scan

Spring 2025

The magazine of the tsa tuberous sclerosis association

Taking on a million steps for TSC awareness

Here for everyone in the TSC community

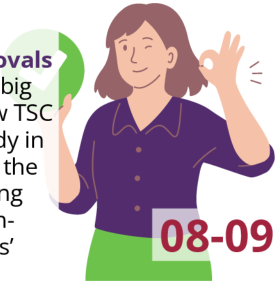
Registered charity 1039549 (England & Wales). Registered charity SC042780 (Scotland)

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

Scan Spring 2025 highlights

Our work in treatment approvals

There have been big approvals for new TSC treatments already in 2025. We discuss the TSA's role in getting medicine decision-makers to say 'Yes'



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Explaining TSC to other people

Yaz is taking on an amazing fundraising challenge. She took the time to explain TSC and its impact, which you can share with others

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Big Day and Outlook return, plus some brand new events happening in Wales!

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New TSA three-year strategy

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Could blood tests be used to diagnose TSC?

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TSC to be highlighted at the RHS Chelsea Flower Show

Two landscape designers will dedicate their exhibit at the Chelsea Flower show to the TSC community

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First UK registry for TSC gets underway

The first registry completely focused on TSC and people in the UK is an exciting next step in knowing more about the condition

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We've made it easier for people to receive grants from us, including a new travel bursary

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Fundraising thank yous

Some of the brilliant people and groups who recently fundraised for the TSA

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Your questions on the TSA Support Line

Some of the things you've been asking us through phone, email and chat on our free TSA Support Line

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The **TSA Support Line** is free and here for **you: 0808 801 0700 / support@tuberous-sclerosis.org / Webchat**


Dr Frances Elmslie

A word from your Chair

"We're in only the first few months of our strategic plan, but new medicine approvals mean it's started in the way that we hoped"

"Our goal is to find a TSC cure. But, what we focus on in the short term sometimes changes, depending on things like the state of the world, TSC research breakthroughs and the shifting needs of the TSC community. That's why strategic plans are so important, as they're an in-depth plan of what an organisation wants to achieve in the next few years and, crucially, how they'll do it.

You can see an overview on **page 6** of our new strategic plan. It includes:

- What you've told us you'd like us to do more of, including local face-to-face events and virtual events for more groups. See some of our event plans on **page 4**
- Pushing TSC research to new and exciting areas, like Dr Dunlop's work on **page 7**
- The wider pressures we face, such as the cost of living. Find out about the updated TSA Support Fund on **page 16**, and information about our new travel bursary scheme

We still need your views on our work and what we should focus on. An easy way to do this is to join our **TSA Feedback Group**, a flexible yet hugely important way to shape the TSA and what we achieve. There's more info at: **tuberous-sclerosis.org/tsavoices.**

We're really optimistic for the next few years. I hope you'll be part of it with us."

Dr Frances Elmslie (TSA Board of Trustees Chair)

TSA Get Together: NEWPORT

Grab a coffee and come along to the Dolman Theatre in Newport on Sunday 11 May to meet with others in the TSC community

If you're looking for a laid back and easy opportunity to meet other individuals and families with TSC, this is it. Have a tea or coffee, a plate of food and chat with others about all things TSC. We're delighted to welcome the All-Wales TSC Clinic to the event – be sure to say 'Hello!'

TSA Get Together events are part of a long-running pilot. If they go well, we hope to expand them to other parts of the UK.

tuberous-sclerosis.org/newport-get-together

Prefer to book your event place over the phone or by email?

Please contact the TSA Support Line:
support@tuberous-sclerosis.org /
0808 801 0700

Come to Clynfyw Care Farm!

The fun in Wales continues on **Friday 25 July** when we visit Clynfyw Care Farm, a care farm supporting adults with learning disabilities. It'll be a fun day in an environment where the challenges of TSC are well understood! Book at: **tuberous-sclerosis.org/clynfywfarm**

Outlook 2025

Sat 26 April 2025, Glasgow. 10am – 5pm

Outlook is the TSA's group for adults who are mildly affected by TSC! You'll receive a warm welcome, whether it's your first time or you come every year. Outlook is a chance for you to meet other adults with TSC, and attend talks all focused on TSC as an adult.

Coming to Outlook for the first time? You can ask to be paired with a 'buddy', who you can contact before the event so you feel more comfortable. We also have a new special range of virtual Outlooks, happening throughout the year! Find out more: **tuberous-sclerosis.org/outlook2025**.

TSA Big Day 2025

Connecting **everyone** in the TSC community

Everyone in the TSC community is welcome to Big Day! Come along to share experiences, make new friends and discuss life with TSC

Saturday 14 June 2025
10am – 4:30pm
DoubleTree by Hilton, Lincoln

At Big Day 2025 you can expect:

- A place where the impact of TSC is understood, with significant time to make new friends
- Discussions on a range of topics, all focused on life with TSC
- Updates on the latest TSC research
- The chance to meet and get to know people and families affected by TSC
- Meet the TSA team and tell us about what is most important to you

tuberous-sclerosis.org/bigday2025

Join feedback group TSA Voices

We need people in the TSC community to join a brand new feedback team so we can do more. It won’t take up lots of time, but will have a big impact on our work.

We’ll contact you once or twice a month for your views on a new idea, or for your experiences on a topic. Your response can be as short or as long you like. It’s a quick, easy and very impactful way to help us and people with TSC!

tuberous-sclerosis.org/tsavoices

New three-year strategy for the TSA

Our ambitious plans for up to the end of 2027 build on the strong foundations we've established in recent years

Our strategy for 2025–2027 builds on the successes of our past and our deep commitment to the TSC community, all underpinned by clear priorities. The next three years are focused on sustainable growth, all while making ambitious and meaningful progress across all areas of our work.

Our strategy's ultimate goal is to ensure that everyone affected by TSC gets the support, care, and research advancements they need and should expect – now and also in the future. Our guiding mission remains the same: "Help for today and a cure for tomorrow."

We're focusing on four key priorities:

Advocacy and awareness. We'll campaign to make TSC a higher priority for decision-makers across the health, social care and education sectors. We want to improve access to specialist care, treatments, and therapies - especially for complex challenges like TSC-Associated Neuropsychiatric Disorders (TAND). Through our work with TSC clinics we'll continue driving care excellence and championing better services.

Research. We'll help to make world-leading TSC research happen. In particular, we'll invest in studies that strengthen evidence-based tools for daily management of TSC, focusing on TAND, emotional wellbeing, and family support. Collaboration will remain key, with the TSC community deciding on the research priorities that we fund.

Support and information. We're determined for everyone affected by TSC to receive direct support and information on all aspects of TSC. We'll create more opportunities for the TSC community to learn, connect, and share together, virtually and in-person. Our popular Big Day and Outlook events will continue, alongside smaller regional meet-ups. We'll also improve our information and platforms, such as our website and welcome pack.

Sustainability. Strong financial foundations will be at the heart of everything, ensuring that the TSA is resilient and adaptable so we can be here in the future. We'll develop our fundraising approach so we can secure reliable income across a range of sources.

We'll do all of this by continuing to foster strong relationships with the TSC community, who remain firmly at the heart of everything we do.

Thank you for helping us reach this exciting milestone. Whether you donate, volunteer, or simply share our message, your involvement is central to the success of our new strategy, and ultimately to conquering TSC. As always, we invite feedback from those who use our services, attend our events, or simply want to shape what we do next.

Researchers exploring new ways to diagnose TSC

Dr Elaine Dunlop and her team at Cardiff University are doing pioneering research to see whether we can one day use blood samples to better diagnose and monitor TSC

Diagnosing TSC can be very challenging, and starts what can be an ongoing journey of managing and monitoring TSC. People might see multiple doctors in different appointments, and undergo many medical investigations. All of this can lead to delays in getting people the treatment that they deserve. However, an exciting and potentially pivotal new area of research is if we can use information in a person's blood to make this easier.

A person's blood can give information or hints about their overall health and any conditions that they might have. These are called 'blood-based biomarkers', a specialist focus of medical research. If we can harness the potential for these biomarkers to provide flags about TSC, it could open up new ways to diagnose someone with TSC or to track its overall progress.

There's lots of different biomarkers. One type, called 'extracellular vesicles' (EVs), are in almost all cells in our body. EVs are like little parcels, wrapped up and passed between different cells with information in them. Dr Dunlop's previous research suggests that the information inside EVs might be different between people with TSC and those without TSC. After receiving a research grant, Dr Dunlop can now look into this idea even further.

The next step for the team involves taking blood samples of people with and without TSC, so we can better understand the differences in their EVs. This is done using a technique called mass spectrometry, which breaks down the EVs into smaller pieces to see what information's inside. Dr Dunlop and the team will then compare the samples that are most different between those diagnosed with TSC and those without.

After gathering samples, the team will take more blood samples from people with and without TSC. But, this time, the research team will be 'blinded' – this means that they won't know which samples are from people with TSC and which are without. They'll then test the blood samples to see whether, based on the differences found in the EV blood samples and comparing with the previously gathered top 10 samples, they can say if the person has TSC or not.

This research is in its early stages, but could revolutionise TSC care, potentially making TSC diagnosis possible as part of routine appointments. In a rare condition like TSC, this is even more vital, where there's always a major need for new and ambitious diagnostic and monitoring tools. However, there's still a long way to go. We'll be sure to keep you updated.

Making sure treatment decision-makers say ‘Yes’

Campaigning for access to new TSC medicines and therapies is always a top priority for us. After some big ‘Yes’ decisions already in 2025, we look deeper at what the TSA and TSC community does to achieve this

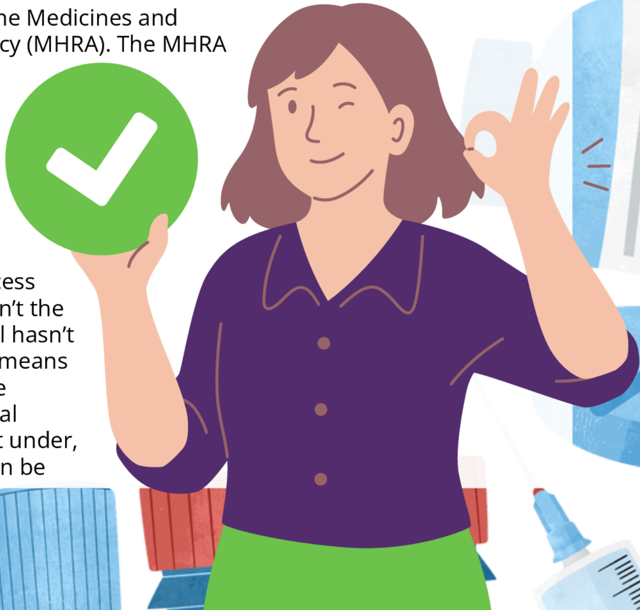
The TSA works tirelessly to make sure that people with TSC can access the support and care that they deserve, and this year is no different. The opening months of 2025 have seen big announcements already, with Hyftor (topical sirolimus) approved for funding by NHS Scotland and Fintepla (fenfluramine) by NHS England and NHS Scotland. Achievements like these don’t come easily, with the TSA working very hard to make sure that the decision-makers say ‘Yes.’

The road to a medicine being allowed to be prescribed can be long and winding, but we’re proud to represent and amplify the voice of the TSC community at every single step. It can take 10 - 15 years for a new treatment to go from the test tube to the medicine cabinet. This is why you might hear about the same upcoming treatments lots of times, and also why the TSA is passionate about funding lots of different potential medicines and therapies - we do this through something called ‘seedfund research’, where we kickstart smaller projects that could lead to big discoveries.

Once the early steps of research into a potential medicine are completed, the next major part of the journey will be clinical trials, which is when information is collected on how effective and safe a medicine is. If clinical trials go well, the next step is to try and get the medicine a licence so that it can be used.

Licensing in the UK is carried out by the Medicines and Healthcare products Regulatory Agency (MHRA). The MHRA reviews everything about a medicine to say whether the treatment is safe, and effective. If the MHRA is satisfied, they’ll issue a licence, allowing the medicine to be sold and used in the UK.

You might think that having a licence means that everyone can now get access to the new medicine, but sadly that isn’t the case. If a medicine has a licence, it still hasn’t been given funding by the NHS. This means that deciding if and how to pay for the medicine comes down to the individual hospitals and the local groups they sit under, and paying for a licenced medicine can be



extremely expensive. This can mean a ‘postcode lottery’ for people with TSC, where some people can access the medicine while others can’t. This sort of situation is completely unacceptable to the TSA, as we think everyone in all across the UK should have the same opportunities to access the same medicines and therapies.

Once a medicine has a licence from the MHRA, the next step is for it to seek funding approval for the NHS. Each UK nation has a different group who says ‘Yes’ or ‘No’ to funding a medicine for their area. This is why a medicine might be available on NHS Scotland, but not on NHS England. You might remember this happening with some very important TSC medicines in the past, such as Votubia (everolimus) where we worked closely with you to turn around the ’No’ from England’s decision-makers to a ‘Yes’, at a time when the medicine was already funded by NHS Scotland.

When a TSC-related medicine is undergoing review for funding by a nation, the TSA submits written evidence to them about why the medicine is so important. As part of this submission, the TSC community’s voice is absolutely vital. We gather your experiences and perspectives about life with TSC and also more specific information about how the medicine would make a big difference to you. Alongside our written evidence, we also participate in committee meetings with the nation’s decision-makers. At this point, the TSA and often people in the TSC community speak directly to the group, to share further experiences about life with TSC. This point is so important, adding things that perhaps the written statements aren’t able to provide.

After all of this, we then hope that decision-makers say ‘Yes’ to funding the medicine. If this doesn’t happen, we don’t just accept the choice - we roll up our sleeves and the work begins on appeals and convincing the funder to change their minds. In the past, when a decision-maker has originally said ‘No’, our further campaigning has helped to change their mind to a ‘Yes’ instead.

Getting funding approval for a medicine or therapy is a long and hard process, but one that’s incredibly important. We’re proud of our work in campaigning like this. However, it would be simply impossible without your input. The testimonies you provide gives us the power to push decision-makers to the right decisions, ensuring that they’re fully informed on the impact of TSC and why access to the medicine is a must. If you’ve provided your voice to approvals, thank you!

Recent medicine approvals

- **Hyftor (topical sirolimus)** was approved by NHS Scotland for treating TSC-related facial angiofibromas (bumps and marks on the face). We continue to work with decision-makers across the rest of the UK. People in other UK nations interested in Hyftor might still be able to receive local funding for it. Your TSC Clinic will be able to talk to you about the possibility of trying Hyftor
- **Fintepla (fenfluramine)** is a medicine for seizures in Lennox-Gastaut Syndrome (LGS), a condition that some people with TSC have. It was first approved in NHS Scotland, followed then by NHS England

TSC-focused garden to be at RHS Chelsea Flower Show

The 'Room to Breathe' garden is created by designers in the TSC community and dedicated to the TSC community and the TSA

A unique garden will raise awareness of TSC at this year's RHS Chelsea Flower Show. Created by landscape designers Jenny Donnelly and Catherine Gibbon, the 'Room to Breathe Hospital Garden' is driven by personal TSC experiences and a shared passion for how green spaces support mental and physical wellbeing.

The garden is deeply personal to Jenny: "It's inspired by my own experience of waiting in a hospital while my son Alex, who has TSC, underwent brain surgery when he was young. Our goal is to raise awareness of this rare disease and highlight the life-changing work the TSA does for families affected by TSC."

Jenny and Catherine

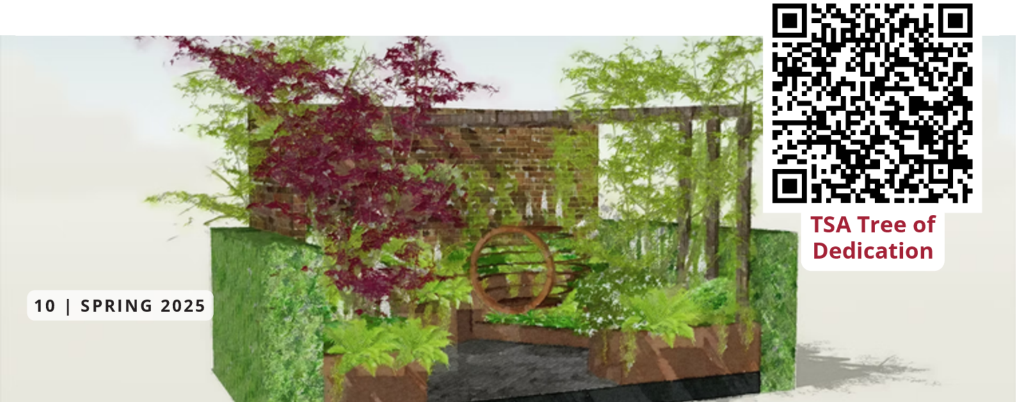
The garden will be a highlight at the RHS Chelsea Flower Show, but its impact won't end there. After the show, the garden will be moved to Amersham NHS Hospital, where it'll provide a much-needed sanctuary for reflection and respite.

Luke Langlands, Joint Chief Executive commented: "The garden is a big opportunity to improve understanding of TSC to people who might not have heard of it before. We're very thankful to Jenny and Catherine for their support."

Alongside the garden, the TSA has a TSA Tree of Dedication. You can dedicate a virtual leaf to someone special in the TSC community. You'll even get a free pack of seeds to create your own calming space at home, a chance to connect, reflect, and grow in solidarity with everyone affected by TSC.

Add your own personal leaf to the TSA Tree of Dedication: **bit.ly/4bp96Qb**.

TSA Tree of Dedication



The role that biological sex might have on TSC

Recent research suggests that a person's biological sex might have a greater impact on how TSC affects them than previously thought

TSC affects everyone differently. However, recent findings now suggest that the sex of someone at birth could be a significant clue to how TSC might affect them over time. So far, we've found a possible symptom-divide between sexes in TSC-related lung problems, TSC-Associated Neuropsychiatric Disorders (TAND), and TSC-related epilepsy.

Lymphangioleiomyomatosis (LAM) is a lung disorder that affects around 3 in 10 women with TSC, yet it's very rare in men. It usually starts sometime between early adulthood and middle age, suggesting that it's got something to do with the hormone estrogen (which women usually have a lot more of compared to men). However, we don't fully understand yet why this happens in people with TSC.

A recent TAND study found major differences in how TAND affects people with TSC depending on their biological sex. Impulsivity, overactivity and attention deficit hyperactivity disorder (ADHD) were found to be much more common in males than females. Yet, anxiety symptoms were significantly higher in females. More males with TSC were also found to have ADHD compared to females in a separate piece of TSA-funded research called TS2000.

Initial research suggests that there are differences in TSC-related epilepsy between males and females. For example, the age of when seizures start in girls may impact overall neurodevelopmental outcomes, whilst this was not the case for boys. TSC animal studies also suggest that males are generally more likely to have a seizure than females.

It's also vital that we think broadly about how biological differences can affect how TSC affects a person's everyday life. For example, women are more likely to have a seizure during certain phases of the post-ovulatory phase, which is part of the menstrual cycle. Using certain medications during family planning could also impact TSC symptoms.

We're now starting to understand and anticipate biological sex differences in TSC much more effectively. This is hugely important, as it means that we have better treatment and management for people living with TSC, ultimately improving quality of life.

Recent medicines shortage

Reports about struggles to get prescription medicines can be worrying, but there's things you can do

If you've seen news stories lately about the shortage of some prescription medications, you're not alone. These reports can feel worrying, especially if you or a loved one living with TSC depends on a regular and specific prescription.

The UK Government recently confirmed its commitment to consider a review of the medicines supply chain, recognising the importance of stable access to these essential treatments. This is something we really welcome, as absolutely no-one should feel concerned about getting access to medicines they desperately need.

The good news is that, so far, we're not aware of anyone being unable to receive their TSC prescriptions. TSC clinics we work closely with have also confirmed that it hasn't yet been a challenge to get TSC-related medicines. However, we're monitoring the situation very closely and will be sure to update you if anything changes.

If you're experiencing any issues getting hold of your usual medication, or find that your pharmacy can't provide your specific brand, please contact your TSC clinic or the TSA Support Line (**support@tuberous-sclerosis.org / 0808 801 0700**). As always, you're never alone with TSC challenges and we're here for you.

TSC clinic network update

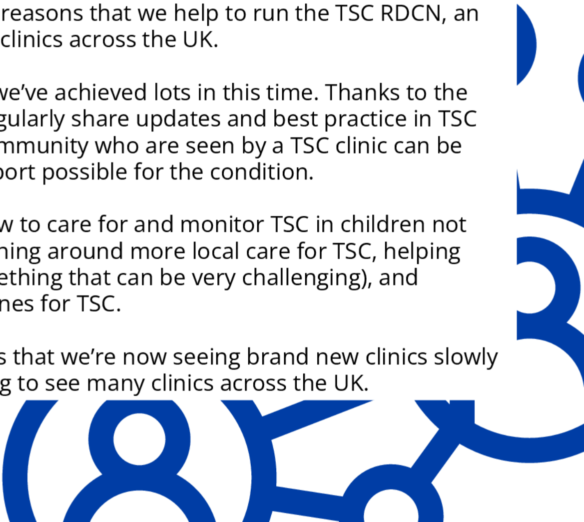
TSC Rare Disease Collaboration Network (RDCN) now in its third year

We're committed to a world where you can get the same level of care for TSC no matter where you live in the UK. This is one of the reasons that we help to run the TSC RDCN, an NHS initiative which is a network of all TSC clinics across the UK.

The TSC RDCN is now in its third year and we've achieved lots in this time. Thanks to the network, clinics have the opportunity to regularly share updates and best practice in TSC care. This means that people in the TSC community who are seen by a TSC clinic can be confident that they're getting the best support possible for the condition.

A big focus of the TSC RDCN this year is how to care for and monitor TSC in children not yet born. As well as this, there's lots happening around more local care for TSC, helping people move from child to adult care (something that can be very challenging), and planning updates to the UK Clinical Guidelines for TSC.

One of the best things about the network is that we're now seeing brand new clinics slowly open up across the UK, with our hope being to see many clinics across the UK.



Leave the legacy of a brighter future for people with TSC

A gift in your Will is a very powerful way to help shape the future of things you care most about, including loved ones and others with TSC

A legacy gift is when a person generously decides to give to us at the end of their life, with the gift outlined in their Will. It's a wonderful and powerful gesture, allowing you to continue to help the TSC community even after you're no longer physically here.

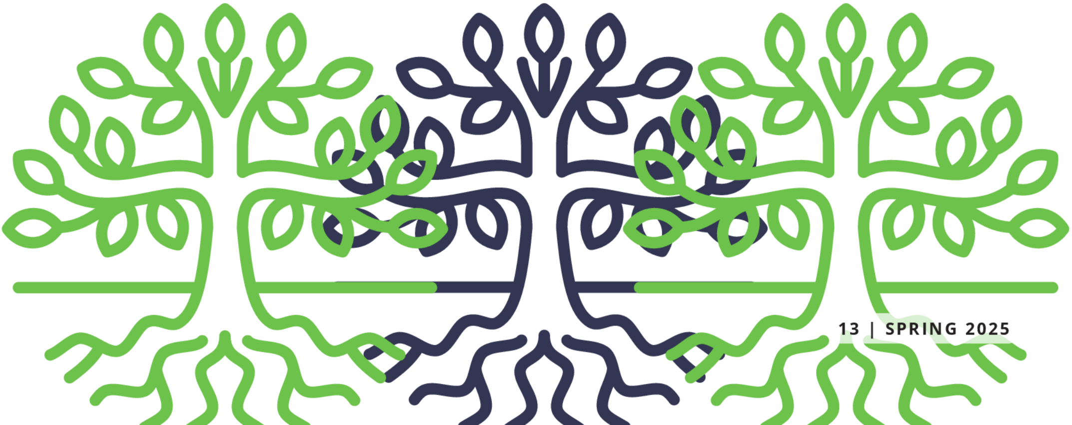
Thinking about the TSA in your Will could help people in the TSC community live fuller, healthier and happier lives. Over our almost 50 years, the TSA has received legacies that've truly changed the way that we all think about TSC. We always treat legacies with great respect, no matter whether they're small or large, because without legacies in our past we wouldn't be looking at such an optimistic future in TSC support and management.

Your gift could be vital to our support and information services. This includes the TSA Support Line and TSA Support Fund, all of the things about TSC on our website and various guides, and our direct work in maximising the impact of TSC clinics. Thanks to you, no-one will face TSC alone.

Alternatively, it might fund our passionate campaigning. This includes us making sure people in the TSC community get access to new medicines and therapies, and our other work with the UK Government and other decision-makers on everything TSC.

Your gift might even unlock the next huge breakthrough in TSC research. We're a passionate funder of all aspects of TSC research, pushing researchers to make that next big discovery. In the past, this has included the TSA being involved in identifying the genes responsible for TSC.

Please consider the amazing step of adding us to your will. To find out more, visit our website **(tuberous-sclerosis.org/legacy)** or contact Laura Larrett (Head of Fundraising): **laura.larrett@tuberous-sclerosis.org.**



RARE TSC: The UK's first TSC registry gets underway

A TSC registry could provide insights into the condition that we've never had before, ultimately leading to better diagnosis and care

A patient registry is a secure database that collects important health information about people with a specific health condition. We're delighted that the National **R**egistry for **A**dvancing **R**esearch and **E**ngagement in **T**uberous **S**clerosis **C**omplex (**RARE TSC**) has begun! RARE TSC is a partnership of all TSC clinics across the UK, who'll work together over the next five years to set up the UK's first TSC registry. The TSA is a proud key partner in the project.

Registries can help to make a big difference to our understanding of a condition, and how we diagnose and treat it. It means that clinicians can more easily track how a condition changes over time, can monitor how well treatments are working, and can help us to answer questions that are basic but also incredibly hard to answer, such as "How many people have TSC in the UK?" or "How many people with TSC are also diagnosed with autism?"

With RARE TSC specifically, it's hoped that researchers and clinicians will be able to gather information about the different signs and symptoms associated with TSC, to a level that's more detailed than we could ever do right now. These discoveries will be possible thanks to us being able to gather a very large amount of data from different people with the condition, meaning that researchers can see connections and similarities in people's experiences. This could be things like at what age certain issues with TSC start to become more of a problem in everyday life, or if taking a specific medicine helps to improve TSC symptoms in ways that we hadn't expected before.

At the moment, we don't have the data for clinicians to be confident about how TSC might progress in an individual with the condition over time, especially as TSC affects everyone differently. This is known in technical terms as the 'natural history' of TSC. We know that lack of clarity on TSC progression can be extremely frustrating and upsetting for people in the TSC community, who often have lots of unanswered questions and uncertainty in their heads. It's also a huge challenge for TSC clinicians, whose work is made much harder because of this uncertainty.

Imagine a time when we can be more confident in how TSC will progress in someone over the next 10, 20, 30 years and beyond. This would mean that treatments and support interventions can be put into place much quicker than we can achieve today. We hope that RARE TSC will make this a reality.

How to contribute to RARE TSC

Over the coming years, people with a confirmed diagnosis of TSC who are registered at a UK NHS TSC Clinic will be invited to be a part of the TSC registry. You'll be provided with detailed information beforehand, including the background to the project, what it means to 'be involved' and what information will be held. You'll be asked to provide consent to have your information stored as part of the registry. If there's anything you don't understand you can always speak to your TSC clinic or the registry project team who will be on hand to help.

What information will be held about me on the registry?

Importantly, no identifying information is held in RARE TSC and all entries are anonymised. This means that it won't be possible for you to be identified by anything in the registry, ensuring your privacy is maintained. If you sign-up to the registry and then change your mind, you can also withdraw consent for your data to be held on the registry at any time, even without giving a reason.

What are the possible benefits of taking part?

By taking part, you are helping researchers and doctors understand how TSC affects people living in the UK throughout their life. You are helping them understand whether there are any gaps in the treatment and care individuals may receive as well as how well commonly prescribed medicines might be working.

Are there any disadvantages to taking part?

Whilst every effort has been made to ensure that the data held on the project database is as secure as possible, the team cannot provide a 100% guarantee that a data breach will never occur. However, in the very unlikely event that this does happen, there is no way for you or your loved one to be personally identified as all the information will be anonymised and no identifying information will be held.

Other TSC registries

RARE TSC isn't the first ever TSC register. However, it is the first to be focused entirely on the UK that's entirely focused on TSC.

You might remember previously hearing about TOSCA (**T**uber**O**us **SC**lerosis Registry to Increase **D**isease **A**wareness), a worldwide registry for TSC. TOSCA was a big step in helping us to understand the way that TSC develops in people more broadly, including things like TSC-Associated Neuropsychiatric Conditions (TAND) affects everyday life. However, it's hoped that RARE TSC will provide more in-depth data, as well as data focused entirely on people in the UK.

Another important registry for TSC is the National Registry of Rare Kidney Diseases, an initiative by the UK Kidney Association initiative that gathers information from people with certain rare kidney diseases, including TSC. This kidney registry helps clinicians to better understand how TSC affects the kidneys, with the information being useful in direct care but also in clinical trails.

TSA Support Fund changes and a new travel bursary

We've updated the TSA Support Fund to make it easier to apply. Plus, a new TSA Travel Bursary makes getting to TSA events easier

Living with TSC can come at a great cost, not only in the way the condition affects someone physically and mentally, but also financially. With the cost of everyday items rising, finances are getting more stretched. In response, we've made some important updates to the TSA Support Fund, including the launch of a travel bursary.

The TSA Support Fund is here for when people in the TSC community are struggling with the ongoing costs of things associated with the condition. We've now increased the maximum amount that you can ask for (up to £400) and tried to make it more straightforward to apply.

We know how much people appreciate TSA face-to-face events. Financial concerns should never be a barrier to attending them. That's why we've also launched the TSA Travel Bursary. This is separate to the TSA Support Fund, offering you the chance to apply for reasonable travel costs to attend our events. Previously, some people applied to the support fund only for travel costs to events - now, you can apply to the travel fund as well as the support fund for something different.

Eligible households can apply for the TSA Support Fund once every 24 months. We know that each TSC journey is unique, which is why the fund isn't limited to any specific type of expense. In the past, we've funded:

- **Home adaptations** to make everyday living easier, such as wheelchair ramps
- **Medical devices** like epilepsy monitors or sensory aids
- **Household items** if things break down unexpectedly, like a washing machine
- **Respite relief** for things like a much-needed break or even a simple meal out

If your need doesn't fit into these examples, don't worry, we consider each application on its own merits. However, be aware that we can't fund items that you've already purchased or booked, or anything that a statutory authority should pay for (such as certain medical or social care costs).

> **"The TSA Support Fund is a lifeline for people who really need help. The TSA, for us, means a lifeline."**
>
> - TSA Support Fund user

For more details on the TSA Support Fund, including how to apply, visit **tuberous-sclerosis.org/tsasupportfund.** For any questions or to ask about the TSA Travel Bursary, contact the TSA Support Line: **support@tuberous-sclerosis.org / 0808 801 0700.**

SUPERHERO Summer

Join us for a summer of celebrating the strength, resilience and generosity of the TSC community as we channel our inner heroes with some Marvel-ous fundraising opportunities

Superhero Tri

Supported by Disney and Marvel, this is an exciting and accessible challenge event on **16 August 2025** at Dorney Lake near Windsor, Berkshire. Open to all ages and abilities, you'll complete the tri-challenge in any way that suits you, with or without a sidekick! All you need is your superhero costume. Places are limited and applications open on 1 May.

Heroes Among Us

Nominate someone for a very special TSA Heroes Among Us award! Perhaps someone with TSC who copes heroically, or a super sibling sidekick that supports them, or anyone else who deserves recognition for their efforts. Nominations will be shortlisted and people asked to vote for a winner. Winner and runners-up will receive superhero prizes!

Heroes Assemble

Let your imagination run wild and escape into your own multiverse! Organise a superhero-themed fundraising event, or a dressing-up day, bake sale, quiz night or whatever you like. We'll provide everything you need, from party ideas, printables, bunting, masks and loads more heroic fundraising tools. You'll also receive a special superhero thank you gift for raising funds for the TSA.

The power's in your hands. Grab your cape, assemble your team, and get ready to unleash your hero for everyone in the TSC community

Start your mission: tuberous-sclerosis.org/Superhero

TSC Stories: Yaz Pomponi

Yaz set herself the target of walking one million steps in 70 days, inspired by her daughter Cobie

“Hi, I'm Yaz. I live with my wife Danielle, our Labrador, Woody and our one year old, Cobie. I’d like to have your time for just two minutes to tell you about our beautiful daughter's TSC, to help raise awareness and understanding of the condition. **If you already know about TSC - please share my story with others to help them understand too.**

Yaz, little Cobie and Woody

When Cobie was 4 months old, she was admitted into hospital because she was having seizures. After lots of tests including an MRI, lumbar puncture, EEG brain scan and more, she was diagnosed with Tuberous Sclerosis Complex, a rare genetic condition that causes non-cancerous tumours to grow in the brain and other vital organs.

9 in 10 people with TSC have epilepsy, like our Cobie. Other common TSC problems include autism, learning difficulties and kidney problems. However, the ways TSC impacts on a person’s life can vary considerably and is different for everyone.

Being told that Cobie has TSC was incredibly difficult for us to hear. We’d never heard of TSC, so spent many hours researching and came across the TSA. They’re the only UK charity dedicated to all aspects of TSC, including support and information, research and advocacy. They’ve been a great help to us, including helping us understand TSC and helping to arrange appointments with TSC experts.

Scan to donate to Yaz’s fundraising

Cobie’s been in and out of hospital since her diagnosis, having further tests like more EEGs, MRIs, kidney scans, skin biopsies and eye tests. It can be very exhausting for all three of us. The TSA has helped us a lot through all of this. We want to help give back to them, so they can continue to help others. To do this, I’ve set myself a challenge to walk one million steps in 70 days, raising funds for TSA and broader awareness of TSC.

Remember that the TSA is always here for you and loved ones, whether you’re new to TSC or have been part of the TSC community for many years. Please also consider donating to my fundraising if you’re able to do so: **https://bit.ly/4iexVAB.**”

> The TSA's been a great help to us, including helping us to understand TSC and helping to arrange appointments with TSC experts.

Guest article: Education failures for children with TSC

Children with additional educational needs are at risk of being overlooked by our education system, including children with TSC

A UK education crisis has been recognised, with different reports calling on UK Government to take urgent action to support the approximately 2 million students who require additional support, including those with TSC. This understandably leaves many families in the TSC community with concerns, questions or frustrations about the support for their children in school and beyond.

We know that TSC comes with a range of challenges that can impact school and education. Around 2 in 3 children with TSC fall behind classmates and academic expectations in maths and English. Additionally, people with TSC might have challenges with things like decision making and maintaining attention. These sorts of skills are important for success in daily life and education, meaning that some children with TSC can require extra support in school.

Teacher training programmes need updating to include more about additional needs, and many students don't receive the specific support they need. This means that some students aren't being properly included in school and can't meet their potential. In response to this, some caregivers are removing children from school environments altogether, instead choosing homeschooling.

In 2024, there were 576,000 requests for Education, Health and Care Plans (EHCP) to support children in education. These plans help students with special education needs and disabilities (SEND) to get the support that they need. Almost all EHCPs requested support in social, emotional and mental health (SEMH - yet another acronym!), autism, and communication needs. The financial costs of EHCPs are expected to rise from £2.9 billion today to £3.9 billion by 2028. Yet, some families must go through complex legal battles, lasting many months, to try and get their children an EHCP. Even when a plan is completed for a child, school inspections have found consistent flaws in overall EHCP quality, such as vague descriptions and outdated targets.

Cheyenne Contreras is a first year PhD student at King's College London, continuing the work of the Early Development in Tuberous Sclerosis (EDiTS) study, which is following children with TSC and their families from birth to primary school. Cheyenne is looking into how executive functions (e.g. memory, attention, and inhibition) in conditions like TSC impact education.

The impact of no or poor EHCPs is clear: 1 in 3 SEND children are three times more likely to be excluded from school and to be Not in Education, Employment or Training (NEET) by age 16. Many of these children also require a referral to child and adolescent mental health services (CAMHS), and waiting lists are at least two years.

One way to support SEND children is to be aware that they're eligible for an EHCP until age 25. This can help the person go through potentially challenging times of transition, such as becoming a young adult, finding further education, or moving into work. This is also an identified gap of care for people with TSC.

A mother recently shared her concerns about additional support in their child's school: "The Headteacher has found it challenging to authorise the attendance of therapists if it detracts from education. It's not clear what the priority is, therapies required for health, or education." This highlights the need for sectors to come together to support children in a more holistic approach. This tailored focus would help to improve outcomes for children with TSC across healthcare, social care and employment opportunities.

Despite these challenges, the UK Government is aware of the issues and is working to address them by:

- Moving EHCPs fully online with a standard template
- Improving transitions for students from primary, secondary and post-16 settings
- Making school enrolment easier, helping to remove barriers
- Ensuring core subjects (reading, writing and maths) are taught consistently
- Expecting primary and secondary school teachers to have qualified teacher status or to be working towards it
- Introducing new professional leadership qualifications to offer additional support to staff, known as the Special Educational Needs Coordinator National Professional Qualification

There's a lot of work for the government to do, with many gaps and inconsistencies in existing processes. However, in the meantime there are still existing policies in place to protect students, including the Children and Families Act 2014, Equality Act 2010 and Children's Wellbeing and School Bill.

For now, much of the work in ensuring proper support for SEND children in education is with caregivers who don't give up, advocating for a child's needs in a way that's clear, consistent and in-line with what local authorities are mandated to offer. If you'd like to discuss how to push for better support for a child with TSC, contact the **TSA Support Line (support@tuberous-sclerosis.org / 0808 801 0700).**

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

Thank you Cheng!

Our fundraising has gone international! **Cheng** ran the Singapore Marathon, motivated by his five-year-old son Joshua, who has TSC. Cheng said the humidity and heat made the marathon tough going, but he did it and raised an incredible **£1,120!** Well done Cheng on your fantastic achievement and your support of the TSA.

Thank you to Dean and the team!

Dean McBain runs an adult football team in Aberdeen, and 18 squad members ran 100km in a February team challenge. The TSA was selected for a portion of the fundraising, after being nominated by a player whose family member has TSC. They've so far raised **£3,000** overall! Thank you Dean and the club!

Brilliant work from Lisa and friends!

Lisa Moore-Ramdin braved the elements and did an 18k Forest Trail run in the mud, floods, wind and rain! They had great wet muddy fun and raised an amazing **£1,208** to help support the TSC community. Thank you so much!

Karen and Richard baked up a winner!

Karen and Richard Vennard wanted to do something to support the TSA as granddaughter Elsie has TSC. They maximised their fundraising by combining the Cardiff Half Marathon with two bake sales! This boost led to the pair raising a fantastic **£1,655!**

Hayley and Luke James went through the devastating experience of losing their daughter, Esme James, at 35 weeks pregnant. Esme had TSC, with tumours found on her brain.

In Esme's memory, Luke took the amazing decision to take on various epic challenges this year, all to raise funds and awareness towards TSC.

Luke's efforts will include the Three Peaks Challenge and different football-based events to name just a few. So far, the amazing couple has raised over **£2,000**, with a many more challenges and events planned to come.

We're so grateful to Hayley and Luke who, in their darkest of times, looked at how to help others in the TSC community. Thank you to Hayley, Luke and everyone who have donated to their efforts so far.

Thank you Hayley and Luke

Scan to donate to Hayley and Luke's fundraising, or go to: https://bit.ly/41vDFPQ

Helen and Ross Kemble's daughter Sennen was diagnosed with TSC after having seizures as a baby. The TSA was there for the family during this time, as Helen comments: "The support the TSA gave us emotionally and practically has been invaluable, we don't know what the future holds but the TSA's ongoing support is of great comfort".

The support we gave Helen inspired her to run the Dedham 10k and the Hadleigh 10 miler. Helen's best friend Steph joined her for the Dedham 10k, and daughter Bonnie ran the 2 mile race in Hadleigh! Helen raised a fantastic **£1,133!**

Not to be left out, Ross has set himself a challenge to take part in the Stour Valley Path 100k Ultra Marathon this year with his friend Steve. They've already got a fundraising total of over **£1,900!**

Softcat's Marlow office put the 'fun' in 'fundraising' when they combined their annual Bring Your Child to Work Day with TSA fundraising. It was a fantastic success, raising an excellent **£480!**

Softcat didn't stop there, also donating laptops to the TSA, which are making a big impact on our work! Thank you to everyone involved.

Getting your company or place of work involved in TSA fundraising can make a massive difference to our work. It's also a great thing for your organisation too! To find out more, contact the team: **fundraising@tuberous-sclerosis.org.**

ATLAS ELEKTRONIK UK
A company of the ATLAS ELEKTRONIK Group

Atlas Elektronik UK is part of the TSA Corporate Community. Being passionate about strengthening their local community and initiatives for good, they invited their team to nominate charities that mean a lot to them for donations.

After reviewing all the nominations, we were delighted to be one of the charities selected to receive **£1,000!** Thank you Atlas Elektronik UK for your generosity and to al the staff who nominated us.

Find out how your company or workplace could join the TSA Corporate Community: fundraising@tuberous-sclerosis.org

Chloee, Elliot and Delphine!

Over the festive period, the **Bird's Nest Cafe** in Shrewsbury ran a luxury Christmas hamper raffle, full of goodies including a bottle of Moët Champagne, a box of Lindt Pralines Classique's, a box of Amaretti Del Chiostro and much more, all presented in a beautiful donated handwoven basket. **Elliot, Chloee and all the team** did an amazing job collecting entries and raising an incredible **£1,507!**

Everyone was inspired by Elliot's daughter Delphine who has TSC. Elliot commented: "It was a pleasure for us at The Bird's Nest Cafe to support such a worthwhile cause, and we're thrilled to have been able to contribute."

England Rare Diseases Action Plan 2025

Published by the Department of Health and Social Care, the plan aims to support people with rare diseases with four key priorities

As many in the TSC community know all too well, the support in place for rare conditions in NHS England requires lots of improvement. As part of this, the Rare Disease Action Plan aims to improve access to essential support for individuals with rare conditions. These are divided across four key priorities:

Priority 1: Help people get a final diagnosis faster

- Better understand what causes the lengthy delay between first symptoms and getting a diagnosis
- Minimise backlogs and the time taken for a genomic test
- The NHS Generation Study is now underway, which aims to undertake whole genome screening on up to 100,000 babies and screen for over 200 rare conditions

Priority 2: Increase awareness among healthcare professionals

- Do more to raise awareness of rare conditions across NHS England staff
- Through the National Genomics Education Programme, develop training and educational resources so rare conditions are included in clinical education and training
- Through the Genomics Education Programme, create specific resources to raise rare condition awareness in nurses and midwifery, and pharmacists

Priority 3: Improve care coordination

- People living with rare conditions need support from many different parts of the health and social care system. Ensure that different aspects of care are coordinated and understand how to best make improvements. Findings will be reported in 2026
- People often need to travel far from home to get care. NHS England has published a toolkit for virtual consultations, which is improving the use of video calls and phone calls for patients with complex, multi-system rare diseases

Priority 4: Improve access to specialist care, treatment and drugs

- Only 5% of rare conditions have an effective and approved treatment. Improving access to specialist care, treatment and drugs is vital to save and improve lives
- Help the public to understand research and find research studies to take part in. The service has been looked at to identify what improvements could be made for those living with rare conditions. The findings are now being implemented
- Make it easier and quicker for people to access new and innovative treatments.

If you've got questions about the Rare Disease Action Plan, contact the TSA Support Line.

What you're asking on the TSA Support Line

Recent key questions and answers between us and you

"My child has TSC. Am I eligible for Disability Living Allowance (DLA)? If so, where do I start?"

Please note: DLA in Scotland has been replaced by a benefit called Child Disability Payment. For more information see www.mygov.scot/child-disability-payment

Disability Living Allowance (DLA) is a benefit to help with additional costs of looking after a child under 16 who needs more care because of a disability, including things like learning difficulties, developmental delay, and physical disabilities. Many caregivers in the TSC community are therefore eligible for DLA.

Claiming for DLA can be a lengthy process and it can be difficult to know where to start. Frustratingly, it can also take many months to get a response. The claim form, DLA1 Child (ALT), is available through the Disability Living Allowance helpline or they'll post it out to you with the date you made your call, so that once you're approved you're paid DLA from the earliest possible starting point. You can also download it from the Gov.uk website.

DLA isn't means-tested, so your current financial situation isn't considered when you apply. It's also not considered income when applying for other benefits. This means DLA can make a more positive difference to your family's income, especially when considering the additional costs that living with TSC can bring.

Things to consider when completing the form:

- Take time to read through the form before filling it out, and again after completing it to make sure it accurately portrays your child's needs
- Don't downplay the challenges. It might feel like you should 'get on with things', but the application should be clear about any ongoing things that are tough, so the assessor gets a good understanding of what life is like for you and your family
- Keep a diary for at least a week before completing the form, as a record of the care your child needs during the day and night. This can be used as evidence
- Give as much information as possible about your child's needs, as it's unlikely the assessor will know a lot about TSC. You might want to include information from the TSA, or your child's TSC doctor to help the assessor understand TSC better
- Take breaks and be kind to yourself. Completing the form can be triggering
- Keep a copy of anything you send. You might need it if you're unhappy with the outcome and want to challenge it

The DLA helpline is available by phone: 0800 121 4600 (England and Wales) / 0800 587 (Northern Ireland). Contact the TSA Support Line if you've got any questions about applying for DLA or any other benefits.

“I’m forty years old and was diagnosed with TSC and epilepsy as a child. I’ve had no other symptoms since, but have been recently told I’ve got TSC tumours on my kidneys. Is this common?”

TSC affects everyone differently, no matter what age you are. The symptoms that someone has because of their TSC depends on the location and size of the TSC tumours that they have. This means that you might get symptoms of TSC in new areas of your body as time goes by. We’re getting better at monitoring and diagnosing TSC, and more people with TSC are registered with a TSC clinic. This means that it’s likely that new symptoms of TSC are being spotted quicker and more often than previously.

For many people in the TSC community, the uncertainty about what symptoms might come next is one of the hardest things about the condition. It’s also one of the most common reasons people contact the TSA Support Line. For some people, it can feel like receiving a new diagnosis all over again. Especially when you’ve got so used to managing life with TSC through previously diagnosed symptoms. When this happens, it’s normal to experience lots of different emotions, regardless of whether you were diagnosed with TSC a long time ago or you’ve only known about TSC for a short while. During these times, all the feelings and emotions that you’re possibly experiencing are valid.

New symptoms might mean that you’ve got to get new scans, tests and treatments. It can feel daunting, but this is the best way to make sure that you’re getting the support that you deserve. Your TSC clinic or doctors will give you recommendations on next steps, but remember that the TSA Support Line is here too and you’re never alone with TSC.

The TSA website is full of information on the different ways TSC can affect the body. You may find it helpful to take your time to read through the information relevant to the new area of your body that TSC is causing some challenges.

We know that the ‘unknowns’ can feel difficult, as nobody can be certain about how TSC will impact you or your loved one in the future, as TSC affects everyone differently. It can help to take things a day at a time and try to not look too far ahead.

It is important that everyone with TSC is registered with a TSC clinic, to ensure that their TSC is monitored for any new symptoms. If you’re not yet registered with a TSC clinic, find more information on our website, or by contacting the TSA Support Line for assistance in getting a referral.

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 the future:

tuberous-sclerosis.org/donate

Switchboard:
0300 222 5737
admin@tuberous-sclerosis.org

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

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