**. It'll be years until any changes are actually implemented. Add your views and voice to the consultation period by going to: bit.ly/3NdPy90

Why this is all happening

SEND provision changes are planned as the current system is considered insufficient or "broken", including by independent public spending group The National Audit Office. The cost of SEND support has increased significantly over recent years, with around 1 in 5 pupils receiving special educational needs support.



How the pledged money will be spent

Extra funding is pledged for the changes to happen, to be spent across three years. The overall focus is to ensure earlier and more consistent support for young people in mainstream education settings. Education Secretary Bridget Philipson has said that she wants support to stretch “from birth to workplace” for all young people with SEND. Philipson also said that the current situation “works well for some children but not all.”

Funding type	How much funding	What this is for
Inclusive Mainstream Fund	£1.6 billion	Broad inclusive provision funding (e.g. targeted and small group interventions, staff support, adaptive teaching styles)
Experts at Hand	£1.8 billion	Local Authority commissioned specialists (e.g. Speech and Language Therapy, Occupational Therapy, Educational Psychology)
Best Start Family Hubs	£200 million	Access to early SEND support through Best Start Family Hubs
Teacher Training for SEND	£200 million	Training courses across multiple types of SEND for all teaching staff
High Needs Provisional Capital Allocation	£3.74 billion	Around 60,000 ‘specialist places’ and ‘inclusion bases’ buildings for all secondary schools

What our view is on it all

Families regularly tell us about struggles regarding SEND support and EHCPs. Changes and investment are positive, as is the understanding that support interventions must happen earlier. As a member of the Council for Disabled Children, we support their view that more integrated SEND support in mainstream school should also be welcomed.

Although these updates show much needed progress, there’s no doubt that many families in the TSC community will be confused or worried about the potential loss of EHCPs, either for children and young people who have them already or might do in the future. The SEND system needs an overhaul, but it’s vital that no child or young person loses support that could help them to thrive.

The TSA also feels that there is not enough information at this point to develop a full picture of how things will work and look once implemented. This is going to understandably lead to more questions. We hope for more information as soon as possible to give better clarity. We’ll be monitoring these developments very closely and will continue to keep the TSC community updated, while sharing the community’s concerns with key leaders.

Play the TSA Lottery!

Play from just £1 to support the TSA and potentially win a big cash prize, just like Brigid did!

Through the TSA Lottery, you've got a chance to win up to £25,000 every week, all while supporting everything we do for the TSC community. For every £1 you play, you'll receive a unique six-digit lottery number. Every Friday, a winning number is drawn at random. If your digits match, you could win anything from smaller prizes right up to £25,000.

It's an easy way to make a big difference. The TSA Lottery helps us continue to provide support and information, fund vital research, advocate for better care and bring the TSC community together. If you ever change your mind you can opt out at any time.

People really do win, just ask Brigid who won £1,000!

What made you start playing the TSA Lottery?

"I'm in the TSC community due to my son's diagnosis. I also work in the charity sector so I know what a difference it can make to charity income."

How did you feel when you realised you had won the lottery?

"Grateful. It's come at a really fortunate time due to a change of financial circumstances."

What is your experience of playing the TSA Lottery?

"It's simple and easy. I've won small prizes before this too and would definitely recommend it."

Well done Brigid. You've got to be in it to win it!



Brigid and her son, who won big!

Find out more about the TSA Lottery:
tuberous-sclerosis.org/tsalottery

Sign up right here



BeGambleAware[®]

Responsible gambling means not spending more money or time than we can reasonably afford on gambling activities, keeping in mind all our other responsibilities in life.

Inequalities in healthcare for people with additional needs

Trigger warning: This article discusses early death and suicide. Reading it might bring up difficult feelings

NHS England has released an updated version of their 'Learning from Lives and Deaths (LeDeR)' report. LeDeR shows that people with a learning disability and autistic people face significant health inequalities, including earlier and preventable deaths. Many of the barriers highlighted in LeDeR, such as delays in care, lack of reasonable adjustments and gaps in staff understanding, will feel familiar to many in the TSC community.

LeDeR shows that adults with a learning disability die on average 19.5 years earlier than the general population, rising to 26.8 years earlier for those with severe learning disabilities. Around 2 in 5 of these early deaths were considered preventable. The report also highlights serious concerns about care quality, with more than 1 in 3 people experiencing care delays or gaps while in 1 in 4 cases the care provided was unsatisfactory or a contributing factor to a person's death.

For autistic adults without learning disabilities (based on a smaller sample of 127 people), suicide accounted for 31.5% of deaths and 44.1% of those who died early lived in the most deprived areas of the UK. LeDeR cautions that these figures are based on limited numbers, but they reinforce long-standing concerns around mental health care.

From the TSA's perspective, the findings underline three urgent priorities:

1. Timely, preventive and coordinated care for people with complex needs. Care must be proactive across all life stages, with swift escalation when things change
2. Genuine improvement in reasonable adjustments and specialist pathways. Standard clinical environments don't work well for people with communication differences, sensory needs or learning disabilities. Access to flexible appointments, quiet waiting areas and personalised approaches should be routine, not optional extras
3. Mental health and suicide prevention must remain a major priority. The data reinforces the need for earlier support, clearer crisis plans and smoother referral routes to specialists who understand neurodivergent minds

Steps you can take

You've got the right to request reasonable adjustments. Longer appointments, quieter spaces or more local care can make a real difference. If you're facing challenges, consider contacting Patient Advice and Liaison Services (PALS), which the TSA Support Line can also help you with. Also remember to check in with loved ones, as simply stepping back and thinking about whether someone's needs are truly being met can highlight gaps that need addressing.

At the TSA, we believe that LeDeR must lead to change. If you're worried about anything in this article, the TSA Support Line is here for you, or contact Samaritans for urgent crisis support (116 123 / jo@samaritans.org)

Meet your London Marathon 2026 team!

Our London Marathon 2026 runners are raising vital funds, spreading crucial awareness, and showing individuals and families affected by TSC that they're not alone



Rebecca Cave-Brown is running for her son Tommy, diagnosed with TSC at 6 months old



Graham Ashbridge is running for his son Elijah, diagnosed with TSC at 6 months old



Ellen Richardson is running for her daughter Connie, diagnosed with TSC at 2½ years old



Aaron Holt is running for his son Jonah, diagnosed with TSC at 6 months old

We wish our incredible team all the luck for the big race!



Lee Phillips is running for his daughter Hattie, diagnosed with TSC at 1½ years old

Calling all

Dog walkers!

Sign up to the

TSA Dog Jog

Walk, jog or run with a four-legged friend in a special fundraising event

The TSA Dog Jog is back for 2026, and we'd love you (and your pup!) to get involved.

Whether you fancy a weekend stroll, multiple jogs across a set period or something even more challenging, you choose the distance and style that's best for you. Plus, your dog gets to join in all the fun!



How it works:

- 🐾 Pick a day this year
- 🐾 Pick a distance
- 🐾 Receive your **FREE** dog bandana
- 🐾 Get sponsors for your challenge
- 🐾 Walk, jog or run your distance

Sign-ups receive a FREE TSA dog bandana, so your pup can proudly show their support in style!

Scan here or visit
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What you're asking on the TSA Support Line

Recent key questions and answers between us and you



"I'm thinking about moving home and there's lots to think about because of TSC. What sort of TSC things should I consider?"

Moving house is a big decision for anyone. When TSC is in your life, it gets even more complicated. Alongside the usual considerations, it's a good idea to also 'Think TSC'.

Keeping medical care going

Some people worry they'll lose access to their TSC specialists or TSC clinic if they're registered with one. It can be especially stressful if it took a long time to find specialists who know TSC well. It might be possible to continue to see the same specialists as you do now, though depending on your circumstances. Speak to your specialist or TSC clinic to see what can be done, or contact the TSA Support Line to support you with this.

It's also worth finding out what TSC or specialist services exist in the new area. Clinics can vary and support pathways might look different from one region to another. The NHS offers some choice about where you receive care, so it's important to know what's possible before you move. If a loved one will be seen at a new clinic for check-ups, you could contact the clinic to share any concerns or required reasonable adjustments, like a quiet waiting room. Clinics have plans to help ease transition to a new medical practice, especially those with learning disability teams. Make sure there's a clear plan for prescriptions and ongoing care, including registering with a new GP. Having this all sorted ahead of time can be a huge help. You might want to make sure you have enough medicine stocked up in case of delays.

Getting support in education

Another common challenge when moving is education.

If your child has an Education, Health and Care Plan (EHCP) or receives other additional support, you'll need to look at how this transfers between local authorities.

Provision can vary, so it's important to ask questions early. Things like this can take time, so try and be as proactive as possible. Any paperwork or documentation you can provide to the new authority as proof will be very helpful.



Maintaining wellbeing

Something to not underestimate when moving is the emotional impact of it all for everyone involved. It's a really big change and those who are neurodivergent and have TSC might find it even harder. Be on the lookout for any possible signs of additional stress or anxiety, such as behavioural changes or different emotional reactions in the lead-up to the move.

“Ask about staff training and encourage the staff to sign up to the TSA's professional online training modules about TSC, especially for social care staff”

You can help to maintain wellbeing and manage stress levels by slowly introducing the idea of moving to all loved ones. You might find that making sure everyone has a voice and role in all the steps, and drip-feeding the topic over a number of weeks or months, is useful. Lots of pictures, videos and visits to the area you're moving to and the new home could also help.

Although there's lots of challenges to moving home, it can also be fun! Involving everyone in the family in the exciting parts of it all might be a good idea. Perhaps your new home will have a garden or is next to a nice park?

The financial impact

Moving home can be a costly exercise in emotions, time and energy, but also in finances. It might be wise to carefully plan budgets for the move, including things like furniture removal services and any potential items you might need in the new home. This includes keeping in mind things like accessible home adaptations, such as if you or a loved one uses a wheelchair or requires different aids in the home.

If you're struggling with finances, contact the TSA Support Line about the TSA Support Fund, which might be able to help. You might also be eligible for a Disabled Facilities Grant, which comes from your local council to help pay for changes to your home.

Residential and supported living

Some individuals and families will be planning a move to residential care or supported living. Think about the level of help required and check whether the service staff understand TSC well. Ask about staff training and encourage the staff to sign up to the TSA's professional online training modules about TSC, especially for social care staff.

It's also important to understand how healthcare will be managed in supported settings, including who coordinates appointments, oversees medication and responds if needs change. If the move involves your local authority, you've the right to be involved in care planning and to challenge decisions if something doesn't feel right. Where possible, visit more than once to get a feel for the environment, and remember that mixed emotions are normal. Gradual visits or short stays can help make the transition smoother.

Moving home is rarely straightforward. But, by giving the whole process a good think, you can make it as smooth as possible for everyone. Contact the TSA Support Line to discuss all things moving home, or anything else at all (details on page 3 and back page).

Celebrating the diversity of the TSC community

TSC and Me is a special social media campaign to remind people that many different people can have TSC

TSC can affect anyone, whatever your background. That's what TSC and Me is all about. Over a month, we invited people to share their TSC stories, celebrating the diversity of our community. We hope it helps people feel more connected!



TSC and Me was so successful, we're keeping it going! On our website there's a 'TSC and Me' wall, which we'll be updating with more stories as we get them

A new way to better understand TAND

A digital tool designed to help people recognise and track TSC-Associated Neuropsychiatric Disorders (TAND) has officially launched

TAND describes the many behavioural, learning, emotional and mental health challenges linked to TSC. Although around 9 in 10 people living with TSC experience some form of TAND, these issues are still often overlooked or not discussed during medical appointments. The new TAND Toolkit app has been developed to be a simple way to help change this.

The app allows people with TSC and their families to identify and monitor TAND over time. By recording experiences and patterns, individuals and caregivers can better understand how TAND affects themselves or loved ones in everyday life. Importantly, it can lead to more meaningful conversations with clinicians and other professionals so that better support and management can be put into place.

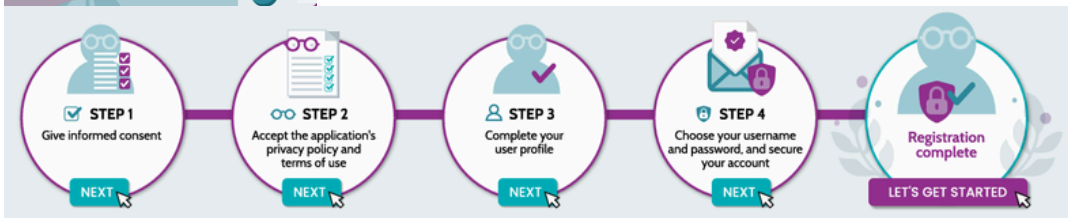
The launch of the TAND Toolkit App also marks the start of the TANDem-2 international research study. Over the next 12 months, around 500 people with TSC and/or their caregivers will be invited to use the app as part of the study. Researchers hope this will help answer important questions about TAND, like how TAND features change over time, identifying patterns of symptoms that may predict future needs, and exploring how TAND affects the wellbeing of caregivers.



The TAND Toolkit was developed by the TAND Consortium, a group of TSC and TAND experts from across the world. We're proud that TSA Trustees, Dr Chris Kingswood and Dr Stacey Bissell, are part of the consortium.

By using the TAND Toolkit app or taking part in the TANDem-2 study, you can help researchers build a stronger evidence base for understanding TAND and improving support for families in the future.

To learn more or to sign up to TANDem-2, visit: tandconsortium.org/join-tandem-2.



We're here for everyone affected by TSC only thanks to the **amazing people and groups** who kindly provide us with **regular and one-off donations**

Help us to continue to be here for you and others, now and in the future:

tuberous-sclerosis.org/donate

TSA Support Line:

0808 801 0700 (freephone and WhatsApp)

support@tuberous-sclerosis.org

Webchat (tuberous-sclerosis.org)

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