

# scan

**JULY 2019**

The magazine of the TSA

**Central support  
service to be  
introduced**

**New research  
strategy  
explained**

**Outlook 2019  
highlights**

**Global TSC  
Awareness Day**

**MOVING  
FORWARD  
AT THE TSA**

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

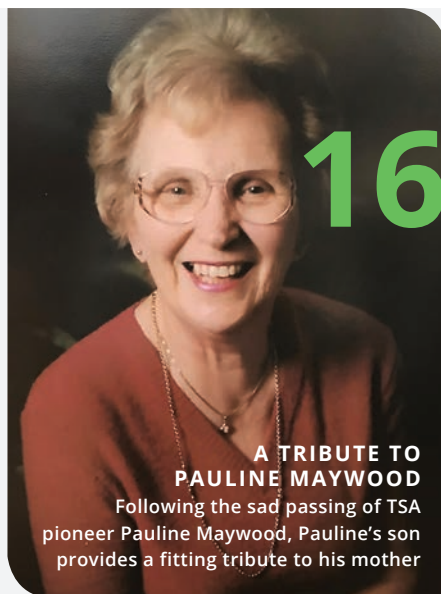
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**LUKE LANGLANDS, EDITOR**

# From the Editor

Summer is upon us and with it comes your latest issue of Scan for 2019, including a makeover for the magazine! We've worked hard to improve the look of Scan, so we can squeeze in and tell you about all of the brilliant things that the TSA and TSC community have been up to.

## Support and Information

**Rachael Wyartt**

(Head of Information and Support)

**Julie Rainer**

(Information Officer)

**Lynn Shields**

(Senior Adviser, Devolved Nations and Adviser, Scotland)

**Claire Kirk**

(Adviser, Northern Ireland)

**Ellie Russell**

(Adviser, Wales)

**Maureen Tossi**

(Senior Adviser, England and Adviser, London and South East England)

**Christine Beal**

(Adviser, North England)

**Kendra Rhodehouse**

(Adviser, Midlands)

**Melanie Feek**

(Adviser, South West England)

**Turn to page 6 for contact details of your local adviser.**

This is also the first issue of Scan that I have had the pleasure of being editor. I want to say a massive thank you to previous editor, Sarah Roberts, who was central to the success of Scan and other TSA communications over recent years. Many of you know Sarah well and I hope to get the opportunity to know you all too. I have already met some of you, courtesy of Outlook 2019 in-between the interesting talks and hands-on workshops! If you weren't able to make Outlook this year, we've got a reminder of what happened on the day on **page 10**. Hopefully, you can make it next year, where you'll be made very welcome.

One feature of this issue is on access to benefits that you might be entitled to. We know that many people in the TSC community can face problems in accessing benefits that are due to them, as navigating the complicated process of finding out about benefits and then applying for them can be difficult. On **pages 12 - 13** we have tried to help by outlining some of the most common benefits that you might be eligible for. Although not an exhaustive list, we have tried to give you a broad starting point that we hope will help.

We would love to hear your feedback on how the TSA is doing, including what you think about the new look of the magazine! Be sure to send us a message, either by email, post, phone or social media.

Here for you,

**Luke Langlands**, Editor

# A word from our Chair and Chief Executive

## HEARING YOUR OPINIONS IS OUR PRIORITY, NOW AND ALWAYS

**The TSA Board remains committed to providing services, investing in research and balancing the TSA's finances**

I joined the TSA thirty years ago and have watched the charity grow from a committed parent-led fellowship of friends into a highly professional organisation. Now and then, the TSA Board remains committed to providing services to support those affected by TSC today and investing in research to help those diagnosed in the future.

Our new five-year strategy continues the charity's pledge to provide help for today and a cure for tomorrow. Importantly, it also commits to balancing the TSA's finances by 2021. Having very positively invested in research in recent years, we now need to rein in expenditure and grow our income so that the charity is sustainable long-term.

As our new strategy rolls out, it is important to know how you are feeling. As the people we serve, we need to know how to best help you. Please get in touch to say what excites you, what concerns you and what isn't completely clear.

Moving forward, we want stronger dialogue between the charity and the TSC community. This is already starting to happen, with community members working with us to shape our Outlook and Big Day events. We will also be reaching out to you to help us shape our updated support services, to make sure they meet your needs.

By talking to each other more, we can make sure that the charity's limited resources focus on areas that make the biggest difference. The TSA recently celebrated our 40th anniversary as a charity. Our new strategy sets us off on the right footing for us to be here for you in the next 40 years and beyond.

With my best wishes, Martin



**MARTIN SHORT,  
CHAIR**

## CHANGE AT THE TSA IS DISRUPTIVE BUT WILL SECURE THE CHARITY'S FUTURE

**We always have the interests of the TSC community and the long-term sustainability of the TSA at our heart**

All activities at the TSA – from support services and fundraising to our events and research – are experiencing change (see pages 5, 7 and 20). These changes are in-line with our five-year strategy for 2019 to 2023, which aims to not only improve our services but also safeguard the long-term future of the charity.

As Chief Executive of this fantastic charity, it is my job to ensure that the interests of the TSC community and the long-term sustainability of the TSA are always at the centre of what we do. The changes mean we can continue supporting people affected by TSC, whilst investing in TSC research and reducing our spending so it is closer to our income levels.

As well as working hard to reduce our spending, we are also looking at how to increase our income. The TSA community does amazing work in raising funds for us and you can find out how to make a regular donation on the back page of Scan.

I know that change can be challenging and unsettling, and possibly even more so for individuals with learning difficulties of various kinds. We are committed to sharing timely information about what is happening and when it will happen, to help everyone who uses our current services know how to get the best from our new services – in particular, the change from a regional support service to a central support service (see page 7).

Ultimately, the changes we are making will mean we can better serve and reach the TSC community. I am so proud of what our charity has achieved in the past few years. I look forward to seeing the TSA emerge from 2019 as a stable, robust and modern charity that continues to support and fight for the TSC community for many years to come.

With my thanks, Louise



**LOUISE FISH,  
CHIEF EXECUTIVE**

# Updates from the TSA

## Welcome to our new board members and a heartfelt thank you to Philip

We are delighted to confirm that Jane Rogers, Annemarie Cotton and Dr Frances Elmslie have agreed to join the TSA's Board of Trustees.

Jane, a nurse for over 14 years, brings valuable experience of the TSC community, having been a key member of our Outlook event group for many years.

Annemarie, a long-standing fundraiser for the TSA, has been long involved with the TSA alongside her husband. Annemarie brings with her a strong professional background in the provision of information and support services for young people.

Frances offers deep insight into the workings of NHS England and clinical knowledge of TSC, with Frances working as a genetics consultant and TSC specialist at St George's University Hospitals NHS Foundation Trust.

The TSA's Board of Trustees is also saying a fond farewell to Philip Goldenberg, former Chair and Deputy Chair of the TSA. Philip had a key role in helping to lead the charity to its current strong position. Everyone at the TSA sends Philip a heartfelt thank you for all of his amazing work.

## New team members across the TSA

The TSA team is full of fantastic new talent (fitting in well with the already brilliant existing staff). New members include:



**RACHAEL WYARTT,**  
HEAD OF SUPPORT AND  
INFORMATION SERVICES



**DR POOJA TAKHAR,**  
HEAD OF RESEARCH



**CHARLOTTE STRAIN,**  
EVENTS AND COMMUNICATIONS  
ASSISTANT

## A new office and new possibilities, TSA headquarters have moved!

The TSA have moved offices! We are now settling in and the space is starting to feel like home.



**(LEFT TO RIGHT): TRUSTEES ROBERT WOODTHORPE BROWNE, JANE ROGERS, REV MARTIN SHORT (CHAIR) AND DR CHRIS KINGSWOOD CUTTING THE RIBBON AT OUR NEW HQ**



**GETTING SETTLED IN AT OUR NEW OFFICE. IMAGE COURTESY OF MIKE DODSON/VAGABOND IMAGES**

Our new address is: The Tuberous Sclerosis Association, Unit 93, Containerville, 1 The Oval, London E2 9DT. Our new switchboard number is: 0300 222 5737.

Our new offices started life as a shipping container, now converted into a great office space. The move is a very significant step for the TSA, offering the opportunity for up to four team members to regularly work together in-person.

## New website coming soon

We are busy working on providing you with a brand new website, which will be easier to navigate and full of up-to-date, original and regular content. The website is due to launch in the latter half of 2019, so keep an eye out!

## Updated look and feel

The TSA has been given a fresh and cost-effective new look, matching the ambitions of everyone at the charity. You should start to spot this new look more and more in the coming months.



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Lynn works Tuesday to Friday.

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# TSA Support Map

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# New central support line to be introduced

## TO HELP US REACH AND SUPPORT AS MANY PEOPLE AS POSSIBLE, THE TSA WILL LAUNCH A FREE AND CONFIDENTIAL CENTRAL SUPPORT SERVICE IN 2020

From early next year, anyone wishing to access our support services can do so through a free and confidential central support service, including a support line that will be open 9am – 5pm Monday – Friday. Although this means transitioning away from our current regional adviser setup, the new support service allows the TSA to deliver sustainable, consistent and high-quality support to the growing TSC community for many years to come.

Our regional adviser setup and the fantastic adviser team have been important to the TSA, particularly when our community grew to such a size that it was no longer possible for all members to be in direct contact with each other. The TSA now faces another milestone in how we engage with and support our community, with more people now expecting to access information and support online or remotely, rather than face-to-face.

One aspect of our current five-year strategy is to grow our services whilst responsibly managing outgoing costs to ensure long-term sustainability. The new central support service allows us to do this. However, although the new service will help us reduce costs, what is driving the change is the desire to deliver a robust and easy access support service.

Face-to-face support will draw to a close, but the availability of our support team on a day-to-day basis will increase for most people. Introducing the support line will also mean that our support service is more balanced. Currently, the level of support that we offer depends on a community member's location. With the support line, everyone who contacts our support services will have access to every support service adviser, regardless of where they or the adviser is based.

In making the decision to move to the new support service, we consulted with professional bodies and charity organisations who successfully run support services similar to the one we will launch. This gave us encouragement and confirmed that this move is the right decision for the TSA. Every member of the TSA Board who looked at the support line proposals and scrutinised them in detail was convinced that this was the right path to take.

We want to get this major transition right. We want to work with you to make sure that any disruption or confusion about changes to our support service is minimised. If you have any questions, concerns or would like to be involved in a pilot scheme of the support line, please get in touch.

### Help us shape the new support line service – join our pilot scheme

Your help in implementing our new support line service is vital. Towards the end of 2019, we will run a pilot of the new service to help ensure that when the service launches it is able to serve the TSC community as effectively as possible. The more information we gather from the pilot, the better the support line service will ultimately be.

To take part, contact Rachael Wyartt (Head of Support and Information Services):  
[rachael.wyartt@tuberous-sclerosis.org](mailto:rachael.wyartt@tuberous-sclerosis.org) /  
 0300 222 5737.

### How will I access TSA support services from next year?

For many people, accessing our support services from 2020 will stay similar. Fully trained advisers will be available from a free and confidential support line 9am – 5pm Monday – Friday. You will be able to call, email, write in or send a message online.

What you talk about will be confidential. You will be free to talk about any TSC-related issue in a safe environment, such as a recent diagnosis, outreach for emotional support or help with filling out benefits forms.

You won't need to 'start fresh' every time you contact our support services. With your permission, a personal and confidential record of your situation and any issues that you have contacted us about will be logged, accessible by the support line team only. This means that when you contact us, the adviser will already have some insight into your situation. Contact can also be anonymous, if preferred.

# News

## THE LATEST TSC NEWS UPDATES FROM AROUND THE UK

### Easy read version of TSC guidelines summary

Earlier in the year, the TSA launched a summary of the first ever UK clinical guidelines for TSC [see Scan Spring 2019 and our website]. Following on from its success, the TSA are now developing an easy read version of the summary, which will be launched in late summer 2019.

### Free training sessions on disability assessments in Wales

As part of their What Matters to Me project, Learning Disability Wales are offering free training sessions and an easy read guide on how assessments for care and support work. The training and guide are aimed towards people with learning disabilities. <https://bit.ly/2Ek9cui>.

### Updated Blue Badge rules for England

New Blue Badge rules in England are to come into force on 30 August 2019. Automatic entitlement to the Blue Badge will be extended to those in England who score 10 points in the Personal Independence Payment (PIP) mobility test. This follows an announcement last year, when the government confirmed its intention to expand the Blue Badge rules in England to make it easier for people with hidden disabilities, such as autism, to qualify.

### Personal care rules improved in Scotland

New rules in Scotland mean that anyone who is assessed and demonstrates a clear need for personal care can now receive support regardless of their age, condition, capital or income. Previously, free personal care was available to the over-65s only.

### New report shines light on children and young people with a rare disease

Rare Disease UK have published the report 'Understanding Children and Young People's Experiences'. The report aims to highlight what it is like to be a child or young person affected by a rare disease. Key findings of the report include that children affected by rare diseases are adaptive and resilient, not seeing their rare disease as a fundamental part of their lives. <https://bit.ly/2KDCOGH>.

### Self-directed support in Scotland survey

My Support My Choice, a joint project between Health and Social Care Alliance Scotland and Self-Directed Support Scotland, are asking for participants in a survey looking at how self-directed support (SDS)

is working in practice with social care users across Scotland. <https://bit.ly/2X4QjWA>.



### TSA campaign nominated for communications award

The TSA's Everolimus for Epilepsy campaign was nominated in the Excellence in Communications category at the Communiqué Awards 2019! Communiqué celebrates great healthcare communication campaigns from the calendar year. The TSA has dedicated the nomination to the TSC community, whose hard work made the campaign a success.



### Toolkit released for new rare disease diagnoses in Scotland

Genetic Alliance UK have produced a helpful toolkit for Scotland-based families who are just beginning their rare disease journey. The toolkit contains information on different conditions and advice on how to access reliable information, care and support in Scotland. <https://bit.ly/2ZjSh2G>.



## Cases of autism on the rise in Northern Ireland

The number of children being diagnosed with autism in Northern Ireland has more than doubled in the last five years. Healthcare professionals and autism charities have pointed to increased awareness of autism as a reason for the jump, with autism charity Autism NI saying that they have been “inundated” with requests for support. In total, 2,345 children under 18 were diagnosed as autistic in 2018, compared with 1,047 five years previously.

## Older people who receive PIP no longer regularly reviewed

People who receive PIP and are at state pension age will no longer be regularly reviewed for the benefit, with a “light touch review” instead taking place every 10 years.

## Survey participants needed for study into caring for young people with emotional outbursts

The Stay Calm Project, in association with the University of Birmingham, is seeking parents and caregivers of individuals aged between 6-25 years that have emotional outbursts at least once a month. Participants will be asked to test a new anonymous online questionnaire, so that researchers can test its accuracy in measuring emotional outburst characteristics. <https://bit.ly/2Ksf09A>.

## Belfast cafe gives opportunities to people with learning difficulties and autism

A new Belfast cafe is to provide work experience opportunities for people with learning disabilities and/or autism. The cafe, called ‘Orchard @ The Grove’, will open next month as a result of a partnership between local charity Orchardville and Belfast leisure centre operator GLL. Orchardville will run the new cafe and use it to provide training and work experience to people who have a learning disability and/or autism.

## Genetic Alliance UK Chief Executive elected to EURORDIS board

Genetic Alliance UK Chief Executive and former TSA Chief Executive, Dr Jayne Spink, has been elected as board member to the European rare disease group EURORDIS. The appointment means that Dr Spink will be able to represent Genetic Alliance UK issues on an international scale. The TSA is a member of Genetic Alliance UK, with a long-standing connection between both groups.



## Positive phase-three results for cannabidiol in people living with TSC-related epilepsy

GW Pharmaceuticals have reported positive phase 3 pivotal trial results for Epidiolex®, a cannabidiol oral solution, in patients that have seizures associated with TSC. The trial results for different dose groups were similar, with seizure reductions of 48.6% and 47.5% from baseline respectively, vs 26.5% for placebo. The trial was conducted at more than 40 clinical sites in more than 6 countries. Full results of the study are expected later in the year.



## Mental health and learning disability patients in Wales transferred to England hospitals

The Royal College of Psychiatrists in Wales has highlighted that, last year, around 30% of 1,000 mental health and learning disability patients based in Wales were placed into hospitals in England “needlessly”. The Welsh Government responded by saying that the number was decreasing, with only “very specialist centres in England” being used for Wales-based patients.

# Outlook 2019

## EARLIER IN THE YEAR WE HELD OUTLOOK 2019, OUR ANNUAL EVENT FOR ADULTS MILDLY AFFECTED BY TSC. HERE, WE LOOK BACK AT WHAT WAS A BRILLIANT DAY!

Outlook is one of the TSA's most important and fun events of the year, where adults mildly affected with TSC come together to make new (and meet old) friends, share experiences about TSC and attend interesting workshops. This year we were in Bristol, with familiar faces and new Outlookers alike joining in on the day!

Outlook kicked off with an introduction from the TSA, followed by a fantastic session from Gerwain Wilson on living with TSC. Gerwain's inspirational stories echoed the experiences in the room, with many people living with TSC sharing the same challenges and breakthroughs as Gerwain. Prof Julian Sampson (Cardiff University) then gave everyone a chance to learn more about some of the latest TSC research and clinical work happening around the UK, including the new guidelines on diagnosing, treating and managing TSC in the UK.



GERWAIN WILSON AND HIS LIVING WITH TSC SESSION



ADAPTIVE MARTIAL ARTS

In the afternoon, a group discussion was held about some of the changes happening at the TSA, including the introduction of a support line (see page 7) and the updates to our website. Afterwards, Outlookers got to hear from Adaptive Martial Arts about how learning martial arts, regardless of ability, can help with personal empowerment and control. Things then got more hands-on, with a chance to even try some martial arts on the day! Outlook 2019 then finished off with a creative artworking session, called 'See Me, Not TSC', courtesy of art group Creative Connection.

Couldn't make Outlook this year? Check our Facebook page to see films from the day. We hope to see you next year!



VISUAL MINUTES CAPTURING THE DAY'S MAIN POINTS



THE OUTLOOK 2019 GANG!



CAROLINE CASSWELL OF CREATIVE CONNECTION, GEARING UP FOR HER ART SESSION



We got an extra bit of special news the day after Outlook 2019, with Adaptive Martial Arts winning the Business Award for Disability at the Bristol Diversity Awards 2019! Well done to Gina and the team!

# Upcoming TSA events

**We still have some fantastic TSA events to come in 2019 all over the UK. Whether you come to these events every year or you fancy coming for the first time, you'll get a warm welcome!**

Would you like to help us organise any of our events? We would love to hear from you! All ideas and voices are welcome, to ensure that our events best represent the needs and interests of the TSC community (see page 3 for contact details).

## Family Fun Day (27 July, Chester Zoo)



The perfect opportunity for families and children affected by TSC to get together for a great day out! Connect with other family units who understand how TSC can affect lives, in a relaxed and easy-going atmosphere where the kids can enjoy themselves.

## Scottish Get Together (31 August, Queen Elizabeth Hospital, Glasgow)

A chance for Scotland-based members of the TSC community to meet and listen to a range of informative TSC-related presentations and interactive sessions, all with a Scotland focus. Confirmed speakers so far include Family Fund and the Scottish Association for Mental Health.

Book your free tickets via Eventbrite here: <https://bit.ly/2x4T1g4>, or contact Lynn Shields (TSA Scotland Adviser): [Lynn.Shields@tuberous-sclerosis.org](mailto:Lynn.Shields@tuberous-sclerosis.org) / 01236 608257.

## Welsh Info Day (28 September, University Hospital of Wales, Cardiff)

Get to know your fellow Wales-based TSC community members! Learn about how the TSA can support you, hear from external speakers on TSC topics and share your stories on how TSC can affect individuals and families in Wales.

Ticket information will be shared soon. For more information contact:

Ellie Russell (TSA Wales Adviser): [Ellie.Russell@tuberous-sclerosis.org](mailto:Ellie.Russell@tuberous-sclerosis.org) / 0300 222 5737.

## Big Day (2 November, Nottingham Belfry Hotel)

Our biggest event of the year! Big Day is our chance to gather everyone in the TSC community from people living with TSC

and their loved ones to clinicians and academics – to share experiences, learn about and work together on improving the lives of those affected by TSC.

We are hoping that this year's Big Day will be the most attended yet! You can expect:

- Keynote speakers, hands-on sessions and helpful workshops
- Talks from external speakers and groups about TSC-related conditions
- An opportunity to hear from and talk with clinicians about TSC research
- A focus on getting the TSC community together to talk about living with TSC

Ticket information will be shared soon. For more information, contact:

TSA Events and Communications team: [comms@tuberous-sclerosis.org](mailto:comms@tuberous-sclerosis.org) / 0300 222 5737.





# Accessing benefits: where to start

Many people in the TSC community could be entitled to different benefits. However, the steps to find out if you are eligible for a benefit and then applying for it can be complex. To help you navigate the often confusing and bewildering world of accessing benefits, we have provided a quick run-down of what you might be entitled to.

## WHERE TO FIND MORE INFORMATION ON BENEFITS AND SUPPORT

### Government information

- UK Government website ([www.gov.uk](http://www.gov.uk))

### Independent advice

- Citizens Advice ([www.citizensadvice.org](http://www.citizensadvice.org) / 0344 411 1444)
- Advice NI (Northern Ireland only) ([www.adviceni.net](http://www.adviceni.net) / 0808 802 0020)

### Other charities

- Turn2Us (<https://www.turn2us.org.uk>)
- Contact ([www.contact.org.uk](http://www.contact.org.uk) / 0808 808 3555)
- Disability Rights UK ([www.disabilityrightsuk.org](http://www.disabilityrightsuk.org) / 0330 995 0400)
- Scope ([www.scope.org.uk](http://www.scope.org.uk) / 0808 800 3333)



Remember that completing benefit forms takes time and should not be rushed. If you need extra help, contact the TSA's regional advisers who will be happy to guide you (see page 6).

## CHECKING WHAT SUPPORT YOU MIGHT BE ELIGIBLE FOR

A great first step to find out what benefits you might be entitled to is to fill out an online benefits calculator, like the one by Turn2Us (available here: <https://bit.ly/2G2eKIO>).

## DISABILITY BENEFITS

### Disability Living Allowance (DLA) for children

The main benefit for disabled children under the age of 16. DLA is divided into two parts: care and mobility. Your child may get one or both of these components, depending on their circumstances. DLA is not means tested.

### Personal Independence Payment (PIP)

The main benefit for disabled adults aged under 65. If successful, PIP can be a passport to other benefits or financial help. PIP is not means tested.

To claim PIP, you must have difficulties with daily living and/or getting around. PIP has replaced the old Disability Living Allowance (DLA) for adults. Adults receiving DLA are being gradually asked to claim PIP instead.

PIP is divided into two parts: daily living and mobility, with each paid at either standard or enhanced rates. The amount you receive depends on how your condition affects you, not the condition itself.

You might need to attend a face-to-face interview with an independent health professional as part of the claim process.

### Attendance Allowance (AA)

For people aged 65 or over who need help with personal care or keeping safe. AA is not means tested.

There are two rates of AA. The lower rate is paid if care is required during the day **or** night. The higher rate is paid if care is required day **and** night.

There is no financial help with AA for mobility difficulties. To claim AA, you must not be receiving DLA for adults or PIP.

## CARER BENEFITS

### Carer's Allowance

For people aged 16 and over who regularly spend at least 35 hours a week, including weekends, caring for someone. You do not have to be related or live with the person that you care for.

Carer's Allowance can affect other benefits that you or the person you care for receives. It is important to get advice before you apply.

If more than one person provides care, only one of them can apply for Carer's Allowance. You do not get paid extra if you care for more than one person.

Carers in Scotland who receive Carer's Allowance might also receive a Carer's Allowance Supplement. This is an extra payment, paid twice a year.

### Carers Credit

Helps with gaps in your National Insurance record, if you are caring for someone for at least 20 hours a week but do not qualify for Carer's Allowance. This means that you can take on caring responsibilities without it affecting your ability to qualify for the State Pension.

## WORKING AGE BENEFITS

### Universal Credit (UC)

For people who are on a low income or currently out of work, to help with living costs. If you currently receive certain benefits you cannot claim UC at the same time.

Whether you can claim UC depends on where you live and on your circumstances.

If you cannot claim UC due to your situation, you might be able to claim Income Support to help with basic living costs.

### Employment and Support Allowance (ESA)

Financial support if you are unable to work, or need help to find work, due to illness or disability.

Your claim will involve several stages and a Work Capability Assessment to assess your ability to work.

There are three types of ESA. Which ESA you might be eligible for depends on the area in which you live and your personal circumstances.

## BENEFITS TO HELP WITH HOUSING COSTS AND BILLS

### Housing Benefit

Help to pay your rent if you are unemployed, on a low income or claiming benefits. It is being replaced by Universal Credit but may still be available under certain circumstances and in some areas of Northern Ireland.

### Discretionary Housing Payment

Extra temporary payments from your local council to help with housing costs.

### Council Tax Discounts and Exemptions (England, Scotland and Wales only)

Your property or household circumstances may mean that you are eligible to receive a discount or an exemption. This includes:

- Someone who has 'severe mental impairment' (this may include some people living with TSC) and is in receipt of certain benefits
- Someone who is a carer

### Disabled Facilities Grant (England, Wales and Northern Ireland only)

You might be eligible for a grant from your local council if you are disabled and need to make changes to your home because of your disability. This could include adapting a room, installing a stairlift, improving access or changing the lighting or heating system.

### Scheme of Assistance (Scotland only)

In Scotland, councils are required to give grants for repairs, improvements and adaptations that are essential to make the home accessible for a person with disabilities.

# Community stories: An adventure in Borneo

Katie Vaughan recently had a once in a lifetime trip to Borneo. Determined that TSC and epilepsy weren't going to stop her enjoying an exciting adventure, Katie told us all about heading to the other side of the world to experience a new culture!

I decided to take the opportunity to go to Borneo because it was an optional module for my course at university. I study BSc Biology and I'm due to graduate this year! I thought I may never get the opportunity to go on this type of trip again, so I filled in an application form as soon as I could. I love wildlife and I wanted to experience a different type of environment and culture in another country, by staying at a research centre in the middle of the rainforest. To my delight, I was chosen, along with 25 others, based on how good our grades were and how well we filled out the forms.

Although I have epilepsy and some tumours because of my TSC, I didn't want this to stop me from going. My family were worried at first – I'd never been that far away from home – but once they found out I'd been chosen to go they were really supportive.

I went on the trip with my university friends who are on the same course as me. There were also a few lecturers and rainforest guides who knew a lot about the area and the animals we were going to see.

I had to have lots of vaccinations. This was quite stressful at times because the GP and travel nurses didn't understand TSC and, as I have a fear of needles, I was very nervous.

A few months before going on the trip, I sent an email to the lecturers who were coming with us to make them aware of my TSC. They were very understanding, and I had some lovely replies to the email, which was encouraging and made me feel less anxious. These kind responses have helped me feel more confident telling people about my TSC and sharing with others has helped me to accept my condition.

The day before my trip, I was very excited but also quite nervous. The flight was 14 hours long. We stopped in Kuala Lumpur and then we travelled to Kota Kinabalu in Borneo, where we visited some amazing mangroves. We then made our way to Danum Valley Field Centre,

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KATIE VAUGHAN





a huge conservation area in the heart of the rainforest. I was very tired due to jet lag. The accommodation was very basic, with no electricity after 11PM, no hot water and a 20-minute walk to the food hall.

Waking up in the rainforest is an amazing experience – at that time in the morning, there's a low mist, and the sound of chirping insects and rain is never ending. There was a range of wildlife close to the field centre – macaque monkeys, orangutans, deer, bearded pigs, monitor lizards, insects and more.

One of the best moments was seeing some Bornean Orangutans, which was a rare and wonderful experience.

We went on lots of walks, trekking through thick trees and bushes. One day, we went to a local village in the mountains – the locals greeted us in ceremonial clothes and performed a dance for us. We all joined in with the dancing, which was lots of fun! Then we walked a few miles down steep hills to some beautiful waterfalls. Sometimes I struggle with walking long distances, but I managed really well, even though it was so hot and humid!

The climate in the rainforest was different to anything I've experienced before – one minute the sun was very intense and the next it was pouring with rain!

We also went to the nearby Gaya Island, where we did lots of snorkelling. I was a bit worried that my epilepsy would be a problem, but after speaking with the instructors it didn't hold me back. I had an amazing time, seeing the tropical fish on the coral reefs, and I was able to enjoy the same experiences as the rest of the group.

We visited Kota Kinabalu which is more of an urban area. I went shopping and bought some gifts for my family and a bandana for myself. I have a scar on the top of my head from brain surgery a few years ago to remove a SEGA, so I have a collection of bandanas from around the world!

I think the experience was incredibly humbling and eye-opening. It made me appreciate what we have in the UK.

It has also helped me with my fear of needles because of all the vaccinations I had to have, so next time I need to have a blood test at the hospital, I'll be a bit calmer.

I now feel more ready to go on future trips to exotic places. I was worried at first because I'd be so far away from home – not being in contact with my family and friends at home every day made me feel anxious. But I met some interesting people, and everyone was friendly and supportive, so I have overcome this.



# A tribute to Pauline

**Everyone at the TSA was very sad to hear of the loss of Pauline Maywood, a TSA pioneer who helped to shape the charity. Pauline's son, Paul Maywood, provided a fitting tribute to his mother:**

"I was diagnosed with Tuberous Sclerosis Complex at the age of five by Dr Trevor Mann at the Royal Alexandra in Brighton. My mother cared for me from seizure onset at seven weeks until I was aged eleven and admitted to Young Epilepsy (formerly Lingfield Hospital School) where I first met the late Steve Dale [see Scan Spring 2019 and our website for a tribute to Steve].

I left there at the end of April 1971 to attend Chalfont Centre for Epilepsy (Society for Epilepsy) in Chalfont St Peter, Bucks, for drug assessment, seizure monitoring and its therapeutic work centre for 2.5 years. I had another three-month spell there in 1975 and since January 1976 I have been in full employment up to the present day with a hygiene company. My mother retired in 1990 as an officer-in-charge at a care home and went on to work with the elderly for a further nine years. Mum was adamant that her knowledge of many forms of dementia would make her immune to the condition. Sadly not.

Before leaving Young Epilepsy (to use its present name), I had been earmarked to be admitted to an institution in Surrey that eventually closed down. My parents and I went to an open day there and that visit has stayed with me, it looked similar to Colditz Castle which I saw for myself as part of a Dambusters tour in 2010. Thankfully, my mother and father (care assistant and police sergeant respectively at the time) put their collective feet down and I was not sent there. I will always be thankful to my mum and dad for their insistence that I not be admitted.

Moving on to 1978 and the formation of the TSA. My late mother attended the first ever TSA Annual General Meeting at The Children's Centre, Wakley Street, London. Mum later assisted in coffee mornings on some occasions and in 1999 was the co-organiser of a charity football match where a TSC United team took on Arsenal Ex Pros and celebs from the Arsenal Charitable Trust and beat them 8-4. In 2005, my mother's special birthday raised £275 on top of £720 by me in the Hastings Half-Marathon in March of that year.

On one occasion, my mother also spoke about Tuberous Sclerosis Complex to a group of doctors. My mum came up to watch me complete the London Marathon for the TSA in 2009. Following this, my mum also attended a Rotary Club Presentation Dinner, receiving a cheque on behalf of the TSA."



PAULINE MAYWOOD



PAUL (FAR LEFT) AND PAULINE (MIDDLE), RECEIVING ANOTHER TSA CHEQUE!



PAUL (MIDDLE-LEFT) AND PAULINE (RIGHT) AT THE TSC UNITED VS ARSENAL PROS CHARITY MATCH



# TSC communities worldwide come together for Global TSC Awareness Day

**Global TSC Awareness Day (15 May) stands as a landmark day for the entire TSC community to raise awareness of the impact that TSC can have on individuals, families and communities. For Global TSC Awareness Day 2019, Louise Fish, Chief Executive of the TSA, discussed how sharing our individual stories about TSC at any time of the year can help push forward the global agenda on improving the lives of people affected by TSC:**

“Every May, Global TSC Awareness Day gives us the opportunity to raise the public profile of TSC worldwide. For the one million people who are affected by TSC globally and their loved ones, Global TSC Awareness Day is often a time of reflection, with many looking back at what living with this diverse condition means to them.

Although everyone affected by TSC experiences the condition differently, the entire TSC community shares a common understanding of the impact that TSC can have on daily life. Yet, outside of the TSC community, knowledge of the condition and what it means to be affected by TSC is less well known.

As is common across all rare diseases, the real-life stories of people who have first-hand experience of TSC are often forgotten. That is why, for this year's Global TSC Awareness Day, the TSA would like to thank everyone – from people living with TSC and their loved ones to the medical professionals and researchers who work with them – for any time that they have shared their personal accounts of how TSC has affected them.

Learning about the daily lives of those affected by TSC helps the wider world see the people behind the condition. It reminds those not part of our community that people living with TSC are not statistics or figures on a piece of paper, but real people and families living full lives whilst facing difficult and unique challenges every day. Only by speaking about our experiences can we highlight the impact that being affected by TSC can have, allowing us to illustrate the importance of identifying ways to improve the lives of the TSC community now and in the future.

By sharing our experiences of TSC, it also means that more people can be brought into the TSC conversation. This can include individuals and families facing a diagnosis of TSC for the first time, researchers seeking ways to make a significant difference to our understanding of TSC, and members of the broader public looking to support an important cause.

What does TSC mean to me? As Chief Executive of the TSA, it is an honour and a privilege to serve the incredible TSC community. Witnessing the bravery, passion and enthusiasm of the TSC community drives myself and everyone at the TSA to do everything that we can to improve the lives of those affected by the condition. We have made some fantastic progress over recent years across awareness, support and research into TSC, but we need to continue to push the TSC agenda forward on a global stage if we are to keep up this fantastic momentum.

By sharing your experiences – including the harder times, obstacles and moments of hope – you can help us to paint a picture of the people who make up our wonderful community.”

- Louise





# On-site at the International TSC Research Conference 2019

**The TSA research team attended the International TSC Research Conference 2019 in Toronto. Here, Bethan Vaughan (Research and Evidence Officer) shares her highlights of the fantastic conference.**

The TSA research team set off from London on Wednesday 19 June, full of excitement for what the next few days would hold. After seven hours on a plane, we touched down in Toronto and wasted no time, heading to a gathering with members of Tuberous Sclerosis Complex International (TSCI), of which the TSA is a member.

There were 37 individuals from 25 different countries at the TSCI meeting, all working for patient organisations like the TSA. I was inspired and emotional to learn that most of the members, like me, had a personal relationship to TSC. The next morning, we were up bright and early for another TSCI workshop in the run-up to the first session of the main conference. At the workshop, we discussed a range of important topics, including the 2012 global TSC clinical guidelines, TSC clinics and early diagnosis. I was delighted to discuss the TSA's summary of the UK's first clinical guidelines on TSC. One of the main discussions was how patient organisations could help towards the proper assessment of TSC-Associated Neuropsychiatric Disorders (TAND), with a suggestion being to raise awareness that TAND symptoms require attention, treatment and/or therapy – in other words, just because something can be a symptom of TSC, it doesn't mean that you have to suffer in silence without treatment for it.

The first session of the main conference kicked off with a community speaker who lives with TSC. The speaker explained that she was “one of the lucky, unlucky ones”. She is a perfect example of someone who doesn't let their TSC define them, learning to accept and live with her condition. The speaker recently graduated from university and was now sharing her experience of living with TSC in front of 200 people. What an inspiration!



**DELEGATES VIEWING POSTERS FROM RESEARCHERS AT THE CONFERENCE**

The conference moved onto presentations about LAM and the skin, hosted by TSC-experts including Dr Thomas Darling (dermatologist) and Dr Kevin Ess (neurologist). I was truly inspired by the time and dedication that they put into their TSC research.

In the evening, we were treated to a range of inspirational speeches from different people in the worldwide TSC community, including Kari Luther Rosbeck (Chief Executive of the TS Alliance, a US TSC charity) and Dr David Franz (neurologist), with Dr Franz giving a detailed account of the journeys of some of his TSC patients.

Day two started with presentations on stem cell research and the use of cannabidiol (CBD) in TSC. Delegates then moved into smaller groups, discussing the genetic diversity of TSC and clinical trial designs for TAND. It was agreed that there is a need for 'virtual' TAND trials conducted from home, without the need of traveling to a clinic.

An exciting session later on day two had researchers give one-minute explanations of their new studies, with the work then presented around the conference centre. I even had an in-depth conversation with the co-chair of this year's Young Investigators Symposium, what a wonderful evening to make vital connections!



**DR CHRIS KINGSWOOD (TSA PRESIDENT)  
PRESENTING AT A TSCI MEETING**

The final day of the conference arrived far too soon, as we were all learning so much. It began with a talk from a parent, who took us on her TSC journey by introducing us to her teenage son and his adorable seizure dog. The family's positivity was inspirational – both parents had left their jobs to work for the TS Alliance after their son's diagnosis and their young daughter is an aspiring TSC researcher!

A parallel session for families ran at the same time, led by TS Canada. This included an overview of TSC, an explanation of epilepsy and a meet and greet with TSC experts.

The final session included a joint panel discussion: *The future of clinical trials in TSC*. Attendees discussed starting trials of mTOR inhibitors in infants as soon as they're diagnosed, in order to try and halt the progression of TSC altogether or to at least to reduce its severity. Attendees then talked about how research should focus on greater inclusion for ethnic minorities, the need to prioritise TAND research, TSC registries and new therapies to improve the quality of life of individuals and families affected by TSC. Everyone agreed on the need for everyone involved in TSC research to communicate more globally, not only to help raise awareness of the condition but to also allow the sharing of research, data and evidence with others worldwide.



I hadn't anticipated the overwhelming emotion, feeling of community and understanding that was shared by the hundreds of registered attendees at the conference. We were all united by the same passions and we were all there for the same reasons – to fight for people affected by TSC, raise awareness of the condition and ultimately find a cure. I already can't wait for the International Tuberous Sclerosis Complex Research Conference 2020, which the TSA will be proudly hosting in London!

# New research strategy at the TSA

**The TSA has introduced a new research strategy, so that every penny and pound invested in research works hard to improve the lives of people affected by TSC.**

The TSA is proud of our position as a world-leader in TSC research. From improving diagnosis of TSC to trialling new strategies and medicines for managing the condition, funding new research will always be a key priority for us. That is why our five-year strategy for 2019 – 2023 is to ‘REACH more people and drive more REseArCH’.

However, the way that we fund new research is changing. Our new research approach is to work closer with other groups who share the same goals that we do in researching TSC. Instead of paying for a piece of research all by ourselves, we will now try to share the cost of a study with other groups.

By spreading the cost of funding research with other groups, we can encourage groups who might not otherwise fund TSC research alone to pledge money by working with us. Often, this will mean that the TSA will offer funds and in return another group will pledge even more!

Our new research approach also means that we can make important links and partnerships with research groups worldwide, whilst minimising the cost impact compared to if the TSA funded research alone.

We are halfway through 2019 and our new research strategy is already going very well. So far in 2019, we have funded £152,000 into three separate joint research projects. Thanks to our new research strategy, this initial £152,000 has sparked a further £738,000 from other groups into the same TSC research projects.

This means our £152,000 research fund for 2019 so far has led to almost £900,000 being invested in research overall!

## IN NUMBERS: HOW OUR NEW RESEARCH STRATEGY IS FUELLING TSC RESEARCH

**TSA research fund:**  
£152,000

**TSA research partner funding, as a result of the TSA's initial funding pledge:**  
£738,000

**Invested in TSC research in 2019 so far, thanks to partnership research funding: £890,000**

### THE TSA'S PRIORITIES FOR RESEARCH INTO TSC ARE:

- 1 Earlier diagnosis, including genetic testing
- 2 Early risk assessment, including natural history registries
- 3 Basic science and pre-clinical work, including lab-based research
- 4 Prevention, including trials of mTOR inhibitors and other therapies for newly diagnosed infants
- 5 Research into new and available therapies, including better and more tailored treatments for TSC-related disorders and measuring unmet needs

### THE TSA HAS CO-FUNDED THREE DIFFERENT TSC RESEARCH PROJECTS IN 2019 SO FAR:

- 1 Research into developing a model of the human circulatory system to better understand LAM ('lymphangioleiomyomatosis') in more detail (see Scan Spring 2019 and our website for more)
- 2 A major project to help understand and treat neuropsychiatric disorders of people living with TSC (led by Prof Petrus de Vries, University of Cape Town, and Prof Anna Jansen, UZ Brussel – Vrije Universiteit Brussel). Co-funded by the King Baudouin Foundation, Belgium (turn to page 21 for more)
- 3 Studying the accessibility of mental health services for children and young people with TSC (Dr Sam Amin and Dr Ingram Wright, University of Bristol). Co-funded by an anonymous major donor (turn to page 22 for more)



# New research funded by the TSA

**The TSA has awarded co-funding to two more exciting TSC research projects!**

## The TANDem Project: Understanding neuropsychiatric disorders of people living with TSC

The TANDem Project is a major worldwide project to help researchers and clinicians better understand and treat neuropsychiatric disorders of people living with TSC. The project marks a significant milestone in improving the lives of people living with TSC.

Nine out of 10 people living with TSC experience TSC-associated neuropsychiatric disorders (TAND), such as autism, ADHD or depression. TAND disorders can have a serious impact on family life, with the number one request from individuals and families affected by TSC being for advice and support to help them manage TAND-related symptoms. However, despite calls for a greater clinical focus on TAND, there has been little evidence-based advice available to help.

The TANDem Project will bring together a worldwide team of families affected by TSC, researchers and clinicians to provide scientific evidence for greater TAND intervention and treatment. The two-part project will first focus on the development of a self-report TAND checklist and smartphone app, to measure how people are affected by TAND. The second part of the study will investigate the best ways to treat TAND, including agreement on suitable clinical guidelines for TAND. Following this work in identifying and treating TAND, the TANDem Project will help to prepare a global team of TAND researchers to raise awareness and lead future research into TAND.

The project will be co-led by Prof Petrus de Vries (University of Cape Town) and Prof Anna Jansen (UZ Brussel - Vrije Universiteit Brussel), with co-funding by the TSA and The King Baudouin Foundation, an independent international foundation which aims to change society for the better by investing in inspiring projects and individuals.

Prof de Vries commented: "Needless to say, projects like this can only happen with teamwork. We have a wonderful network of families, TSC organisations, academics and clinicians who are all passionate about TAND and who all understand the urgent need for impactful TAND research. I really believe this project has the potential to change the global landscape of TAND research."

The TANDem Project will commence worldwide during the second half of 2019.



**PROF JANSEN AND PROF DE VRIES, DURING A PREVIOUS INTERVIEW**

**VISIT OUR WEBSITE AND FACEBOOK PAGE TO WATCH TAND-FOCUSED FILMS FROM OUR BELFAST CLINICIAN MEETING EARLIER IN THE YEAR, INCLUDING AN INTRODUCTION TO TAND BY PROF DE VRIES.**

# New research funded by the TSA

## Understanding the accessibility of mental health services for children and young people with TSC

Dr Sam Amin and Dr Ingram Wright (University of Bristol) are aiming to develop an understanding of appropriate and effective ways for children and young people with TSC to access available mental health services and psychological support. The study will contribute towards recognising and supporting the mental health needs of individuals with TSC and addressing barriers to access effective treatments.



University of  
BRISTOL

As many people in the TSC community will be well aware, access to mental health services for children and young adults with TSC can be very restricted. This is because the relationship between an underlying health condition and the mental health or emotional issues the individual experiences is poorly understood.

The lack of understanding and clear direction of how children and young people with TSC should have psychological needs treated means that individuals are often excluded from accessing mental health services that they desperately need. On occasions that access is granted, services for children and young adults with mental health problems may not be as effective than when a child or young person does not have a complex health condition.

It is hoped that this new research, co-funded by the TSA and an anonymous donor, will demonstrate a clear benefit of providing therapies to children and young people with TSC who are experiencing psychological or emotional distress.

Dr Amin and Dr Wright will carry out their study by first reviewing previous treatments that children and young adults with TSC have had for psychological or emotional issues, as well as reviewing psychological treatments for children and young adults with neurological conditions (such as epilepsy) more generally. Then, the researchers will conduct a survey of mental health and psychological health services to assess whether they are currently accessible for individuals with TSC. Finally, a trial will be conducted to determine the effectiveness of treatments for emotional distress and mental health problems in individuals with TSC.

# Fundraising updates

Hi everyone,

The longer days are here and it's so lovely to hear about all of the different things that you are taking part in to raise money for people affected by TSC. You really are an active bunch, taking on all types of challenges over the summer months! Across the UK, we have people doing activities in the warmer weather, from running events and cycling sessions to walking vast distances, all to raise money so that we can continue to support people affected by TSC and fund important TSC research.

Mikaela is unexpectedly taking on the Great North Run this September for the TSA, following a 'lucky' selection in the public ballot, meaning that she is walking the walk! Do please visit her JustGiving page, where all donations will be gratefully received (wink wink!)

You don't have to be sporty to be part of TeamTSA, with many people fundraising by doing something they love! We have people doing everything, from holding tea dances and hosting darts exhibitions to organising craft days. We challenge you to find a hobby we can't turn into a fundraiser!

We are also delighted to confirm that the TSA has joined forces with Genetic Disorders UK to take part in Jeans for Genes 2019. Jeans for Genes takes place every September to support a range of charities and it's simple to get involved. All you have to do is ask everyone at your school, club or workplace to wear denim for the day! If you choose the TSA as your elected Jeans for Genes charity, we receive funds from your event and you raise awareness of TSC. If you're interested in choosing the TSA as your Jeans for Genes charity, do please get in touch!

We have recently received some fabulous donations from businesses who have supported us following requests to them by community members. Remember to check if your place of work offers charity schemes, such as partnerships or matched funding. If they do, please do suggest the TSA!

To all of our fundraisers and donors – Thank you! Put simply, the TSA would not be here without your generosity.

**Mikaela, Tanya and Kathryn**

[fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org) / 0300 222 5737



(LEFT TO RIGHT): MIKAELA, TANYA AND KATHRYN, TSA FUNDRAISING



# An evening with David Suchet CBE

## Thursday 19 September 2019

The Tuberous Sclerosis Association (TSA) is delighted to host 'An Evening with David Suchet CBE' on Thursday 19 September. The award-winning actor will reflect on his stage and screen career, including his early roles portraying an impressive catalogue of Shakespeare characters, twenty-five years of bringing Agatha Christie's iconic Poirot to life and the roles that he has enjoyed most since bidding farewell to the famous detective.

The evening will raise funds to support people living with Tuberous Sclerosis Complex and their families today and invest in research to find a cure for tomorrow. This is a cause close to David's heart as the grandfather of a young child born with this rare genetic condition.

Drinks 7pm, dinner 7.30pm, speeches end 10pm, bar closes 11pm

The National Liberal Club, Whitehall Place, London SW1A 2HE

Dress: Black tie

Nearest tube station: Embankment



£95 per ticket or  
£900 for a table of 10



Tickets sold in aid of the  
Tuberous Sclerosis Association  
[www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)



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# WEAR JEANS CHANGE LIVES



MON 16 – FRI 20 SEPT

**tssa**  
tuberous sclerosis  
association

For more details and to register please visit:  
[www.tuberous-sclerosis.org/J4G](http://www.tuberous-sclerosis.org/J4G)

# Fundraising thank yous

Send your fundraising plans and post-event pictures to [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org) for a chance of featuring in the next Scan or our social media!

## EVENTS

The sky wasn't the limit for the incredible **Grace Peak**, who completed a skydive and raised an amazing £1,200!



GRACE TAKING TO THE SKIES!

Big thank you and well done to **Laura Dunkley** who raised £500 by hosting a quiz night in aid of Tommy Rasho! Here is the team, including Tommy himself and his mum Becky.



LAURA, TOMMY, BECKY AND THE REST OF THE QUIZ HOSTING TEAM!

**Dale Mitchell** arranged a cricket tournament and quiz in memory of his late brother Anthony, gathering a fantastic £600. Thanks also to **Sarah Hatter** who also fundraised in memory of Anthony, putting on a crib night and raising £970. This was generously matched by Barclays Bank, leading to a grand total of £1,940!

Thank you to **Nigel Heydon**, organiser **Kevin Davis** and everyone who attended Nigel's darts exhibition in Stratford-upon-Avon, you hit the bullseye for people living with TSC with a brilliant £600!

## FUNDRAISER IN SPOTLIGHT

### A family affair – Jan Baynes and family

Jan, from Chatteris in Cambridgeshire, recently started fundraising for the TSA, having become inspired by her great granddaughter, Olivia, who has TSC. However, Jan isn't fundraising alone, with lots of Olivia's friends and family helping too!

#### What fundraising have you been up to and what has the response been?

"I've been overwhelmed by the support from the local community! My friend Anne and her friend Penny did a sponsored walk around the lake at Gratham water, raising over £1,600.

Our family held a Tea & SCones for TSC event at our local community centre, raising a further £1,100 and getting featured in the local newspaper. We made biscuits stamped with a TSA logo and even had a queue forming for our sausage rolls!"

#### What motivates you to do all of this?

"I am motivated to fundraise when I see my family. Clarissa (granddaughter) and Daniel (Clarissa's partner) are coping so well with Olivia and her brother, Oakley. I am really proud of them and Olivia and Oakley are both beautiful children. I want to do whatever I can to raise funds for research into TSC and to help the TSA support families like ours."

#### Any advice for people who want to support the TSA but don't know how to get started?

"It's so easy to fundraise for the TSA, I just look for opportunities in the local community. It can be as simple as asking the local coffee shop to host a collection tin. The TSA fundraising team are always around if you have question or need something!"

We cannot thank Jan, her family, friends and the wider community of Chatteris enough for all that they are doing to support people affected by TSC!



JAN BAYNES (FAR RIGHT) WITH GREAT GRANDDAUGHTER OLIVIA AND JAN'S FAMILY

## GIFTS IN CELEBRATION

Thank you **granny Gail Gray** and **great-nanna Maisie Luke**, who celebrated their 70<sup>th</sup> and 90<sup>th</sup> birthdays and gifted the TSA with an amazing £1,500! Happy Birthday Gail and Maisie, the generosity of you, your friends and family is incredible!

Happy birthday and thank you to **Paula and Mike Mapley**, who kindly asked for donations to the TSA for their joint 50<sup>th</sup> birthday in support of their Grandson Harvey, amounting to £400! Lovely generosity!

Congratulations and thank you to **Johnathan and Judith Gordon** on their golden wedding anniversary, who asked for donations in lieu of gifts and gathered an fantastic £500!

Thank you to **Eileen Webber**, who raised £270 in lieu of gifts for her 80<sup>th</sup> birthday! Happy birthday, Eileen!



**GRANNY GAIL GRAY AND GREAT-NANNA MAISIE LUKE. HAPPY BIRTHDAY!**

## Facebook fundraising



Since the start of the year, many of you have celebrated your birthday by asking for donations to the TSA via Facebook, raising a staggering total of over £4,200!

On behalf of the TSA we would like to wish you all a VERY happy birthday!

## London Marathon 2019

The incredible TeamTSA London Marathon runners took on the 26.2 miles to help support people affected by TSC, eating up the miles while TSA team members and volunteers cheered them on!

Sarah, Jamie, Daniel, Lauren, Stephen and David have raised a jaw-dropping **£15,400** so far, with money still coming in!



***We absolutely loved the marathon! Jamie said he wants to run it again next year so if you need runners, he's your man! I think I'll stick to spectating next year!***

**Sarah Ridings and Jamie Heselden**

***Thank you for letting me join your team, it was such as great day. Everything was so overwhelming - I wasn't expecting so much emotion!***

**Steve Picton**



***This was a life-changing experience. A tough challenge, but worth every penny raised! There was a buzzing atmosphere from the crowd.***

**Lauren McWhinnie**

***Thank you so much for all of your time and support in making this day one to remember, the work of the TSA is outstanding and we appreciate everything you all do.***

**Daniel Marks**



**Are you interested in running the 2020 London Marathon as part of TeamTSA? Email [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org) for an application form.**



## BUSINESSES GIVING BACK

**Edale** held a puzzle competition for charity and mastermind **Matthew Harker** solved the puzzle, kindly nominating the TSA for the £617 prize!

TSA collection tins have been working hard! Thank you to Tracey and the team at **Glamour Salon**, Beeston, whose generous customers donated £30. Nick and the team at **The Armoury Gym**, Crockerton, raised £75 and another £75 was gathered by **Andy** and **Sally White** and their customers at **The Gift Horse**, Market Rasen. Brilliant!

**QuriosIT Solutions Ltd** gave us a very generous donation of £1,000, with Director **Richard McManus** saying: "We certainly needed and appreciated the help and support of the TSA in the early years". Richard's son, Jack, lives with TSC.

We have also recently received funding from BP, Barclays Bank, Boots and Honda UK, who either matched employee fundraising or directly supported the TSA.

### Tea & SCones for TSC 2019

Our annual fundraising bake Tea & SCones for TSC was a brilliant success this year, with events popping up throughout the UK! Thank you to everyone who kindly hosted or went along to an event.

**Victoria Mair Collins** had a get-together at Thornhill Primary School, which raised £100!

**Jack Gray and The Little Acorn School** had a bug-themed biscuit fundraiser, coinciding with their study of creepy crawlies! The total count of over £300 left us 'buzzing'!

**Sue Miles-Pearson** held a cake sale at the University of Roehampton, in honour of Sue's granddaughter who lives with TSC, raising £321!

**Sally Turnbull** put on a Tea & SCones for TSC afternoon at her home in Nottingham, supporting her granddaughter who lives with TSC. Sally was able to collect £220!

**Craig Ireland** and everyone at Mears Care in Alloa for took part in Tea & SCones for TSC and gathered £70! The TSA cupcakes look amazing!

**Emily Cooper**, TSC Clinic Nurse Specialist, collected a fantastic £90 at Queen Elizabeth Hospital Birmingham.

**Dr Elaine Dunlop** and the TSC research team at Cardiff University raised £79!

The **Northern Ireland Regional Team** in Belfast City Hospital collected a wonderful £100 from generous staff!

**It isn't too late to get involved with Tea & SCones for TSC, you can fundraise at all times of the year!**



VICTORIA AT THORNHILL SCHOOL



JACK AND THE LITTLE ACORNS GETTING STUCK IN WITH TEA & SCONES



SUE'S TEA & SCONES BAKESALE



DR DUNLOP AND SOME OF THE CARDIFF TSC RESEARCH TEAM



SHIRLEY DAVIS

### In memory

We have received many generous gifts in memory of loved ones. A special thank you to family and friends of those no longer around who choose to support the TSA during such a difficult time.

Everyone at the TSA would like to thank the family and friends of the late Shirley Davis, who donated £382 in Shirley's memory. In the words of Shirley's son, Steven: "One of Shirley's grandsons was diagnosed with TSC. Shirley did all she could to support him and his parents."

### Trusts and foundations

Thank you to the following for their generous donations:

Ardwick Trust  
British Association of Dermatologists  
Douglas Heath Eves Charitable Trust  
Grace Trust

JTH Charitable Trust  
James Roll Charitable Trust  
Joseph Strong Frazer Trust  
Martin Connell Charitable Trust

Michael and Anna Wix Charitable Trust  
P F Charitable Trust  
The Tregelles Trust  
Thomas Sivewright Catto Charitable Settlement

# Ways you can give to the TSA

Donating to the TSA is easy, whether you've been fundraising at home or running a marathon! Here are just some of the ways that you can provide us with much needed funds



## Make a donation online

Give online by filling out the donation form on our website: [www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org). You can now also give via a direct debit!



## Send a cheque

The Tuberous Sclerosis Association, Unit 93, Containerville, 1 The Oval, London E2 9DT



## Get social

**Start your own Facebook fundraiser in aid of the TSA!**

This is a new option for the TSA and we're thrilled that our supporters are already using it!

Got a celebration coming up? You could ask people to donate via your social fundraiser instead of receiving other gifts!



## eBay love to buy and sell?

On eBay you can now donate a percentage of any money earned to the TSA!



## Planning ahead?

You could leave the TSA a gift in your will, or a percentage of what is left of your estate once you have provided for your loved ones.

For more details contact Head of Income Generation, Mikaela Conlin-Hulme, at [Mikaela.Conlin-Hulme@tuberous-sclerosis.org](mailto:Mikaela.Conlin-Hulme@tuberous-sclerosis.org)



## Amazon Smile

Amazon will donate 0.5% of the purchase price on selected items to your chosen charity if you login via Amazon Smile, at no additional cost to you!

It's really easy to do:

1. Go to [smile.amazon.co.uk](http://smile.amazon.co.uk) and login into your regular Amazon account
2. Choose the TSA from the charity options
3. Shop as usual and raise funds for the TSA!



## Give from your pay!

Payroll giving allows you to donate straight from your salary, before tax is deducted. This means that if you decide to give £10 a month, it will only cost you £8 if you pay tax at the basic rate. Ask your payroll team if this is a scheme your employer offers.