

scan

AUG 2022

The magazine of the TSA

**Research
update
from The
Stay Calm
Project**

**Big Day -
our biggest
annual event
- returns with
a new look**

**Welcome
to your
new Chief
Executive**



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IN LOVING MEMORY

We receive many generous gifts in memory of loved ones who have sadly passed away, including the loved and lost individuals celebrated here

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Quick-fire news

An overview of important updates in the world of TSC and the TSA



Thank you Mikaela, you'll be missed!

After many dedicated years of at the TSA, we're saying goodbye to Mikaela Conlin-Hulme (Head of Income Generation), as she moves to a new passage of her professional life with the Cleft Lip and Palate Association (CLAPA).

Mikaela's incredible passion and teamwork as part of the TSA team has shone through all of her work at the charity. Joining in 2018, Mikaela's strong fundraising knowledge was central to ensuring that the TSA survived the devastating impact of the Covid-19 pandemic.

Mikaela commented: "I've loved working at the TSA and raising funds for such a vital cause, I'll especially miss working with the amazing fundraisers in the TSC community. It's been a privilege to be part of #TeamTSA and I'll be sad to leave. But, I'm also looking forward to a new challenge and leave the charity knowing it'll continue to thrive. Thank you all for your support."

The TSA team will miss Mikaela's positive mindset, 'can-do' attitude and willingness to help out everyone.

Legislation changes to the Mental Health Act

The TSA welcomes planned reforms to the Mental Health Act which will mean that neither learning disability or autism alone will be considered reasons for someone to be detained for treatment. Instead, a person will be detained only if a mental health condition is identified by clinicians.

People experiencing a mental health emergency will be able to access more care in the community, such as through crisis houses and safe havens, and those detained under the Mental Health Act will benefit from landmark reforms which will provide patients with more control over their care and treatment.

Updates to NHS TSC clinical guidelines for epilepsy in children, young people and adults

The National Institute for Health and Care Excellence (NICE) recently updated their recommendations on how to diagnose, treat and manage epilepsy. The guidelines have a major focus on learning disabilities and new epilepsy therapy cannabidiol (brand name Epidyolex).

The TSA worked with NICE during the process, ensuring that the TSC community's voice was heard and recognised.



**The TSA Support Line is here
for you Mon - Fri 9am - 5pm:
Freephone (0808 801 0700)
Email (support@tuberous-sclerosis.org)
Webchat (on our website)**

A word from your Chair

For everyone in the TSC community, we know that the only constant in life is change. But, we remain here for you

The TSC community has no doubt had a bumpy ride recently, including us at the TSA. However, the determination of the TSC community to stand against ongoing challenges has remained resolute, including standing together with European organisation E-TSC to support the TSC community in Ukraine - this is something that we'll continue to do (see [page 21](#) for more).

With the worst of the pandemic now (hopefully) behind us and a new TSA strategic plan due next year, I'm looking forward to a prolonged period of growth and development for everyone connected with our charity, building upon our strong foundations created over the last five years.

We recently said farewell to Louise Fish as our Chief Executive, who has moved on to a new role with Genetic Alliance UK. What Louise achieved with us during her time at the TSA cannot be overstated, expertly negotiating us through what were extremely difficult times. Louise's departure is met with the welcome of John Shepherd, our new Chief Executive. Having John as TSA Chief Executive marks an exciting new period, where fundraising will take priority to provide help for today and a cure for tomorrow.

One thing that will bring joy back to many people in the TSC community is the reintroduction of our face-to-face events. Earlier in the year we were delighted to hold a face-to-face Outlook event, gladly held for the first time since 2019, for adults mildly affected by TSC. On 8 October, the TSC community will be heading to Manchester for a new look Big Day, our biggest annual event. I hope to see as many of you as possible at Big Day, where the focus will be on connecting with others and making new friends (more information on [page 9](#)).

Although I speak of optimism and hope, many people in the TSC community are feeling the full force of recent cost of living rises across the UK. Astronomical increases in fuel, electricity and gas, along with higher prices on food and clothing, have left many in the TSC community to stretch income further than usual. A lot of people are now at real financial breaking point, a completely unacceptable situation to be forced into when the daily impact of living with TSC is difficult enough. We're currently looking into ways that we can work together with other charities to highlight to local and national government the difficulties that these increased prices are having on rare disease communities like ours.

If you need help right now, speak to the TSA Support Line who can signpost you to wider help, whether emotional or financial. Also remember that we can help in a small way through the TSA Support Fund, if appropriate.

One reason to be optimistic is the exciting progress we've had in TSC research. It's a positive and ever-developing time in the diagnosis, care and management of TSC. At the TSA, we've seen this during our research funding application round for the year, as well as our exciting new partnership with Epilepsy Research UK which will help us to identify new research into TSC-related epilepsy (see [pages 16-17](#)).

Beyond the hardships let's look ahead, to positive change.



Best wishes,
Sanjay Sethi
TSA Chair

SANJAY SETHI, CHAIR

'Thank you' from Louise



LOUISE FISH, FORMER CHIEF EXECUTIVE

After over five years, Louise Fish (Chief Executive) is leaving the TSA. In her final message to the TSC community, Louise looks back on her time with the charity, including her highlights, and what she hopes we achieve in the future

It feels like only yesterday that I was starting out in my exciting new role as Chief Executive of the TSA. Yet, when I think about all of the incredible ups and downs of the last five and a half years, I can't help but be amazed at what the TSC community and the TSA team achieved in this time.

Leading this amazing charity has been wonderful and I'm very thankful to so many people, especially the TSC community – I still remember how welcome you made me feel during my opening weeks and months. Helping to improve lives in the TSC community has been humbling and hugely rewarding, especially with you being such a warm and passionate group. This is something that will always stay with me.

There are so many people that I'm very glad to have met and it's impossible to list them all here. This includes our long-standing and newer Trustees, our incredible ambassadors, and the committed professionals in

every NHS TSC clinic. I've been blown away by the drive that everyone puts into improving the lives of people living with TSC and their families. This includes the small TSA team, who make sure that the charity's vision and values come to life.

Some of my fondest memories at the TSA have been spent directly with the TSC community, whether this has been at monthly virtual get-togethers or face-to-face events like Big Day and Outlook. During virtual and face-to-face TSC events, I was always inspired by the support, care and encouragement that the community showed one-another. I want to give a special 'Thank you' to the TSC community members that form our Outlook steering committee and help ensure that the event continues to grow. If you've never been to an Outlook event before, be sure to give it a go!

There have undoubtedly been times of great challenges during my time as Chief Executive, not least the devastating impact that Covid-19 had on the TSA's finances and working practices. Another moment that strongly sticks in my memory, and that I'll never forget, is the departure of TSC community member Zoë Bull. Zoë is sorely missed by everyone who was lucky enough to know her, including her lovely parents, Gordon and Jean. Zoë's book 'Rare: A Journey of Self-Acceptance' is a wonderful and illuminating read into the life of someone living with the impact of TSC every day.

Although I'm no longer going to be at the TSA, I'll still be flying the flag for greater support, research and advocacy for genetic conditions in my new role with Genetic Alliance UK. In a fantastic twist of fate, I'll be following the great footsteps of Ann Hunt (joint TSA founder), who was the very first Chair of Genetic Alliance UK. This means that my work after leaving the TSA will still go towards improving lives in the TSC community.

To (mis)quote Woody and Buzz from Toy Story: The TSC community will always "have a friend in me".

Welcome to your new Chief Executive

The TSA has been delighted to welcome John Shepherd as our new Chief Executive, following the departure of Louise Fish. The appointment of John marks a major step in our ongoing and ambitious work to improve lives in the TSC community across the UK

John joins the TSA as an experienced senior leader with proven success across the private and charity sectors in a range of roles. A committed and passionate leader, John spent five years as Chief Executive of Trailblazers Mentoring, where he developed a charity with strong foundations and a notable reputation, celebrated for its top-class user services and sustainability. John also brings to the TSA his professional experience as a Trustee for a housing charity and his personal experience as a parent-carer for his adult daughter, who lives with another rare condition.

The TSA's immediate targets and milestones from the charity's 2022 business plan will continue, under John's guidance. The TSA's next strategic plan, outlining our key projects for 2023 – 2027, is set for development and launch next year.

John Shepherd succeeds Louise Fish as Chief Executive, who commented on the appointment: "John is not only an experienced leader, but one who is also empathetic and committed to helping people who live with a rare condition. During what was a very competitive recruitment process, these qualities set John aside from other strong candidates. There is no-one better for me to pass on this important role onto, and I'm really looking forward to seeing the TSA prosper and grow under John's leadership".



**JOHN SHEPHERD
NEW CHIEF EXECUTIVE**

The TSA's Annual General Meeting (AGM) will take place virtually on **Monday 21 November, 7pm - 8pm.**

Join the meeting to hear updates from the TSA, and to make sure that we understand what is most important to you:

www.tuberous-sclerosis.org/agm2022

What better way to get to know your new Chief Executive than to hear directly from him? John was keen to speak to the TSC community right away, and wanted to share this “Hello” in Scan

Although the way that TSC affects people can be dramatically different, one thing that everyone in the TSC community knows is that reasons for change can be incredibly powerful. This could be unexpected results from a recent hospital visit (for better or worse), exploring new treatment options as recommended by your TSC clinician, or finally securing suitable social care measures for yourself or a loved one.

When I heard about the prospect to join the TSA as its Chief Executive, this opportunity for change in my own life was one that I grabbed without hesitation. I said ‘Yes’, despite being fully aware of the hard work needed to continue the TSA’s great efforts across support, research, fundraising and advocacy.

The TSA has never accepted anything less than the best for the TSC community and this will certainly continue with me, as I endeavor to push this wonderful charity to be a spark for positive change in the TSC community.

I’m only just starting my TSC journey, but my own personal experiences of the devastating impact that a rare genetic condition can have on individuals and families is nothing new to me. I’m a proud dad of two wonderful daughters – my youngest, Sophie, lives with a rare condition. Sophie is now an adult, but I continue to be not only her father but also her carer – with this comes the many years’ experience of hospital visits and consultations, and the daily challenges of home, school and elsewhere.

My personal background of the impact of a rare condition provides me with an insight into what life is like for individuals and families affected by TSC, including the moments of joy, frustration and everything in-between.

From a professional perspective, I hope to build on my knowledge and learnings from being Chief Executive of Trailblazers Mentoring, a national charity launched to mentor young offenders (aged 18-25), with the primary objective of helping them to reduce their re-offending. Trailblazers taught and showed me the value of a listening and empathetic ear, being unwaveringly committed, and exploring new opportunities. All of these values are traits that have led the TSA to being the wonderful charity that it is today. I hope to continue to build on these values during my time as Chief Executive of the TSA.

I’ve already been very impressed with the rest of the TSA staff across all teams, with the bond between TSA staff and the TSC community being resolute. This is testament to the hard work of our small team, who never settle for less and regularly ask “Is the TSC community at the heart of this?” My initial aim is to provide the TSA team with the means to continue with its great work, as we look towards the new year and our ambitious plans for the future.

If there’s one thing I want you to know about me, it is that I am here for **you**. Whether you and your family have very mild or very significant TSC support needs, or whether you are new to the TSA or have been with us since our launch almost 50 years ago. As your Chief Executive, the TSA will continue to be warm, open and listening. I hope we get to meet and chat soon.

Don’t be a stranger, as I’m keen to chat with as many people in the TSC community as possible – you can send me a message (John.Shepherd@tuberous-sclerosis.org) or connect through my LinkedIn profile (www.linkedin.com/in/johnshepherd-relationshipbuilder).

An update from the TSC Research Volunteer Network

The TSC Research Volunteer Network is a special group of TSC community members who are helping to identify and shape what are the most important areas for TSC research

Launched in 2021, the network includes passionate and committed people living with TSC and their loved ones. This provides us with a vital viewpoint into daily life when living with TSC, which is vital for directing new TSC research.

The TSC Research Volunteer Network has helped the TSA research team and TSC researchers in many different ways, such as participating in workshops, providing feedback to medicine decision-makers like the NHS, and telling us about the biggest challenges people face because of TSC.

TSC Research Volunteer Network



The voice of the TSC community in TSC research

The TSC Research Volunteer Network has achieved so much already:

Attending a conference organised by Epilepsy Research UK at the Frances Crick Institute in London. The event covered a range of research topics, with network attendees also raising awareness of TSC	Reviewing different leaflets and other documents on behalf of TSC researchers working on TSC projects. This helped ensure that content was written in a way that was easy to understand for non-researchers
Helping a TSC researcher apply for funding from the UK Medical Research Council. This was done by reading a summary of the researcher's work, to ensure that the work was impactful and meaningful	Participating in workshops focused on NHS Genomics England's Newborn Genomes Programme. The Newborn Genomes Programme is a plan to create an NHS pilot study to offer whole genome sequencing (WGS) to all newborns.
Giving feedback on a draft information leaflet written by a pharmaceutical company conducting a trial into a TSC medicine. The leaflet will help explain the study and how to be part of it	It's hoped that WGS of newborns in NHS England will make it quicker and easier to identify and also treat rare conditions, like TSC

The TSC Research Volunteer Network has achieved a lot already, but is just getting started! Only by getting involved can you help us to ensure that people affected by TSC are at the heart of research into the condition.

For more information on the TSC Research Volunteer Network, including how to register, visit: www.tuberous-sclerosis.org/research/tsc-research-volunteer-network

TSA Big Day



Bringing everyone in the TSC community together

Big Day is back! Our biggest annual event of the year returns with a new look

Big Day 2022 will take place on **Saturday 8 October** at the **Innside by Melia Hotel** in **Manchester***.

Big Day is one of the TSA's longest-running events, where everyone who is affected by TSC is invited to come along in-person to meet with other people who understand the impact that the condition can have on daily lives. It's a full-day event, with talks, opportunities to make new friends, and the chance to speak with the TSA team.



Tickets for Big Day 2022 are now available on the TSA website: www.tuberous-sclerosis.org/big-day-22

Big Day 2022 is focused on connecting the TSC community. You can see our working agenda below (subject to changes):

- **10:00 – 10:30:** Doors open, teas/coffees/pastries
- **10:30 – 10:45:** Welcome and introductions
- **10:45 – 11:15:** Recent research wins, plus TSA Q&A (Dr Pooja Takhar, TSA Head of Research and Policy)
- **11:15 – 11:30:** Break
- **11:30 – 12:15:** Challenges in the TSC community – findings from the TSA Support Line and TSCensus (Annemarie Cotton, TSA Trustee)
- **12:15 – 13:30:** Lunch, plus meet the TSA team
- **13:30 – 14:15:** Slot to be revealed
- **14:15 – 15:00:** International TSC Research Conference update (Dr Chris Kingswood, St. George's TSC Clinic)
- **15:00 – 15:30:** Break
- **15:30 – 16:30:** The Importance of Sleep (Kerry Davies, The Sleep Charity)
- **16:30:** Thank you and close, opportunities to connect and network continue

At Big Day you can expect to:

- Be in an environment where people understand the impact that TSC can have on lives, with significant time allowed for networking
- Discuss a range of topics, all focused on TSC
- Have the opportunity to meet and get to know individuals and families affected by TSC
- Meet the TSA team and tell us about what is most important to you

Everyone is welcome, so be sure to come along!

Unlike at previous Big Days, the TSA is not able to offer care support at Big Day 2022, or any sort of creche facilities. If you require a carer at Big Day 2022, we kindly ask that your carer comes with you.

If paying for at-home care support to attend Big Day is a challenge for you, you might want to consider applying to the TSA Support Fund (details on our website).

*Innside by Melia is in central Manchester, a short taxi journey or 20 minute walk from Manchester Piccadilly station. Secure parking is available at the hotel.

Travel insurance and living with a rare condition



Going on holiday should be a time of excitement. But, for those affected by TSC, finding affordable travel insurance can be confusing and frustrating, with some insurers hesitant to offer policies to people affected by TSC

At this time of the year, we get lots of questions on the TSA Support Line from individuals and families struggling to get travel insurance. Instead of looking forward to an upcoming holiday - perhaps the first in many years - travel insurance challenges mean that many in the TSC community are finding this time stressful and overwhelming.

Why is getting travel insurance harder for someone with TSC than those without the condition?

As with other insurance packages, travel insurance is charged depending on how likely the insurance company thinks you'll need their services. For example, someone who has recently passed their driving test will likely pay more for car insurance than someone who has been driving for many years without a claim. This is because, in the eyes of the insurer, there's a greater chance of a new driver having a problem, compared to someone who has been driving for a long time and hasn't made any claims. It's the same for travel insurance - companies believe it's more likely that someone with certain medical conditions (such as TSC) will need medical attention during their holiday, compared to someone with no pre-existing conditions.

This means that insurance for people with pre-existing conditions can be expensive, or even difficult to find.

However, it's still very important to have travel insurance when you go abroad - it gives peace of mind, and protects you from medical expenses which could cost tens of thousands of pounds.

Do I need to tell travel insurance companies about a medical condition?

It's very important to be open and honest about all medical issues when applying for travel insurance. If you don't tell an insurance company about everything (such as TSC), and then claim for medical costs, your provider might decide to not give you your costs back.

How can I find insurance that is affordable and applicable?

Travel insurance should be purchased before your journey starts. You can buy travel insurance directly through a travel insurance company. You can also search through online comparison websites, which often also allows you to filter for policies that consider pre-existing conditions.

The Financial Conduct Authority has created a directory of travel insurance companies that service people with medical conditions. Visit their website (www.moneyhelper.org.uk) and search 'Travel insurance directory'.

You may already be applicable for cheaper or free travel insurance through your credit card company or bank - many offer travel insurance to their customers, as a perk of using their services. However, be sure to read their policies carefully, and don't assume that you're covered without checking with them first.



What should I look for when choosing a policy?

Not all travel insurance policies offer the same things. It's important that you check the details of your policy for what is and isn't included, and what the policy limits are. Some insurance companies will charge you an upfront fee for claiming anything with them, while others won't. Some policies may also cover you for things like cancelled flights or lost luggage.

Make sure that you read the small print and are confident on what the policy covers you for.

I have a UK Global Health Insurance Card. Can I use this instead of travel insurance?

UK Global Health Insurance Cards (GHICs) recently replaced the old European Health Insurance Cards (EHICs). If you're travelling in the European Union and carry a valid GHIC, it means that you can access state-provided healthcare during your stay. The GHIC is free to apply for.

GHICs are not a replacement for separate travel insurance. GHICs cover a lot less than a comprehensive travel insurance policy. In fact, some insurers will not agree to give you a travel insurance policy if you don't have a GHIC.

I've found a policy. What else do I need?

Take the policy documents with you on holiday so you can have them handy. Make sure that every adult in your group knows where the policy information is, in case you need it.

Many insurance companies have a 24-hour emergency helpline - save this number on your phone, so that you have easy access to it.

We've got more useful tips to make your adventures as easy as possible, even if you're going away for just a local one-day break:

Take time to prepare and talk about the holiday or trip

If your loved ones have additional challenges, talking about the trip and showing them pictures, along with a detailed plan, can help to make things less daunting. You could even get them involved in the planning!

Write a 'Does it have...' list

A 'Does it have' list can help you tick off all the things you want an attraction or destination to have. Points could include things like 'Does it have wheelchair access?' or 'Does it have staff that understand our needs?'

Autism-friendly attractions

Many attractions and places focus on being as accessible as possible, including having special autism-friendly times or offering things to make autistic visitors as comfortable as possible (such as ear defenders).

Disabled person railcard

You or a family member might be entitled to a disabled person railcard – giving you 1/3 off train travel across the UK.

National key scheme

The National Key Scheme (NKS) offers the opportunity for disabled people to access over 7,000 otherwise locked accessible toilets across the UK. NKS toilets can be found in most public places, such as pubs, restaurants, airports and train stations.

TSC stories:

Gary Lillywhite

After being rushed to the emergency room as a child, Gary Lillywhite's family was told that he would never leave the hospital. However, Gary is now thriving in independent housing with a busy and fulfilling life

Gary was just two years old when he was taken to Great Ormond Street Hospital, after collapsing at nursery. This was where Gary's family heard the words 'Tuberous Sclerosis Complex' for the first time.

The unexpected trip to hospital with Gary was made even worse when the family was told that he might never be able to go back home. "Having a child with TSC can be hard and in the beginning, you have no idea what this illness may do to your child. It is worrying," commented Gary's mum, Sandra. Yet, Gary was set to progress further than what the clinicians who treated him on the day he collapsed thought was possible.

Now aged 46, Gary lives in independent housing with other residents. His days are full of activities and he has a busy social life, with Gary regularly meeting a friend for a coffee. Although Gary loves to be with others, his real passions are knitting, tapestry and sewing.

Gary learnt to knit when he worked at a residential home for the elderly, over 20 years ago. He was taught by a resident and has continued ever since! He used to attend a knitting club in Chichester Library, and a friend has helped him to further develop his skills. Gary is confident with advanced stitching methods, and recently even started to use a loom.

Gary's crafty skills have been used to help others, as he knits hats and blankets for a local maternity unit. He celebrated the recent Jubilee by making a fabulous bag for his mum! Gary has also made other bags for friends and family, which have all been gratefully received. One of Gary's greatest crafting achievements was a gift to his mother: A large tapestry which takes pride of place in her home. Gary is proud of the size and detail of the tapestry, but is still most delighted with the blankets he made for the maternity unit.

Knitting, sewing and other crafts help Gary not to feel lonely, as well as giving him a way to keep calm and to focus on something positive. He finds knitting to be a great stress reliever, which has been especially important for him lately to reduce anxiety around social isolation.

"The key is to enjoy it, and my friend is always excited to see me" says Gary, who goes to see a friend who shares his passion for knitting once a week at a local coffee shop.

"The key is to enjoy it, and my friend is always excited to see me" says Gary, who goes to see a friend who shares his passion for knitting once a week at a local coffee shop.

Although Gary has an active life and a real passion that he shares with the world, the TSC journey can sometimes be difficult for Gary and his family – like many others in the TSC community. According to Sandra: "Life can be difficult due to the things Gary isn't able to understand. There are no local services around that can help." Gary found the Covid-19 pandemic particularly difficult, but Gary's TSC consultant was able to offer him and his family support during the pandemic. Gary was very thankful, and even bought his consultant some flowers.

Gary's hobbies give the family an outlet and a way to come together with other people in the local community. Sandra



says that joining a care society also really helped the family to connect with others and to get out and about: "We have a care badge so we pay less for activities. Now we get half price activities which really helps!"

To add even more to Gary's list of hobbies, he's now started to volunteer at a café and is also taking on a theatre course, making props with the group Making Theatre Gaining Skills. Making Theatre Gaining Skills aims to improve people's lives by opening pathways to employment. They support people who are unable to find other places of work due to disability, social isolation, lack of qualifications, mental health problems, and/or learning difficulties ([MakingTheatre.co.uk](https://www.makingtheatre.co.uk)). Following the course, Gary and his new friends will be off to a local primary school to put on a play!

After the early years of Gary being rushed into Great

Ormond Street Hospital and possibly never leaving, his life has turned into one with independence, passion and joy.

If anyone would like to follow in Gary's crafting footsteps, he says that learning to knit or sew is best done by going online or finding a local craft shop that offers courses.

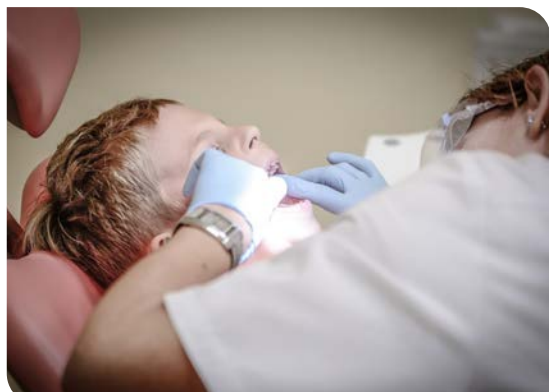
The TSA thanks Gary and his family for taking the time to tell us all about Gary's life and hobbies. It was a real pleasure to talk to them all.

If you'd like to feature as our next TSC Story, get in touch: admin@tuberous-sclerosis.org

Dental care in TSC

It's important for everyone to have good dental hygiene. For people affected by TSC, problems with teeth and gums can happen at different times, whether it's because of a direct or indirect result of the condition

There are many reasons why people affected by TSC might need extra care and attention to keep their teeth healthy. This could be from growths in and around the mouth, or wider reasons such as daily challenges in brushing, or even negative relationships with food.



Tackling the costs of dentist visits

- In England and Northern Ireland, dental treatment is free for:
 - Children aged under 18
 - Those aged 18 and in full-time education
 - Women who are pregnant or have given birth in the last year
- In Scotland, dental checkups are free to everyone but you have to pay for treatment. In Wales, dental examinations are free if you're aged under 25 or over 60
- You might be entitled to free dental care if you're on certain benefits. If you're on a low income, but not entitled to free dental care, you might be able to get help with costs on the Low Income Scheme. You can apply for this using the HC1 form, and find more information on your relevant government website

The physical impact of TSC on oral health

The most common dental issues in people with TSC are overgrowths of the gums (called 'gingival fibromas') and areas of teeth losing their enamel (called 'dental pits'). Fibromas sometimes don't cause any long-term problems, but they might grow larger and cause irritation or bleeding. Dental pits provide an area for bacteria on teeth to grow quickly, which can lead to cavities.

Other ways that TSC can impact on teeth and gums

Many people who live with TSC also have autism, other neurodivergent conditions or further challenges. This might mean that brushing regularly or seeing a dentist can be incredibly challenging because of sensory issues.

If you or a loved one struggles with the taste or texture of toothpaste, try switching to a flavour-free or plainer toothpaste, such as an 'original' flavour instead of mint. Low-foaming toothpaste might also reduce sensory challenges.

There are teeth cleaning visual aids and pictures to help children or those with additional needs have good oral hygiene. Try searching online for these and sticking them up in the bathroom.

Restricted diets and TSC

Some people with TSC can tolerate only very restricted diets. Often, these diets may include fizzy drinks or other sugary snacks. It might be possible to reduce sugar in a loved one's diet by replacing these foods with sugar-free alternatives. However, this isn't always possible, such as if the sugar-free version has a different texture.

Finding a dentist right for you and your family

As with everyone, it's important that people with TSC see a dentist regularly. Some dentists have more experience than others in supporting people with additional needs. You can find these dentists on the NHS website. Some specialist centres can also offer treatment involving sedation or general anaesthetic. However, all dentists must make reasonable adjustments when they are needed, such as extra time or care where required. If your loved one has additional needs, it could be useful to give the dentist a call to have a conversation about what care and support you and your loved one need.

TSC and nails

Around 1 in 5 people with TSC develop growths under fingernails and toenails, which are often painful and frustrating

People with TSC can develop growths on the hands and the feet (called 'ungual fibromas'), with those on the hands being more common. Nail growths can impact people differently, from being very mild and no treatment needed to being very painful and requiring treatment.

If a growth is under the fingernail or toenail, it's called a 'subungual fibroma'. If a growth is around the fingernail or toenail, it's called a 'periungual fibroma'.

For people with ungual fibromas, a growth forms under or close to a nail which pushes on the nail and causes pressure and pain. It's also more common for the growths to start in adulthood, rather than in children.

How to spot an ungual fibroma

Ungual fibromas are smooth, firm and flesh-coloured. Look out for a long groove in or around the nail, or short streaks that are red or white (called 'splinter haemorrhages' and 'leukonychias'). The growth itself isn't always clearly visible – if you can't see the growth, it might still be an ungual fibroma causing the problems.

The impact of nail problems because of TSC

Ungual fibromas most commonly cause problems when there's added pressure on the nail that's affected, such as when walking, writing or typing. As well as pain when doing everyday activities, ungual fibromas can have a big impact on a person's self-esteem and confidence.

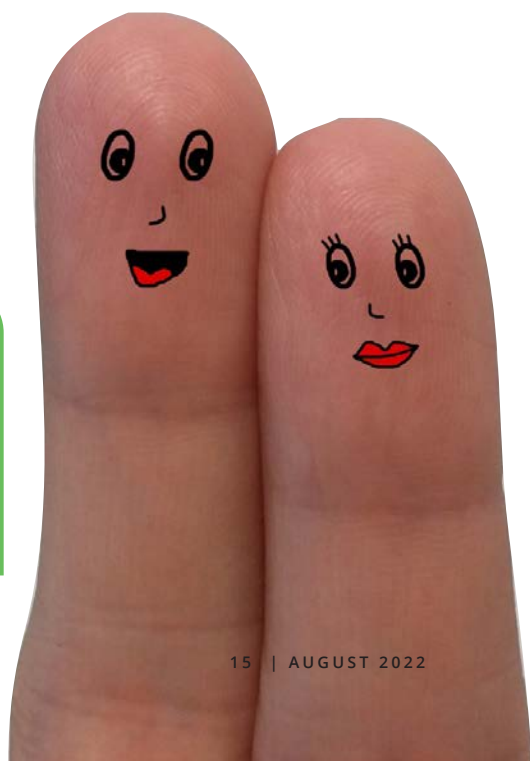
How ungual fibromas are treated

Ungual fibromas might be left alone if they're not causing any major problems. However, if you've any doubts it's always important to speak to your GP or TSC clinician. For more troublesome ungual fibromas, a referral to a dermatologist is usually recommended (ideally to someone with experience in TSC). Treatment options can include surgery, use of lasers and electrodesiccation (use of an electric current passed through a needle-shaped instrument).

Some NHS TSC clinics have direct access to dermatologists: Addenbrokes (Cambridge), Bath, Birmingham, Glasgow and Newcastle. You can find contact details for these clinics on the TSA website, or contact the TSA Support Line for more information ([0808 801 0700](tel:08088010700) / support@tuberous-sclerosis.org / [webchat](#)).

Look out for a long groove in or around the nail, or short streaks that are red or white –

We recently held a virtual event focused on the skin, with Dr Lea Solman (Paediatric Dermatologist, Great Ormond Street). You can rewatch the session in full: www.tuberous-sclerosis.org/tsc_affects_the_body/skin



Working in partnership to fund TSC research

For over 40 years, the TSA has been at the forefront of funding research into areas most important to people affected by TSC. With TSC being such a wide-ranging condition, we often work in partnership with other organisations to tackle issues that matter most to the TSC community together

Many years of relationship-building and collaboration have allowed the TSA to develop valuable partnerships with organisations similar to us. In TSC research, likeminded organisations work alongside the TSA so that we can come together to increase our knowledge on a specific area or issue in TSC.

Through research teamwork and partnerships, the TSA can access more resources, brainpower and opportunities to push TSC research into more discoveries and breakthroughs. This year, we've been pleased to develop fantastic research partnerships with two different organisations, who are both focused on some of the most pressing areas of living with TSC: TSC-Associated Neuropsychiatric Disorders (TAND) with research group TANDem and TSC-related epilepsy with Epilepsy Research UK.

Working with the TANDem team during our most recent funding grant round

In the last issue of Scan, we discussed how the TSA funds research, including how grant rounds take place. Put simply, grant rounds involve researchers submitting applications to us about what TSC research they'd like to do.

In 2019, we funded the TANDem Project, which is bringing together a worldwide team of families, researchers and clinicians to help us to better understand the best ways to identify, manage and treat TAND. This year, we're working alongside the TANDem team to select the best TAND-focused applications in our research grant round. The funding opportunity is open to TSC researchers across the world and is aligned with our priority areas for TAND.

By working with TANDem Project researchers, we can access the expertise and experience of TAND researchers to identify the best new research that we can fund in the area.

We're delighted with the response of the international research community to our TAND-focused grant round. The TSA research committee and the TANDem team are now reviewing these applications, to choose who to award funding to.

Working with Epilepsy Research UK on their 'Emerging Leader' award

Around 8 in 10 people who have TSC also have epilepsy. TSC-related epilepsy can be difficult to treat, with around 3 in 10 people with TSC-related epilepsy not able to control their seizures with medicines that are currently available.

With epilepsy being such a major and life-changing challenge for many people who live with TSC, we're delighted to join forces with Epilepsy Research UK as part of their 'Emerging Leader' award for 2022.



Every year, Epilepsy Research UK gives their Emerging Leader award to a researcher investigating a specific area of epilepsy. The award is given not only as a way for research to happen, but also to allow the chosen researcher to acquire greater knowledge and skills in epilepsy research, so that the researcher can continue to develop.

The Emerging Leader award for 2022 will be chosen in partnership with the TSA. The selected researcher will work on an area of epilepsy research that will benefit not only epilepsy as a whole, but also TSC-related epilepsy.

Being part of the decision-making process for the Emerging Leader award in 2022 is an exciting opportunity for TSC-related epilepsy research to extend beyond the boundaries of TSC, into researchers and experts who may not have otherwise encountered or focused on TSC-related epilepsy previously.

Louise Fish (TSA Chief Executive at the time of the announcement) commented: "I'm delighted that we've secured this partnership to fund a fellowship that will drive TSC-related epilepsy research forward. Collaboration brings expertise from different areas together, it helps to avoid duplicating efforts, and it makes the most of available funds. By partnering with other organisations like Epilepsy Research UK, we can make an even bigger impact on people affected by TSC-related epilepsy, as well as raise wider awareness of the condition."

Maxine Smeaton (Epilepsy Research UK Chief Executive) also commented: "We are proud to be joining forces with the TSA to develop a future leader in epilepsy and TSC research. The research funded through this important collaboration will provide vital evidence needed to improve diagnosis, treatment and prevention of epilepsy in TSC. Integral to the assessment and implementation of the proposed research will be meaningful involvement of members of the TSC and epilepsy community, to ensure that the priorities of the people most affected are central to this work."

Applications for the Emerging Leader 2022 award are now open, with the chosen researcher to be announced next year. The TSA will keep everyone updated on our latest funding grant round, as well as Epilepsy Research UK's Emerging Leader award.

TSC Clinics Virtual Challenge 2022

Earlier this summer the TSC community took on our biggest group fundraising challenge to date: To complete a virtual loop of every NHS TSC clinic in the UK, a journey of 1,670 miles in total!

We're proud to highlight the amazing work of NHS TSC clinics across all UK nations. One way we do this while fundraising is through the TSC Clinics Virtual Challenge, which entered its second year.

Throughout June, the TSC community walked, ran, cycled and even swam, racking up the miles towards our goal of completing a full virtual loop around every TSC clinic in the UK. Starting on 1 June at St George's Clinic (London), we all took our first virtual steps, hoping to arrive back again by the end of the month!

The TSC community were united on this epic challenge, logging miles to raise vital funds to help others affected by TSC. Throughout June we made steady progress, passing Liverpool, Belfast, Glasgow and Nottingham (amongst many others) on the way.



On the final day, we were in danger of missing our target by just a few miles and with St George's TSC clinic on the (virtual) horizon. Yet, a final late burst of miles from you got us to the finish line! This included miles by **Louise Fish** on her last day as TSA Chief Executive. We made it with just hours to spare – phew!

We knew that the determination of the TSC community would allow us to finish this challenge, mirroring the support and helping hand that everyone affected by TSC shows each other daily. You raised a wonderful **£2,353**. Thank you to everyone involved – we hope that you wear your TSA Champion medals with pride!

Fundraising thank you's

Thank you to everyone who has been busy fundraising for the TSA to help improve lives in the TSC community. We can only be here for the TSC community thanks to your support



What a superstar! A massive thank you and well done to 7-year-old **Ruby Rasho**, who had a huge 25cm of hair cut off, making a massive difference to people in need. Ruby donated her hair to the Little Princess Trust (who provide real hair wigs to children and young people who have lost their own hair through cancer treatment and other conditions), and also asked for donations to the TSA, as little brother Tommy has TSC. Ruby's incredible selflessness raised a massive **£1,055!**



A huge thank you to **Jamie Wearing** who raised over **£2,928** by running the Manchester Marathon and then also hosting a charity event at his local golf club! Jamie's not finished there, as he's

also joined #TeamTSA for the London Marathon 2022, all in honour of his daughter Elsie, who lives with TSC.

Thank you to **Sarah Wade**, who held a special gala dinner in aid of the TSA at Aldwick Estate, North Somerset. An amazing 174 people came long, raising a fantastic **£7,977!** Sarah organised the event in celebration of her nephew William, after seeing his bravery in dealing with TSC-related epilepsy seizures.



A massive thank you to the **Daisychain** preschool team, who organised a fundraiser over the Easter Bank Holiday at a local farm shop. The team raised a fab **£130**, in honour of Cody who lives with TSC. The event included face painting, a bouncy castle, an egg hunt and fun crafts!



Margaret Fletcher and other Sunderland AFC fans in the Wingate and Sedgefield supporters branch raised a brilliant **£160** to improve lives in the TSC community, holding a quiz on the supporters' coach to a recent match! Thank you! This generous support shows that there's fundraising opportunities everywhere!



Thank you once again to **Linda Smith** and the wonderful staff and patrons of The Swan in Needham Market, who dedicated their weekly quiz nights to the TSA and raised **£146!** Linda has also been running a weekly bingo event including a 'Jubilee special', raising another **£820** to date. Thank you for your continued support!



Sarah, Darrell, Otto and Cody celebrated Global TSC Awareness Day 2022 by holding a garage sale, raising an excellent **£71**. Fundraising, awareness-raising and even decluttering in the process – amazing!



Ricky Jones and Piroska Larsen took on the Big Black Mountains Challenge – a 30km walk that includes over 1,000m of ascents and descents, in the heart of the Brecon Beacons National Park. Piroska and Ricky's hard work raised an amazing **£900**, with the pair generously choosing to support the TSC community because their colleague's daughter lives with TSC.



A big thank you to **Tariq Farooqi** for completing the RideLondon - Essex 100! Tariq cycled 100 miles and raised an amazing **£1,945** for the TSA. Tariq said: "It was a tough slog over six hours, but worth it!"

Although she had to withdraw from the TSA's London Marathon team, it didn't stop **Nicola Daykin** and her family and friends from raising funds in honour of her son, Cole. Following the success of making Easter crafts in 2021, they raised another **£270** by selling more crafty gifts and treats, all in aid of the TSA. Cole's Aunt Tracey and the team at **Glamour Salon** also got involved with a collection box in the salon and a birthday fundraiser. Excellent work everyone!



The **Chloe's TS Warriors** team took on the epic 26 mile Aberdeen Klit Walk, raising a brilliant **£2,216** in honour of Chloe who lives with TSC. Chloe braved the Scottish rain to cheer on the group's team members Kerry, Josh, Emma, Steven and Jordan over the finish line! Well done all!



Linda Morley took on our 5k in May running challenge, raising **£65**! Linda did this (in her words) by the 'old fashioned' way, with a paper sponsor form! Great work Linda!



Trusts and foundations

We would like to thank the following trusts and foundations for their generous support:

- Friarsgate Trust
- Hamilton Wallace CT
- Hobson Charity
- Joseph Strong Frazer Trust
- JTH Charitable Trust
- Meikle Foundation
- P F Charitable Trust
- Street Foundation
- The Michael and Anna Wix Charitable Trust

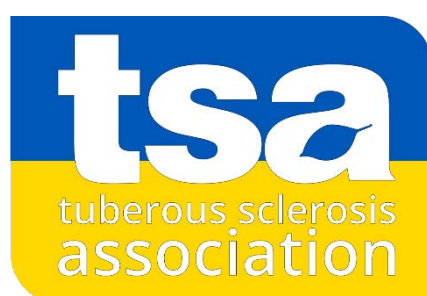
Corporate support

Thank you to our corporate partners for all of your support. Thank you also to everyone who nominated us with employers, made a donation from your own company, or asked local or family businesses to consider supporting the TSA



Hiscox London's Market Operations team have come to the end of their epic fundraising for the TSA and the TSC community. Their final effort was a 'survival of the fittest' challenge, with the team taking on health kicks like no alcohol, going veggie and even running 100k over one month – showing that there's always a way to get involved in fundraising, whether it's something done at home or elsewhere.

To boost the wonderful efforts of the market operations team over the last 12 months, the **Hiscox Foundation** even match funded the team's fundraising, bringing the total raised by Hiscox London's Market Operations team to a brilliant **£6,640!** Thank you for all of your hard work.



Back in April, we appealed to the TSC community to support **E-TSC**, a European TSC organisation, with their special Ukraine appeal. E-TSC are helping ensure that the TSC community in Ukraine gets the help that they need. This includes working with charity TSC Poland, who are working on many complex and vital areas to support people from Ukraine with TSC who have experienced the conflict. TSC Poland's work includes transporting much-needed goods across the border into Ukraine, and helping those in the TSC community who have entered Poland from Ukraine.

Although the TSA continues to be here only thanks to the generosity of people's donations and giving, the situation is so severe in Ukraine for people affected by TSC that we took the unprecedented step of asking you to donate to E-TSC's special Ukraine appeal fund.

Your response was incredible, with your efforts meaning that **£2,170** was donated from the UK TSC community to the E-TSC's special Ukraine appeal fund.

We also want to thank our amazing **anonymous donor**, who mirrored this generosity with a donation of **£2,000** to the TSA to support our work in the UK.

We're incredibly grateful to **Sir David Suchet CBE** for his continued support of the TSA and the TSC community. Amongst his ongoing efforts to improve lives in the TSC community, Sir David's recent stage tour 'Poirot and More' raised a jaw-dropping **£35,818**. As well as this, Sir David used a book signing session at **The Fishmongers' Company** Family Day as an opportunity to increase awareness and raise further TSC research funds, with **£620** raised. We're forever in gratitude to Sir David and all of his work for the TSC community.



Results from the Stay Calm Project

We asked you to get involved in the Stay Calm Project, to help us better understand emotional outbursts in children and young people with TSC. The results have now been published, with some useful and important findings

Led by Dr Justin Chung (School of Psychology, University of Birmingham), the Stay Calm Project involved parents and caregivers of children and young people aged 6 – 25 years old who have emotional outbursts at least once a month.

Participants submitted an anonymous questionnaire, which covered things like when, how long, and what happens during their loved one's outbursts. The questionnaires asked people about what is specifically happening in the environment when outbursts happen, such as things in the background, location, and situation.

The aim of the study was to broaden understanding of emotional outbursts in children and young people with neurodevelopmental disorders, like TSC. It was hoped that the research would allow researchers and clinicians to better identify patterns and triggers in emotional outbursts – this would then help parents and caregivers put in place ways to reduce and better manage these kinds of behaviours.

The researchers were keen to use appropriate language in the study, such as 'emotional outbursts' rather than things like 'temper tantrums'.

The Stay Calm Project received 268 questionnaire responses, with a wide range of backgrounds, symptoms and support needs amongst the parents' and caregivers' children. This was considered a high level of data for Dr Chung and his team to work with, meaning that any findings or patterns that were identified could be considered strong examples of how other people outside of the study might behave.



**DR JUSTIN CHUNG,
DOCTORIAL RESEARCHER**



Findings showed that children and young people who have emotional outbursts can be placed into one of three groups: Those who have outbursts in any situation, those who have outbursts in 'safe' spaces, and those who have outbursts in 'unsafe' places

Research highlights

When the team at the University of Birmingham analysed the questionnaire responses from participants, they found three distinct groups and patterns in how the children and young people involved in the study experienced emotional outbursts:

- **Group one: Emotional outbursts in all types of situations.** This group experiences outbursts no matter where they are, and regardless of the situation. Children and young people in this group may process things like sounds, smell and sight differently to other people. For example, imagine if a bright light, pattern or noise was so overwhelming, no matter where you were, that you couldn't think about or do anything else. Therefore, it's likely that the children and young people in this group live with an extreme sensory sensitivity. The researchers think that this sensory sensitivity is so strong for the people in this group that managing emotions at the same time is too challenging, which causes emotional outbursts to happen
- **Group two: Emotional outbursts when in places thought of as 'safe'.** This group experiences outbursts usually in places where they feel safe (like at home or a familiar location). It's likely that outbursts for people in this group are related to perceived safety. In other words, children and young people in this group might hide their true feelings when an unfamiliar place is uncomfortable or challenging. These negative emotions build-up, only to then be released when the person returns to a place that is 'safe' – like a pressure valve, releasing emotions when in a comfortable place to do so. For example, imagine feeling very uncomfortable about being in a new friend's house but only feeling like you can show your true emotions when you return back home
- **Group three: Emotional outbursts when in places thought of as 'unsafe'.** This group experiences outbursts usually in places that are unfamiliar or challenging (perhaps somewhere they're never been or experienced before). In contrast to the children and young people in group two, those in group three experience outbursts during the time that they are in the place considered 'unsafe', and don't wait to return to their 'safe' place to have an emotional outburst. It's believed that those in group three have challenges in understanding the true level of danger that they're in when in certain situations. For example, imagine an unfamiliar bus journey, while your brain is also telling you that you're in real danger

Based on the findings of the Stay Calm Project, it's believed that the majority of children and young people across all groups experienced outbursts because there was more than one challenging thing happening in the environment at the same time, such as loud noises and bright lights. This suggests difficulties in processing more than one challenging thing at a time.

The Stay Calm Project's results also highlighted that fewer than one in four families and caregivers receive effective support for emotional outbursts. This shows a need for more accessible and more effective support.

Building on the Stay Calm Project

Thanks to the Stay Calm Project, we've identified important information about how children and young people process challenges, and how this can lead to emotional outbursts in a wide range of environments. It's hoped that this research can now lead to the development of more targeted strategies to help manage outbursts.

The child or young person's diagnosis alone did not fully predict what group they would be part of (for example, participants who lived with autism were found across all groups). This means that future research might want to further investigate and divide the three main groups identified from this study.

Free parent guide on emotional outbursts

The Stay Calm Project team has used findings from their study to create a free guide on emotional outbursts for Cerebra, a UK charity supporting children with brain conditions. You can read the guide online here: www.cerebra.org.uk/download/emotional-outbursts.

How we work with the pharmaceutical industry

When done appropriately and ethically, working collaboratively with the pharmaceutical industry can lead to huge benefits in improving the lives of people affected by TSC. But, we'll only ever do this when it's of clear benefit to the TSC community

Working with pharmaceutical companies gives the TSA an important opportunity to drive forward our mission of providing help for today and a cure for tomorrow. It also means the TSA can work more effectively in achieving our goals.

From their perspective, pharmaceutical companies might like to work with the TSA as we can provide them with expertise and knowledge on the impact of living with TSC daily.

Ways that we might work with the pharmaceutical industry

The ways that we might work with a pharmaceutical company include:

- When a new TSC medicine is being considered for approval and funding by UK decision-makers. This helps to increase the likelihood of people with TSC getting access to new medicines
- Providing a pharmaceutical company with an overview of the challenges of being affected by TSC. This helps to make sure that pharmaceutical companies have those that matter the most – people affected by TSC – at the forefront of their work
- Increasing awareness of TSC across non-specialist clinicians (like GPs). If more non-specialist clinicians know about TSC, the easier it will be for diagnosis, treatment and management of the condition

We're always focused on the TSC community, no matter what

Although we welcome working alongside other organisations, including pharmaceutical companies, we'll never permit any individual, group or company to directly influence our important work for the TSC community if they're interested purely in profit.

The TSA is passionately independent, and loyal to the TSC community who are at the heart of our work. We'll only collaborate with pharmaceutical companies when we believe that the partnership can enhance our own work for the TSC community and will ultimately improve the lives of people affected by TSC.

Our commitment to ethical working

We're a member of the Association of Medical Research Charities (AMRC). The TSA's commitment to ethical collaboration with the pharmaceutical industry is in-line with the AMRC's own principles of working with independence, integrity and transparency. In addition, most pharmaceutical companies that we may consider working with are bound by the Association of British Pharmaceutical Industry's (ABPI) Code of Practice, which states clear and strict working practices when cooperating with charities like the TSA.

If a pharmaceutical company wants to sponsor the TSA

A pharmaceutical company might sometimes work with or sponsor a charity. Many charities do this and the TSA wants to be open and transparent about this with the TSC community.

Sponsorship funds might be used to help the TSA in different ways, such as to help manage ongoing costs or to allow us to fund new projects. This allows the TSA to continue to be here for the TSC community, with our charity able to operate only thanks to donations from a wide range of stakeholders, including the incredible individuals and families who choose to give to us.

Any sponsorship that we might occasionally receive from the pharmaceutical industry is only a small portion of what we need to operate. We rely on a wide range of donations and income, including all of the kind individual givers and fundraisers within the TSC community.

The TSA will only accept funds from the pharmaceutical industry when there's a clear strategic fit between us and the company, ultimately with the aim of improving lives in the TSC community. We're strict and clear with pharmaceutical companies that they sponsor us in the knowledge that that this in no way represents an opportunity to influence our focus, policy or direction. Any sponsorship does not in any way offer an opportunity to influence policymakers or to develop commercial advantage of any sort.

Working with Jazz Pharmaceuticals and PlusUltra Pharma



This year, the TSA has been pleased to work with Jazz Pharmaceuticals and PlusUltra Pharma on a range of projects, all focused on our daily work across support and information, research and advocacy. Jazz and PlusUltra have both committed to developing different TSC medicines.

Jazz and PlusUltra have kindly sponsored two TSA projects: The NHS TSC Clinics Network, and the NHS TSC Clinics Educational Meeting. This sponsorship ensures that the TSA can continue with our ambitious plans to enable TSC clinics to communicate, learn and grow together more effectively.

John Shepherd (TSA Chief Executive) commented: "The TSA is always open to working alongside other organisations who are focused, like we are, on improving the lives of the TSC community. This includes pharmaceutical companies when it's appropriate to do so. Sponsorship from Jazz Pharmaceuticals and PlusUltra Pharma for our work with NHS TSC clinics is a fantastic example of how charities and industry can come together for a common good."

The NHS TSC Clinics Network remains completely independent, but with the sponsorship providing the TSA with the means to help to run the network and its associated education meeting.



TSA Festive Greeting Card Design Competition 2022

It's still the summer and the festive winter time is still a very distant idea, but the festive elves at the TSA are already getting ready for winter 2022 and we need your help!

Are you a budding artist, or passionate about design? Or maybe you just love the winter season? If so, then be sure to enter the ever-popular TSA Festive Greeting Card Design Competition 2022, for a chance to have your work proudly used as a TSA card for winter 2022!

The competition is open to everyone of all ages in the TSC community in the UK. You can even submit more than one entry, and your entries can be done in any way that you like! Perhaps a line drawing, painting, photograph, or even something done digitally?

The winning entry will be printed and sold in our online shop, as one of our very popular seasonal cards for winter 2022. All profits will go towards supporting the work of the TSA to improve lives of people affected by TSC.

The winning designer will also receive three packs of their printed card, plus a TSA hoodie! Entries close **12:00pm (noon) on Friday 12 August 2022.**

**For full details and to enter please visit
tuberous-sclerosis.org/festivecardesign2022**

In loving memory

Many people put plans in place to give a gift to the TSA when they pass away. Families also often donate funds to the TSA in memory of recently deceased loved ones



A special thank you to the family of **Margaret Bird** for the generous donation of **£5,000** made in her memory, as outlined in her Will. Margaret was actively involved with the TSA in the early years of the Association when her daughter Sarah was first diagnosed with TSC, with Margaret finding great support from the TSC community. Sarah was also an active member of our Outlook group. Following Sarah's death in 2000, Margaret kept in touch with the TSA through Scan and was delighted with the progress being made in TSC research. Our thoughts are with everyone close to Margaret.



Loved ones of **Derek Noble**, a great supporter of the TSA, raised **£1,140** in his memory. Over the years Derek took on several long-distance cycling events to raise awareness and money to help people affected by TSC, including his daughter Hannah. Thank you to everyone who contributed.



Jean Johnston's granddaughter, Sophie, lives with TSC. Jean wanted nothing more than to help find a cure for TSC, to help Sophie. That's why one of Jean's final wishes before passing away was for no funeral but instead to have donations made to the TSA. **£2,160** was raised, thanks to Jean and her friends and family, which we are very thankful for.



Thank you to the family of **Maureen Morbin** who raised **£905** in her memory. Maureen's family had asked for donations to the TSA in place of flowers, in honour of granddaughter Tara who lives with TSC. Tara was a very important part of Maureen's life. Thank you to all of Maureen's friends and family for their kind donations.



Thank you to everyone who donated to the TSA in memory of **James William Thomas Newnham**. **£550** has been donated to the TSA in James' memory, which will help to improve lives in the TSC community. James was a beloved son and brother, who will be greatly missed but always remembered by his family and all his carers at the David Lewis Centre.

If you and your family have recently experienced a bereavement, the TSA Support Line is here for you (0808 801 0700 / support@tuberous-sclerosis.org)

New ways to donate

There are lots of different ways to donate to the TSA, to help us with our work across support, research and advocacy. As well as fundraising or direct giving, there's other nifty ways to go about your daily life while improving lives in the TSC community. Here are just a few options:



Had a clear out of your clothes? Thrift+ is a brilliant way to donate unwanted clothes, all while raising funds for the TSA.

All you need to do is order a ThriftBag by typing out the link below. Then, post your unwanted clothes to Thrift+ for free and they will sell them. You can then decide to donate either 33% or 66% of the proceeds to us!

https://thrift.plus/pages/_go?ref=9769:284993



Donating to the TSA is easy, but with Toucan it's made even easier! Featured on Dragon's Den, Toucan gives you a way to manage all charity giving, including regular and flexible giving, from one place.

www.thetoucan.app or search 'Toucan Giving' on your preferred app store.



Lots of people help to improve lives in the TSC community by using Amazon Smile – be sure to select us as your nominated charity!

Amazon Smile is a way for you to give to the TSA every time you shop on Amazon, at no extra cost to you!

We've already raised a fantastic £2,000 thanks to Amazon Smile – with every penny going towards our work, at no additional costs at all to the community.

Spread the word, ask family and friends to get involved, and select the TSA as your charity of choice.

**For more details on all the ways to support the TSA
please visit: tuberous-sclerosis.org/donate**