

scan

Spring 2023

The magazine of the TSA



Cover design by illustrator Annaliese Howard, who lives with TSC. Annaliese was asked to create a cover based on the theme of this issue's Scan: Togetherness'

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A word from your Chair

We've all gone through some very difficult times over the last few years. But, some recent key milestones in TSC have given us a big boost

Whether it's been the pandemic, the cost of living crisis or the daily challenges of living with TSC, we've all been having a rough time of it lately. However, the approval of the medicine cannabidiol (brand name Epidyolex) for TSC-related epilepsy in England, and the forming of an NHS Rare Disease Collaborative Network for TSC, have been massive triumphs.

The decision to fund cannabidiol came after months of hard campaigning by the TSA and TSC community, ensuring that the National Institute for Health and Care Excellence (NICE) came to the right choice. The TSA played a crucial role in the outcome, which demonstrates the power of our small but mighty charity, alongside the TSC community, to make real change.

The good news continued after NICE's decision, with NHS England accepting our application for the formation of a TSC Rare Disease Collaborative Network. This could mean real change in awareness and education about TSC in the NHS across the UK.

Despite these victories, we've also been through very sad times recently. Towards the end of last year, we felt the sudden passing of TSA Vice Chair, Robert Woodthorpe Browne MBE. Robert's passion for improving the lives of people affected by TSC was always very welcome by myself, the entire Board and the wider TSA team. Robert's departure has left a big gap in the TSA family, and our thoughts and best wishes are with Robert's loved ones.

These opening months of 2023 have been positive for the TSA, and we're looking to build on this. However, securing short and long-term financial security for the TSA remains a concern. Our plans are ambitious, but we can only be successful if we're given the means to continue.

Best wishes,
Sanjay Sethi
TSA Chair



SANJAY SETHI, CHAIR

Epidyolex now available across the UK



Important treatment option for TSC-related epilepsy given a 'Yes' across all nations

Decision-makers in England recently approved funding of cannabidiol (brand name Epidyolex) for TSC-related epilepsy. We were delighted with this result, as it means that cannabidiol will now be available throughout the UK!

The National Institute for Health and Care Excellence (NICE) is responsible for deciding if a medicine should be given funding by NHS England. The TSA worked very closely with NICE to make sure that they came

to the right decision. We had already campaigned for and received positive decisions from healthcare leaders to fund cannabidiol across Scotland, Wales and Northern Ireland. This meant that England was the final step for approval of the medicine across the UK.

Cannabidiol can potentially reduce seizure frequency and severity. The medicine has also been found to lower the risk of sudden unexpected death in epilepsy (known as SUDEP). It's estimated that over 1,000 individuals and families with TSC could benefit from access to cannabidiol in the UK, marking a major next step in TSC care.

Dr Pooja Takhar (TSA Joint Chief Executive) commented: "We're thrilled that people with TSC across the UK will now have access to cannabidiol, a potentially life-changing medicine for the 8 in 10 people in the UK who have TSC and also difficult to treat TSC-related epilepsy. Epilepsy can have a massive impact on overall quality of life for individuals and entire families, meaning that this approval could have a huge benefit to many people with TSC-related epilepsy."

This successful campaign was a long journey for everyone involved, but with a very positive ending. Our campaigns across all UK nations included the vital step of making sure that the TSC community, the most important representative of all, was heard loud and clear by decision-makers across the UK.

Thank you to everyone who spoke to us during the consultation and was involved in the process. It's only thanks to you that UK decision-makers understood the potential benefits that cannabidiol might have for some people with TSC-related epilepsy.

Facial angiofibroma medicine campaign continues

We were delighted to secure access to cannabidiol, but our work never stops

We got a 'Yes' for cannabidiol across all UK nations, but we've also been campaigning for access to another medicine – a cream that can help with facial angiofibromas (red bumps and marks on the face caused by TSC).

Around 9 in every 10 people with TSC will develop facial angiofibromas. These facial markings can have a major impact on a person's life, mentally and physically. Facial angiofibromas often bleed and can be painful, and can cause anxiety and low self-esteem.

A new cream made with the medicine sirolimus has been shown to reduce the size and severity of facial angiofibromas. We want to do everything that we can to make sure that people with TSC have access to this medicine.

Some TSC clinics already offer a sirolimus face cream, which they make themselves by crushing sirolimus tablets into an ointment. However, we're now campaigning for decision-makers to approve a new cream that is especially made for facial angiofibromas. Compared to the creams made by clinics, this new cream should be easier to use and have a much nicer consistency – some people find the clinic-made cream to be very gritty and they can't tolerate its use.

The first step of the campaign is to make sure that decision-makers understand the cream's importance. We've already submitted our report to them, which includes lots of views from the TSC community – thank you to everyone who shared their voice with us.

We're expecting a response to our report later in the year. We'll keep you updated!

Whether it's cannabidiol, a sirolimus cream or future new medicines, we'll never stop working hard for the TSC community so that you get access to important treatments.



TSC Rare Disease Collaborative Network

The NHS has given official recognition to our clinics network, a major step forward in TSC care

Rare Disease Collaborative Networks (RDCNs) are an important part of the NHS, giving clinicians who are focused on a rare condition greater opportunities to connect and learn. Recently, NHS England approved our application for TSC to get its own RDCN!



The approval means that all clinics who are part of the network will have a much stronger role and capability in:

- **Improving knowledge and awareness of TSC in the NHS.** More healthcare professionals will gain a better understanding of TSC
- **Standardising clinical and care pathways.** It should become easier to access TSC experts when in clinical care
- **Fostering greater engagement between healthcare professionals and the TSC community.** People with TSC and their families will have a louder voice

There will be an initial 15 NHS TSC clinics who are part of the TSC RDCN with opportunities for other clinics to join the network in the future. The TSA will continue to work just as closely with any clinics who are currently not part of the RDCN, ensuring that high standards of care continue to be met by all providers.

Clinics in the TSC RDCN will also be recognised as leaders in TSC diagnosis, care and management. Best of all, clinics from throughout the UK can benefit – even though NHS England gave the approval, clinics in Scotland, Wales and Northern Ireland will have just as much voice and will be just as welcome to be part of the RDCN.

Formation of the TSC RDCN is an important step forward in TSC care across the NHS, providing renewed hope and greater possibilities in diagnosis, care and management of the condition.

TSC training modules

We've launched the very first training modules focused exclusively on TSC for education and social care workers

On the TSA Support Line, we speak not only to individuals and families affected by TSC, but also professionals who are supporting people with TSC. This includes social workers, teachers and residential care workers, who want to do their very best for people with TSC.

To help these professionals feel more confident about TSC, we've launched special online TSC training packages. This will mean that TSC is better understood and that people with TSC can have healthier and happier lives.

Our first training modules are focused on training education professionals and social care professionals. They are the first training packages of their kind, anywhere in the world!

We've provided lots of training and ongoing support to social and education professionals in the past, with feedback always positive. However, this training was sporadic and not consistent. We wanted to do more, and offer something more structured so that as many professionals supporting people with TSC can benefit as possible. Our new training modules allow this to happen.

Our TSC training modules for social care and education professionals consist of five different modules. Each of these modules focus on a different area of TSC:

- An overview of TSC
- The brain and epilepsy
- TSC-Associated Neuropsychiatric Disorders (TAND)
- Other ways TSC can affect people
- Supporting individuals with TSC in education, Supporting individuals with TSC in social care

The modules are an important milestone in how we support the non-clinical professional community. We're even applying for the modules to receive Continuing Professional Development (CPD) accreditation, which will mean that the courses can be used as part of a person's official career progression.

If you know an education or social care provider who could benefit from learning more about TSC, direct them to tuberous-sclerosis.org/professionaltraining or you can speak to us on the TSA Support Line (support@tuberous-sclerosis.org, 0808 801 0700, [webchat](#)).

New TSA team members

The small TSA team is in the middle of an exciting time of recruitment. As part of this, we've been delighted to welcome Jan Burns (Head of Fundraising) and Amy Duncan (TSA Support Line Adviser)

“



Hello to the TSC community! I'm Jan and I've just taken over as Head of Fundraising for the TSA.

A little bit about me: I spent the early part of my career working in the financial services industry. A life-changing event took me on a journey into the world of fundraising. I've worked for a children's hospice charity, an adult care charity and a charity that supports disabled children and their families. Privately, I've raised over £130,000 for charities.

I personally understand first-hand how important charities are. I've been supported by a charity in memory of my little boy, I volunteer for a charity, and I'm a Trustee of a charity. I'm happiest when I'm making a difference to people's lives. From running and walking to skydiving, I'm always looking

for my next challenge. Fundraising isn't just my job, it's my passion.

Everyone at this wonderful charity is working tirelessly for the TSC community. But, as much as we're committed to helping you, we also need you to help us. This is the perfect time to look into fundraising for the TSA, to help improve the lives of people with TSC.

If you're thinking of a physical challenge, we've joined forces with Run for Charity and Ultra Challenge to offer a place at over 350 different events across the UK. From 5ks and funruns to marathons and even further distances, there's something for everyone!

Talking of stamina, I want to give a shout-out to the #TeamTSA runners taking on the London Marathon 2023. There's just weeks to go before the event itself on 23 April. As someone whose marathon days are long past me, I'm in awe of their dedication and commitment.

Not everyone enjoys physical challenges, but you can definitely get involved too! No matter what your skill or hobby is, if you've got an idea and want to turn it into a fundraiser, I'd love to hear from you. Please don't hesitate to contact me at fundraising@tuberous-sclerosis.org or check our website for tips and ideas.

I look forward to meeting many of you at the Outlook and Big Day events in April and May. In the meantime, if there's anything I can help with please get in touch.

”

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**Hi everyone! My name is Amy and I've joined the TSA as a Support Line Advisor.**

I've always worked in roles involving helping people. I worked for 7 years in the control room for a fire service. In this role I would take 999 calls, dispatch crews and coordinate responses to large incidents. Although challenging, taking 999 calls was extremely rewarding, I would speak with people during some of their worst or scariest moments and keep them safe. I left this job after I had my daughter and moved to the Midlands to be closer to my family.

My next role was coordinating projects at a local charity, which involved supporting vulnerable adults in the community. During this time, I worked with people and their families who were isolated as a result of

medical and mental health conditions, helping them to access services and get back into the community when possible. I also worked with a team of volunteers who did things such as befriending and shopping for those who were housebound. I really loved speaking with people who we supported, hearing their stories and supporting them where needed.

I have a daughter who is autistic, and we're on our own journey exploring whether there is a genetic condition causing other medical symptoms that she has. At times it's been challenging emotionally and practically, so I really empathise with other individuals and families who are on similar journey as us.

My spare time is spent with my family. My daughter is a great explorer, so we spend a lot of time outdoors with our dogs. We live close to a canal and a river, so we've just bought some paddle boards and are planning some more family adventures. I also love to read and crochet when I can. This year, I'm also hoping to become more involved with my local SEND community at their events and volunteering.

I'm passionate about ensuring that the TSC community is treated fairly and has access to great healthcare, education and activities.

I'm really thrilled to be a part of the TSA and I'm really looking forward to getting to know the TSC community on the support line and at upcoming events.

”

TSC Together group meetings

A new pilot project by the TSA is helping local TSC communities come together



Coffee, tea, cake and chats – what's not to love?! The TSA is launching TSC Together group meetings, a new way for you to connect with others who are affected by TSC in your local area.

We know from the TSA Support Line that many people want regular, informal, and easy opportunities to be with others in the TSC community. Balancing the need for these sorts of get togethers alongside larger meetings has always been a challenge for the TSA, due to our limited resources.

After much planning and discussion on how to create simpler opportunities for people affected by TSC to come together, the TSA has developed TSC Together group meetings. They give YOU the opportunity to organise and host your own events, all while connecting with the TSC community and raising much-needed funds for the TSA.

TSA Together meetings make smaller and more intimate meetings a possibility. Your TSC Together meeting can be whatever you want, wherever you want. As long as you have permission from the venue they can be held anywhere, such as a community hall, office or even a driveway.

TSC Together meetings don't need to be face-to-face. You might want to host your event online, giving you the chance to connect regardless of distance. Perhaps you could setup a regular book club, or focus on another passion?

How TSC Together group meetings work

1. Register your meeting, telling us things like where you're going to host it or if there's a specific theme or focus
2. Think about setting up a fundraising page for the meeting
3. We'll tell people about your event, giving them the chance to register
4. We'll then pass the details of people who registered over to you
5. Host your meeting, connecting with others in the TSC community



Through TSC Together, you have the power to host the sort of event that works best for you and your local area, whether it's a quick 30 minute catchup or something that lasts all day.

You might also want to make your TSC Together group meeting a closed group, such as one for your family, colleagues or other loved ones only. This would give you a great opportunity to tell them more about TSC so they can better understand the condition and the needs of people with the condition.

Although the events are community-driven, the TSA will be here to help you. We'll have lots of materials we can share to make your day as brilliant as possible. Whenever we have the chance to do so, we'll even do our best to come along ourselves.

To get started, you can join our pilot by heading to tuberous-sclerosis.org/TSCTogether. Or, get in touch with the TSA Support Line (support@tuberous-sclerosis.org / 0808 801 0700)

TSA events calendar 2023

We've still got lots of great events to come in 2023, with even more still to be confirmed!



Wills and future planning
(with The Monday Charity)
Wednesday 11 January
6pm – 7pm, virtual



TSC and pregnancy
(with Antenatal Results and Choices ARC)
Wednesday 22 February
6pm – 7pm, virtual

Rare Disease Day
Tuesday 28 February



TSC, epilepsy and the ketogenic diet
(with The Daisy Garland)
Wednesday 8 March
6pm – 7pm, virtual



Approaches to Behaviours that Challenge in TSC
(with Bath TSC Clinic)
Wednesday 13 July
6pm – 7pm, virtual

TSC drop-in session
Wednesday 20 July
5:30pm – 6:30pm virtual



Cardiff TSC Clinic catchup
Wednesday 9 August
6pm – 7pm, virtual



TSC, bullying and wellbeing
(with Changing Faces)
Wednesday 6 September
6pm – 7pm, virtual

Be sure to come to our special drop-in sessions, where you're encouraged to say 'Hello' and get to know others in the TSC community



April

April Outlook 2023
(for adults mildly affected
by TSC)

Saturday 22 April,
Leicester
10am – 4:30pm

London Marathon 2023
Sunday 23 April



May

Big Day 2023
(for everyone in the TSC
community)

Saturday 13 May,
Manchester
10am – 4:30pm

Global TSC Awareness Day
Monday 15 May



June

Belfast TSC Clinic
catchup

Thursday 15 June
6pm – 7pm, virtual

TSC drop-in session
Wednesday 29 June
5:30pm – 6:30pm virtual



Oct

St George's TSC Clinic
virtual catchup
Wednesday 11 October
6pm – 7pm, virtual



Nov

TSC drop-in session
Wednesday 1 November
5:30pm – 6:30pm, virtual



Dec

Outlook Festival
Special 2023
Saturday 9 December
1:30pm – 3pm, virtual

Register for TSA events through our website or by contacting the TSA Support Line

Outlook 2023

The ever-popular event for adults mildly affected by TSC is back for another year – this time, we're heading to Leicester on Saturday 22 April



10:00 – 10:30. Tea and coffee
10:30 – 11:00. Welcome and icebreaker
11:00 – 11:15. Update from the TSA (TSA staff)
11:15 – 12:15. All about Gestalt Counselling (Katie Eliot, TSC community member and Outlooker)
12:15 – 13:30. Lunch
13:30 – 14:30. Life as a TSC Researcher (Felix Chan, Lecturer in Neuroscience, Aston Pharmacy School)
14:30 – 14:45. Coffee break
14:45 – 15:30. Living with TSC (Corinne Swainger, TSC community member and Outlooker)
15:30 – 16:00. How the TSA can help you (TSA staff)
16:00. Thank you and close, group chats continue

Outlook is one of our most-loved regular events, where adults who describe themselves as mildly affected by TSC can connect and be with likeminded people from the TSC community.

With a history going back many years, Outlook has given countless people with TSC the opportunity to make new friends and be in a supportive and understanding environment. On **Saturday 22 April**, we'll welcome people to Outlook 2023 at the **Devonshire Place Conference Centre** in **Leicester**.

Outlook 2023 will include the chance to chat with the TSA, attend workshops, and speak with others mildly affected by TSC about the highs and lows of living with the condition.

We know that attending your first Outlook can feel daunting, and it's normal to feel anxious. However, everyone who comes to Outlook will be given a warm welcome, whether you've been many times or if this is your very first.

New for this year is the Outlook buddy system. If you're coming to Outlook for the first time, get in touch and we'll connect you with a longstanding Outlooker so that you can start to connect with people before the day itself (support@tuberous-sclerosis.org / **0808 801 0700**).

Register your place and find out more at: [tuberous-sclerosis.org /event/outlook-2023](https://tuberous-sclerosis.org/event/outlook-2023)

Big Day 2023

Our biggest event back at long last! Come along to the Ininside by Melia Manchester Hotel on Saturday 13 May

At Big Day, the doors are open to everyone in the TSC community. Whether you have TSC yourself, or you're a loved one of someone with the condition, or you support someone with TSC in your profession, you'll be in a space that understands TSC and welcomes you with open arms.

Confirmed talks and workshops so far include:

- Challenges and opportunities in the TSC community
- Past progress and the future direction of TSC research (Dr Chris Kingswood, St. George's TSC Clinic)
- Transition from child to adult care services (Catherine Swales, Evelina TSC Clinic)
- The Importance of Sleep (Kerry Davies, The Sleep Charity)
- An update on TSC epilepsy trial (Dr Sam Amin, Bristol TSC Clinic)



Most importantly, Big Day is an opportunity for the TSC community to come together, meet and connect in a welcoming environment. If you've ever felt isolated or disconnected from others that truly understand TSC, Big Day is an opportunity to be with likeminded individuals and families.

The TSA team is excited to finally hold Big Day after last year's event was postponed due to transport strikes. This is partly why tickets to this year's Big Day are completely free!

Big Day is a rare opportunity to be in a place with a range of TSC interests and where TSC is well understood. Register at tuberous-sclerosis.org/event/big-day-2023.

Ways to fundraise

"Hello to the TSC community! During my first few months with this amazing charity, I've been amazed at the wide range of ways that people choose to fundraise or give to us. We recently added even more fundraising options available to you, so we wanted to give you a recap on just some of these.

If you'd like to discuss any fundraising ideas or want tips and advice, you can speak to us at fundraising@tuberous-sclerosis.org or **0300 222 5737**."

Best wishes,
JAN (TSA HEAD OF FUNDRAISING)



Take on an event

No matter where you live in the UK, we've got an event for you!

We've partnered with RunForCharity, Ultra Challenge and Kiltwalk to give you access to over 350 local events. From 5k fun-runs and obstacle courses to marathons and ultra runs, there's something for everyone!

But, if there's nothing you fancy you can always do your own fundraising challenge.

We're here only thanks to donations and fundraising. There's loads of ways to give to the TSA and make a massive difference to people with TSC

Try your luck

Our weekly lottery gives you the chance of winning a £25,000 jackpot, all while giving back to the TSA. Tickets start at just £1! Head to tuberous-sclerosis.org/tsalottery.



Get your company involved

From a one-off fundraiser or donation, payroll giving, or a long-term partnership like Charity of the Year, having your workplace involved in supporting the TSA and people with TSC can be huge.



Do the can-can

A charity collection can, placed in a good location, earns on average around £100 a year. Placing and managing these cans in your local area could help to make a big difference!



Use your passions

Use a personal passion to raise funds! Something that you love or find joy in – whether that's gaming, crafting or something completely different – could be the key to unlocking a fundraising opportunity for the TSA.



Give in memory or celebration

Honouring someone's life, or marking a special occasion, are incredibly kind ways to give to us. Many people ask for donations instead of flowers, or instead of things like birthday presents.

These are just some of the countless ways that you could fundraise or donate to us. If you've got an idea, we guarantee that there's a way to give it a fundraising spin!



TSC stories: Annaliese Howard

Annaliese Howard is a talented illustrator who is mildly affected by TSC. Annaliese shared her experiences of TSC, including its impact on her mental health

My name is Annaliese Howard, I'm 23 years old. I was officially diagnosed with TSC in 2011 at 11 years old, after begging my mum to find out why the other children at school were bullying me for the way I looked. I was diagnosed with very mild LAM (a lung problem that affects around 3 in 10 women with TSC and some men) in 2022.

Nothing was really suspected until I was about 3 years old, when my mum noticed facial angiofibromas developing (that started as red freckles) along with white patches on my body. Doctors pieced these symptoms together along with a couple of little seizures I had as a baby and thought that I might have TSC. But, after a

follow-up when I was aged 5, they ruled out TSC as I was developing physically and mentally as normal with no further seizures.

I'm an extremely creative person and have been since I was little. I found my passion for illustration at the end of my GCSEs and decided to take Art & Design at sixth form and then further my studies at university in 2018, successfully graduating from the University of Lincoln in 2021 with an Honours degree. While I currently work part time in retail, I aspire to be a full-time illustrator, aiming to secure a tattoo apprenticeship in the near future and to one day publish my own children's books. I recently



Battling with the hospitals and GPs has been the biggest ongoing struggle with this condition. I have fought an awful lot getting appointments made, chasing departments, asking admin staff and consultants for feedback on test results

won the 2022 TSA Christmas card design competition with my Snowman & Turkey design which I am really proud of. Illustrating helps me focus and allows me to express my ideas and emotions to create art that other people can connect with and love.



Having this condition affects my mental health a lot. I suffer from high-functioning anxiety and depression which I got diagnosed with in 2020. Battling with the hospitals and GPs has been the biggest ongoing struggle with this condition. I have fought an awful lot getting appointments made, chasing departments and asking admin staff and consultants for feedback on test results. I have been ignored a few times when I ask for updates. This would be stressful for anyone, but when you have a condition like TSC, you can end up seeing quite a few consultant

specialists for various parts of the condition and it can become quite overwhelming.

Although I haven't had any major surgery yet, I have a large benign brain tumour (called a 'subependymal giant cell astrocytoma' or SEGA) that neurosurgeons have decided needs to be removed in the near future, so the anxiety of waiting to get a follow up can make my day a little extra stressful sometimes. I strongly believe that my mental health is the way it is primarily because of my health issues, but also because nothing seems wrong to the majority of people other than the way I look as I have no physical or mental disability. This can sometimes be awkward to deal with.

I would like others who have TSC or parents / carers of those who have loved ones with TSC to know that you are not alone and that a lot of people are going through the same emotions and hurdles that you are. If you have a passion for something then chase it – go to university to study your passion or apply for a job in your dream career field. You are just as worthy and skilled as everybody else. You can still live a full and happy life no matter how mild or severe your condition is.



I aspire to be a full-time illustrator, aiming to secure a tattoo apprenticeship in the near future and to one day publish my own children's books

Researcher in focus: Izzy Hyde

Izzy, granddaughter of TSA co-founder Anne Hunt, hopes to follow in Anne's significant footsteps in medical research. She plans to study biochemistry at university, and recently got to visit TSC research laboratories as part of a work experience placement

Izzy is currently in her final year of A-Levels and plans to study biochemistry at university. She told us about her recent experience of getting first-hand access to TSC laboratories and researchers in a work experience placement:

"The TSA means a lot to me and my family because my uncle James, who was born with TSC in 1971, had such an impact on his family and my grandmother. I never got to meet him as he died when he was 13. My grandmother Ann Hunt was so inspired by him, which is why she wanted to improve the lives of people affected by TSC. This led to her co-founding the TSA in 1977, as a way to help families and also increase awareness of TSC.

My grandmother died in 2014, and as I was so young we never really spoke about her research and work within the TSC community. I knew her as a very caring, intelligent and strong woman. It was only later, as my interest in biology and genetics grew, that I found out how instrumental she had been in TSC research. I find it a real shame that I never got the chance to talk to her about TSC and her accomplishments.

It was amazing to talk to TSC researchers, like Professor Tee, who had met my grandmother and sat next to her on a flight to an international TSC conference. To be able to get



IZZY AS A CHILD, WITH TSA LEGEND ANN HUNT AND ANN'S GRANDSON, JULES

to know this side of my grandmother and to feel closer to an uncle I never had the pleasure of meeting is something I'm very grateful for.

Being able to get into a lab with Dr Dunlop and Professor Tee was an amazing opportunity that gave me a taste of what my future in research could look like. I was able to deepen my understanding of TSC as a condition on a cellular level which really interested me in a biological sense. It also gave me the ability to explain the smaller details of my uncle's condition to my mother.

Interacting with PhD students and participating in their research was a nerve-wracking but enjoyable experience. Nerve-wracking because my skills weren't always golden, but it was enjoyable as it was the first proper lab I had ever been in. It was definitely very different to a school setting.

My placement let me develop skills with equipment and technologies that I'll take with me through university and beyond. I could clearly see myself being in the shoes of the researchers in the future, and to hear some of them had taken biochemistry for their undergraduate was quite affirming. It would be amazing to be able to take an active role in the TSC community to aid those like my uncle and other families."

In memory: Robert Woodthorpe Brown MBE

The TSA team was very shocked and saddened at the passing of Robert, TSA Vice Chair and a longstanding TSC advocate



ROBERT WOODTHORPE BROWNE MBE

For everyone who met Robert Woodthorpe Browne MBE, his name will evoke words such as hard work, determination, and great knowledge. For the TSA, Robert was central to the development and ongoing management of the charity, with Robert having a personal family connection to TSC and being involved with the TSA for many years.

A well-travelled business enthusiast who visited over 150 countries and was fluent in four languages, a conversation with Robert involved enthusiasm, dynamism, and passion for a wide range of topics and areas, including TSC.

Robert's commitment to helping the TSA overcome the various challenges of a small charity - in particular finances, governance and strategy - was always incredibly valuable. He'll be missed by everyone at the TSA and the TSC community.

Away from the TSA, Robert was a very well-respected businessperson and political head, in particular his many decades as a central figure in the Liberal Democrats and his role as Vice President of the Liberal International British Group. Across all his interests and ventures, Robert was never a passenger and always a leader, resulting in great success and very high respect.

Luke Langlands (TSA Joint Chief Executive) commented: "Robert was a central pillar to the TSA and the TSA Board of Trustees. It was always a privilege and a pleasure to be with and work with Robert, and we as a team learned a lot from him. Even now, and I suspect for many years to come, I think 'What would Robert do?' during key strategic moments for the TSA. The gap Robert's left at the TSA, and within everyone who knew him, is considerable".

The passing of Robert following a short illness has left the TSA with a feeling of great loss. Our thoughts are with Robert's family – including his wife Barbara and son Rob – and his very wide circle of friends.

Fundraising thank yous

We give thanks to some of the incredible fundraising taking place, allowing us to continue to be here for the TSC community

Marathon masters

A massive thank you and well done to **Steve Ford**, who took on a self-made marathon around Rosliston Forestry Centre in Derbyshire and raised an amazing **£1,165!** Steve's inspiration is his family friends and their daughter, who was born with the condition. In Steve's words: "Both knees gave up after nine miles, but I hobbled on regardless!"



It's that time of year again! Good luck to our amazing **London Marathon 2023 team**, whose efforts will make a massive difference to our work: **James Black, Hayley Grainger, Lewis Bastin, Duncan**



Warner, Jennifer Knaggs, Claire Felstein, James Harper, Daniel Marks, Sam Cooke and Chris King. Thank you again to the amazing people who took on last year's event, raising a fantastic **£10,300!** Donation page: **www.bit.ly/40lyV8e**.

A massive well done to **Sarah Bell**, who has set herself the epic fundraising challenge of completing a marathon a month throughout 2023! Sarah's smashed her first two marathons, with 'just' 10

more to go! Incredible work! Sarah was inspired to take on the challenge thanks to daughter Emi, who was diagnosed with TSC at just four months old. Donation page: **www.bit.ly/3X8gB5a**.





Thank you to every single one of our fab Facebook fundraisers. Whether you organised a fundraiser yourself or if you donated to another person's, your support is so appreciated. Many people do Facebook fundraisers for things like milestone celebrations, birthdays and anniversaries. Recent Facebook fundraisers include **Katie Vaughan, Kayleigh Burness, Aman Ahluwalia, Jurgita Bartkuvienė, Jennifer Seddon** and **Natasha Hodges**. Last year, Facebook fundraisers raised over **£6,000** for the TSA!



Thank you once more to avid TSA supporter **Linda Smith!** Linda's ongoing fundraising to us continues, including a recent fundraising bingo session at Needham Market Community Centre that raised **£300!** Thank you to Linda and everyone involved for your regular efforts.

Thank you to our Great North Run team in 2022, including



the brilliant **Muzzy Gün!** Muzzy took on the biggest half marathon in the world in honour of his five-year-old son, Emre. Muzzy raised a fantastic **£1,071!**

A massive thank you to **Ian Gould** and everyone at **Nuneaton Golf Club** for their incredible fundraising throughout 2022. Ian kindly chose the TSA as the team's charity of the year, with everyone at the club involved in many activities including an 80s fancy dress disco, casino night, dinner and dances, raffles and many more!



Their hard work paid off, with over **£9,000** raised to make a massive difference to people with TSC! Ian chose the TSA after his son, Charlie, was diagnosed as a child: "Choosing the TSA to benefit was an easy decision to

make. The TSA supported us as a family to learn about TSC and to understand the effect it has on Charlie's health."

It feels like a long time ago now, but we're still so pleased with your response to last year's festive cards. Thank you to everyone who purchased our lovely cards and other winter goodies – you helped to raise a brilliant **£2,485!**



Thank you to **Heathfield Riding Club** for your recent fundraising! The club made a donation to us following a charity event. Pictured is **Indi Adamski** who took part in the day. Well done Indi!



Towards the end of last year, we asked you to get involved once more with The Big Give. We hit our target for the second year running, with a brilliant **£8,000** hit that will go towards our support services in 2023!

Trusts and foundations

Thank you to the following trusts and foundations for their amazing recent support:

- Medical Research Council
- Dunn Family Charitable Trust
- Beechwood Trust
- Lorimer Trust
- The Reed Foundation
- Swann Morton Foundation

One of the most emotive and powerful ways that people choose to support us is through 'In memory' donations. Recent donations to celebrate someone's life include for the passing of: **Alice Dew, Amelia Kline, Audrey Colvin, David Stephen Smith, Graham Harker, Graham Smith, Maurine Youles** and **Robert Woodthorpe-Browne**. Thank you to everyone for their generosity.

If you've recently lost a loved one, you can use **MuchLoved.com** to setup an online tribute for free. You can also setup donations and many other tribute options.



Fundraising champion: Sam Cooke

Fundraising Champions are those who go above and beyond to fundraise for people with TSC

Sam Cooke is part of the incredible #TeamTSA at the London Marathon 2023. He told us about what's driving him to conquer the 26 miles and why the TSA is close to his heart:

"My niece, Avery, was born with TSC in 2019. The early signs began when Avery was only three months old. She began to startle in her movements and it wasn't clear what the cause was. Initially Avery was prescribed anti-reflux medication, but it didn't have any effect on her. Following discussions with Avery's auntie (my amazing wife) and some of her colleagues within the NHS we began to suspect this could be infantile spasms.

Avery's mum returned to A&E and persisted to get Avery the help she needed, again being told it was just a reflex startle. She battled to get Avery seen by a specialist. Eventually, Avery was given an MRI scan and the results changed our family's life forever.

Avery had two white masses on her brain, confirming TSC. Since the diagnosis, Avery has been seen by numerous professionals and specialists. Avery is on the autism spectrum and TSC has affected her development. She



Despite everything this little girl has gone through in four short years she is quite possibly one of the happiest and bravest people I've ever met

regularly has appointments with speech therapists, physiotherapists and other healthcare specialists. Avery undergoes regular MRI scans to monitor the growth and spread of the tumours.

Despite everything this little girl has gone through in four short years she is quite possibly one of the happiest and bravest people I've ever met. She takes everything in her stride and is progressing well. Unfortunately, TSC is a lifelong prognosis, so the family has to take one day at a time.

I began this journey to raise awareness and money for this amazing charity back in 2020, when I was originally due to run the London Marathon. However, due to covid the event was cancelled just weeks beforehand. This affected me mentally and I gave up with my training and myself... I'm ashamed of that. Avery doesn't have the opportunity to give up. She has to get up and battle every day, a true inspiration."

Everyone at the TSA thanks Sam for his incredible efforts, we've no doubt that his family and Avery are incredibly proud!

Donate here: <http://bit.ly/3kNAkKr>.

In loving memory

Graham and Georgina had major roles in the TSA's development

The TSA was saddened to hear of the loss of two people very close to the TSA. Graham and Georgina's families took the time to share their memories.

Liz Harker shared this about her husband, Graham Alan Harker (21/11/43 – 26/12/22):

"After the birth of our fourth child, James John, in 1978, Graham and I were devastated, like some readers of this issue of Scan may too have been, to learn that the seizures that James John had been having for the previous five months were due to the genetic condition Tuberous Sclerosis Complex.

From then onwards, Graham and I did all we could to support not only our beautiful son, but everyone and their families who have this life-changing diagnosis.

Graham, who was a solicitor, joined the TSA in 1979, headed at the time by Ann Hunt and Ester Galbraith. Graham soon became TSA Treasurer, and then Chairman. We made wonderful lifelong friends among the committee members and the families, especially around the local area where we live. Later, friends were made much further afield in places as far flung as Norway and New Zealand!

James John died in 1996, but Graham asked that any donations on his death should go to the Tuberous Sclerosis Association as it was so dear to his own heart."



David Medcalf shared this about his daughter, Georgina Claire Medcalf (11/05/76 – 12/12/22):

“Georgina had very intractable epilepsy, particularly when she was younger. When she was 20, she had a partial nephrectomy to remove a suspicious lump. The lump was harmless but she was left paraplegic.

Georgina spent the next 6 months in hospital and regained some function, able to crawl or even walk a bit with assistance. Her strength of character was described as “inspirational” by her carers, and someone said she was the happiest person in the hospital – and that included the staff!

Georgina had been in an excellent residential home since she was 19, but in 2003 the owners decided to sell up. Her mother Janet (TSA Support Services Coordinator at the time) had seen this coming and had prepared a professional plan that meant we were able to sort out the finances. Some of you will be aware that Janet passed away in 2006. With one month's notice we converted our new garage to provide a flat, and with the aid of direct payments recruited a team of carers.

This arrangement was the best thing that could have happened, as Georgina was now a 30 second trip away, instead of an hour! We were now able to be closely involved with her ongoing medical issues.

In 2008, Georgina was the recipient of one of my kidneys. The first time I saw her after the operation I was amazed. She had gone from



the rather sallow complexion of someone on dialysis to being pink! Miraculous!

The transplant lasted 12 years, but she was then once again back on dialysis. By this time her LAM had progressed and she now needed permanent oxygen but she coped with everything and was world famous at the hospital where she often brightened up the ward with her happy vocalisations.

Georgina was amazingly tough, amazing and inspirational. She is sorely missed by family and our amazing team of carers.”

We're here for everyone affected by TSC only thanks to the people and groups who kindly take the amazing step to provide us with donations.

**Help us to continue to be here for you and others:
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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