

# scan

MARCH 2022

The magazine of the TSA

**Strategic  
plans for  
2022 and  
beyond**

**How to be  
financially  
resilient**



**Thank yous  
to incredible  
fundraisers**

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## RESEARCHER IN FOCUS: DR KACPER ROGALA

In this new feature, we get to better know some of the incredible individuals, researchers and teams who are focused on new TSC discoveries. In this issue, we meet Dr Kacper Rogala and learn about his work in TSC



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We welcome some recent changes to the TSA Board of Trustees: Rajan Khullar as TSA Treasurer and Robert Woodthorpe-Browne MBE as Vice-Chair. We find out more about Rajan and Robert, and how their experiences will help the TSA

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## PLANS FOR NEW ONLINE TRAINING MODULES

As part of our work to ensure that people in the TSC community get the support that they deserve, we're planning on developing a range of innovative and robust training modules. The modules will be specially designed to help different professionals better understand TSC

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## LAUNCH OF THE TSC CLINICS NETWORK

We're launching the NHS TSC Clinics Network, a new project to maximise the work of all 19 NHS TSC clinics across the UK. Through the network, TSC clinicians can connect, learn and drive forward care and support for TSC

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## TSC CLINICS VIRTUAL CHALLENGE RETURNS

Last year we introduced the TSC Clinics Virtual Challenge – an opportunity to celebrate the work of clinicians in TSC clinics with a fun and inventive way to fundraise. The event was so successful in 2021, that it returns for 2022!

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## HOW THE TSA FUNDS RESEARCH

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The only way that TSC research is successful is by getting the TSC community involved in its planning, development and execution. There are lots of exciting pieces of TSC research taking place right now, including some that need your help right away

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## FUNDRAISING THANK YOUS

We exist and can work hard for the TSC community only thanks to the generosity of the incredible people who kindly fundraise and donate to us. We take time to thank some of our recent fundraisers

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## IN LOVING MEMORY

We've received many generous gifts over recent months in memory of loved ones who have sadly passed away, including the loved and lost individuals celebrated here

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## NEXT STEPS IN TSC-LAM RESEARCH

The recent International TSC and LAM Research Conference welcomed clinicians from across the world to virtually come together and drive vital next steps into this area of TSC

## Registered address

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# TSA team updates

## More about the team behind the TSA and what we've been up to



### Thank you for everything Kathryn!

After six years of hard work and dedication, the TSA said a heartfelt "Thank you and goodbye" to Kathryn Worden (Fundraising Manager), as she moved to another important role in her local community, working for North West Cancer Research.

Kathryn did an incredible job during her time at the TSA. Many in the TSC community will know Kathryn well, as she provided a vital link in helping us to boost our income and stay connected with our amazing fundraisers and donors.

### New skills and knowledge in the team

Anna Gaunt (TSA Support Line Manager) has recently started an exciting new part-time Masters course focused on emotional wellbeing and coaching.

Passionate about helping people to overcome barriers, Anna thinks that the course will benefit her work at the TSA: "My Masters course has already been really interesting, and I'm learning a lot. My experiences with the TSA have definitely given me good grounding for the course, and I'm confident that the course in turn will also help me in my role at the TSA!"

### New Years Resolutions are still going strong!

At the start of the year, Luke Langlands (Head of Communications and Support) committed himself to taking more time to learn Polish: "I've been passionate about the Polish language for many years, but it's only until recently that I've become confident in using it. It's been a long time coming and I'm really pleased. Learning one of the hardest languages in the world is fun, because any improvement is a big cause for celebration!"



### Looking for a new team member

The TSA is looking to bring in a new member of the team, focused on trusts and foundations. The Trusts and Foundations Fundraiser will work closely with Mikaela Conlin-Hulme (Head of Income Generation) to help us tell organisations about the great work of our charity, and why it's important to support us with grants and giving.

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

**Contacted the TSA Support Line? We want to hear from you! Fill out a survey so that we can continue to improve the service:**

<https://bit.ly/2NkZiww>



# A word from your Chair

**The TSA's five-year strategy is back on track, with ambitious plans for 2022 and onwards across support, research, fundraising and advocacy to improve lives in the TSC community.**

Over the past 18 months, we focused on delivering the areas of our five-year strategy for 2019 – 2023 that would most help the TSC community during the early stages of the ongoing covid-19 pandemic. Now, our focus has returned to considering all areas of the five-year strategy.

Here, I've listed the aspirational projects that we're working on over 2022, alongside our day-to-day work across support, income generation, research and advocacy:

**Further improving our support and information so it continues to be readily available and timely.**

Information is only useful if it is punctual and meaningful. That's why we're continuing to build upon and improve all of our support and information materials, including our website, e-newsletters, social media pages and regular events. The TSA Support Line also continues to be invaluable for the charity and the TSC community, with demand in 2021 outstripping enquiries from the previous year.

**Providing ongoing opportunities for people affected by TSC to connect, support and learn together.** The TSA's events calendar for 2022 has been expanded, with virtual and face-to-face events throughout the year on a range of topics and themes. As part of this, we're delighted to bring back a (new look) Big Day, where the focus will be not only on listening to talks but also on real-life connection and conversation with people who know what life with TSC can mean (see [page 12](#)).

**We're also committed to knowing you better.** The TSCensus gives us the chance to better understand who the TSA is supporting, where there are gaps in the people that we reach, and if there's anything more that we need to be doing to support you and your loved ones.

**Growing the knowledge and expertise of professionals working with people who live with TSC.** The TSC community should receive the best care and support possible from professionals. That's why we're developing a new range of online training modules, for social care and education professionals (subject to funding) who are working with people affected by TSC (see [page 8](#)).

Since the beginning of the year, we've also started to invest more time into how we work with NHS TSC clinics through

the NHS TSC Clinics Network. It's hoped that this network will help support NHS TSC clinics so that their incredible work can be maximised.

**Driving the TSC research agenda, to improve outcomes and quality of life.**

We're continuing to support vital TSC research through our research funding grants, including research that is ongoing and also new opportunities for TAND-focused researchers to apply for grants.

Our work across TSC research in 2022 also goes beyond proudly funding research. An important new study into how TSC-related epilepsy develops will be undertaken in partnership with the TSA, as well as a review of the UK Clinical Guidelines into the diagnosis, care and management of TSC – ensuring that UK standards are consistent with those used internationally.

**Pushing for better access to TSC treatments and care.**

Our work continues in pushing the TSC agenda in treatment access and the horizon of new TSC medicines and therapies. We're continuing to share the views of people living with TSC and their families with decision-makers across the UK to fund Epidyolex (cannabidiol) for TSC-related epilepsy, so they come to the same positive decision as authorities in Wales and Scotland (see [page 6 and 7](#)). We'll also continue to push for the TSC community to be at the heart of TSC research into new medicines, including through our research volunteer network.

If one word best described the TSA right now, it is 'Ambition'. We won't stop working for the TSC community, and our small team is determined to do everything that we can to ensure that we have the greatest impact on those affected by TSC. If we're to be successful, we need your help: We can only achieve all of our goals for the TSC community if we're financially secure. We receive no government funding and exist only thanks to kind donations. Please consider giving by going to [tuberous-sclerosis.org/donate](https://tuberous-sclerosis.org/donate) or by calling **0300 222 5737**.

Best wishes,  
Sanjay Sethi  
**TSA Chair**



**SANJAY SETHI, CHAIR**

# Changes to TSA Board of Trustees

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*“My TSC connection is through a close friend. In my free time, I like to meet friends, keep fit and travel”*

**Rajan Khullar, TSA Treasurer**

**Since the last TSA Annual General Meeting, the charity's Board of Trustees has been updated, including different roles for old and new faces**

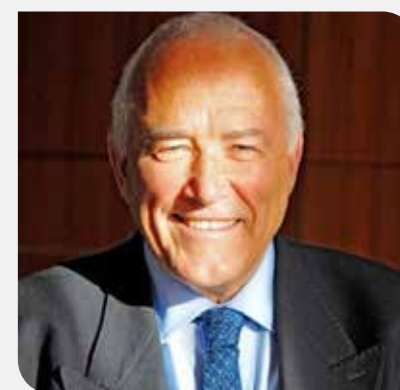
The TSA is overseen by the TSA Board of Trustees, a diverse and passionate group of volunteers who focus on ensuring that the charity is fulfilling its aims across support, fundraising, research and advocacy. Without our trustees – many of which have a direct connection with TSC – the TSA wouldn't be the forward-thinking, innovative and groundbreaking charity that it is today.

New trustees and new roles for current trustees are highlighted during the TSA's Annual General Meetings, including our latest general meeting. Rajan Khullar was appointed as the TSA's new Treasurer, helping to oversee financial matters at the charity. Robert Woodthorpe-Browne was voted in as Vice Chair of the Board, assisting with overall direction and strategy.

Rajan Khullar is a Chartered Management Accountant with a strong commercial background of driving revenue and optimising costs to support profitable growth across a range of market leading businesses. Rajan does this through streamlining processes and solving problems to improve financial transparency which supports smarter and faster decision making. Rajan aims to apply his experiences on behalf of the TSC community, who he's proud to support as the new Treasurer of this great charity.

Robert Woodthorpe-Browne MBE was born in Hertfordshire and studied at the Universities of Poitiers (Barcelona) and Birkbeck College (London). Robert's career was in reinsurance, travelling to a total of 155 countries. A Liberal Democrat, he has chaired the Party's international relations committee and is a Bureau member of Liberal International, representing over 100 liberal parties worldwide. A former Council Member of Chatham House, Robert is the current Chairman of the Paddy Ashdown Forum think tank, Fellow of the Royal Geographical Society and Committee Member of the Gresham Society. Robert collects Lowestoft Porcelain from his ancestral factory.

Martin Short, who many in the TSC community know very well thanks to his previous time as Chair of the TSA, stepped down as Vice Chair but will remain a vital member of the TSA's Board of Trustees. Previous TSA Treasurer, Rob Vaughan, has stepped down as both Treasurer and trustee after many years in these roles. Rob's tireless work for the charity has been hugely significant to the growth of the TSA, and everyone here is thankful for Rob's commitment.



*Robert will utilise his vast experience across businesses and organisations to benefit the TSA as our Vice Chair*

# Epidyolex (cannabidiol) for TSC-related epilepsy: Next steps

**The TSA has been campaigning hard for UK nations to approve funding for this important TSC-related epilepsy medicine. Wales and Scotland have said 'Yes', and work continues in England and Northern Ireland**

Cannabidiol (brand name Epidyolex), a medicine option for those in the TSC community who live with epilepsy, was recently approved as being safe to use by the Medicines and Healthcare products Regulatory Agency (MHRA). However, the MHRA's approval was only the first step on cannabidiol's journey to being readily available to help people who could benefit from access to it.

Although the MHRA has said that cannabidiol is safe to prescribe in the UK, it is now down to decision-makers across all UK nations (England, Scotland, Wales and Northern Ireland) to review the medicine and say whether they will provide funding for it to be made available in their own nation.

The TSA has been working with decision-makers across all UK nations to try and make sure that everyone who could potentially benefit from cannabidiol has the opportunity to get it. Our campaigning has included the vital step of making sure that the TSC community – the most important representative of all – is heard loud and clear by decision-makers. This has included gathering your thoughts and experiences of what living with TSC-related epilepsy every day is like.

The TSA believes that everyone affected by TSC should be able to get the medicines and therapies that they deserve, no matter where you live in the UK. We won't stop until everyone in the UK who could benefit from cannabidiol has access to it. With the horizon for medicines and therapies to diagnose and manage TSC also looking promising, our work will continue beyond cannabidiol.

Other treatment campaigns that we've recently led, which have made a big difference to treatment options in the UK, include the 'Everolimus for Epilepsy' campaign, which ensured that everyone has access to everolimus (brand name Votubia). The TSC community's efforts in that campaign were incredible, and your work in cannabidiol is just as important!

We're making sure that all UK nations understand what life with TSC-related epilepsy can mean, and the potential benefits that access to cannabidiol could have for individuals and families. However, this would not have been possible without those in the TSC community who spoke with us and got involved: Thank you!

## Wales and Scotland say 'Yes' to cannabidiol!

We were delighted to receive the news in December 2021 that the All-Wales Medicines Strategy Group (AWMSG) and Welsh Government approved funding of cannabidiol for TSC-related refractory epilepsy. The positive response from Wales was then followed by the Scottish Medicines Consortium (SMC) in February 2022, who also agreed to fund the drug for use by NHS Scotland.

Decision-makers in Wales noted the "real difference" that the input of the TSA and the TSC community had on the approval process, underlining the importance of the TSA's work with decision-makers and the work of the TSC community to share your experiences.

Based on guidance from the decision-makers, cannabidiol should be available to the TSC community in Wales from around March 2022, with access in Scotland following from May 2022.

**Anyone who lives in Wales or Scotland and would like to discuss cannabidiol as a possible treatment option for TSC-related epilepsy should speak to their GP, neurologist, paediatric neurologist or a specialist clinician working in an NHS TSC clinic.**



## Next steps in cannabidiol access: England and Northern Ireland

It's fantastic that the AWMSG and SMC came to the right decisions to fund cannabidiol in Wales and Scotland. But, we're not slowing down until all UK nations agree to fund this important medicine.

Our work continues with the National Institute for Health and Care Excellence (NICE), to ensure that they come to a positive decision to fund cannabidiol in England. The assessment stage is expected to be longer with NICE than other decision-makers, with a ruling expected 23 November 2022 at the earliest. If NICE agrees to fund cannabidiol for NHS England, the earliest that we can expect access to the medicine in England would be three months after a final decision by NICE (March 2023).

If NICE's initial view of cannabidiol is negative, they will hold a public consultation in autumn/winter 2022 to gather wider views of health professionals and the public before making a final decision. This consultation will make the process longer. If NICE consults on cannabidiol, we will reach out to the TSC community for your help, so that your voices are heard loud and clear.

Unlike England, Scotland and Wales, there's no separate body in Northern Ireland that decides if medicines are funded for use in the country. Usually, Northern Ireland's health decision-makers review and adopt the decision made by NICE in England.

## Lennox-Gastaut Syndrome

A small number of people in the UK already have access to cannabidiol, either as part of trials for TSC-related epilepsy or because they also have a condition called Lennox-Gastaut Syndrome (LGS, which has already been approved for treatment with cannabidiol across all UK nations).

LGS is a severe form of childhood epilepsy, but it can start as late as teenage years. People with LGS may experience multiple types of seizures, learning difficulties and/or challenging behaviours. If you live in England or Northern Ireland and your child has severe epilepsy with multiple types of seizures, you may wish to speak to your child's hospital specialist (usually a paediatric or adult neurologist) to see if a secondary diagnosis of Lennox-Gastaut syndrome can be made.



**Campaigning for access to important medicines and therapies is a key part of our work. We can do this only if we receive donations. Please consider making a donation at [www.tuberous-sclerosis.org/donate](http://www.tuberous-sclerosis.org/donate) or by calling 0300 222 5737**



# Passing on our knowledge

## New TSA training modules planned to upskill and educate social care and education professionals

We often speak with and provide information to people working with someone in the TSC community for the first time, like social care workers, residential care workers or teachers. To help these professionals provide the best support as possible to people affected by TSC, we're launching training packages (subject to funding) so they can learn more about the condition.

Despite an estimated 40,000 people being affected by TSC in the UK, the condition is often not well understood by professionals who have never been connected to the condition before. We receive very positive feedback for the ongoing information and support that we currently offer to non-specialised professionals – but, we want to do more, and reach as many people as we can who might be supporting someone living with TSC for the first time.

The training package for social care and education professionals will be a series of modules, developed for these roles. The modules will be an important milestone in how we support the non-clinical professional community. The modules will also be approved for Continuing Professional Development (CPD) points, allowing those taking the courses to use them as part of their official career progression.

To make sure that the training modules are as robust as possible, we want to speak with you! Get in contact through the TSA Support Line ([support@tuberous-sclerosis.org](mailto:support@tuberous-sclerosis.org), 0808 801 0700, webchat) about what content would most benefit you or loved ones. Subject to funding, the modules will be finalised by summer 2022, in time for the new school year.



# TSA Support Fund continues thanks to the TSC community

## We asked, and you delivered! Your response to the Big Give Christmas Challenge 2021 allows the TSA Support Fund to continue through 2022



Thank you to everyone who supported the TSA during the Big Give Christmas Challenge 2021 – an annual matched funding campaign that raises millions of pounds for good causes. Astonishingly, we hit our fundraising target in less than one day!

Your incredible generosity means that we can run the TSA Support Fund throughout 2022. The TSA Support Fund is a monetary grant provided to people in the TSC community when the financial impact of TSC becomes too much. In total, we raised **£8,673!**

We also want to thank everyone who shared our Big Give campaign far and wide, helping to raise vital funding and also awareness of TSC and the work of the TSA. You're all heroes!

# Working more closely with TSC clinics

## A new strategy has been developed at the TSA to work more closely with NHS TSC clinics across the UK – helping the incredible TSC clinicians to continue with their vital work

There are 19 NHS TSC clinics across the UK, helping with diagnosing, monitoring, treating and managing TSC. Many of the doctors and nurses in these clinics work voluntarily at their TSC clinic, or have many competing priorities and challenges. The TSA is proud to help these extraordinary professionals, and we're working on ways to further boost what we can do for TSC clinics.

Our work with NHS TSC clinics is very broad and focuses largely on: Connecting TSC clinics with each other, developing materials in partnership with clinics, and maximising the medical knowledge of TSC clinics. With our new TSC clinics engagement strategy, we will do this in a more focused and progressive manner. Ultimately, it is hoped that the new strategy can allow TSC clinicians more opportunities to learn from one-another, as well as encourage best practice and consistent standards of care across clinics.

The TSA recommends that everyone who lives with TSC is registered with an NHS TSC clinic, so that they can receive the medical care and support that they deserve. You can learn more about NHS TSC clinics on our website.

# TSA Support Line receives official accreditation

## The TSA Support Line – our helpful support service to give information or a listening ear to the TSC community – has received official recognition by membership body Helplines Partnership for the high quality of its service

Helplines Partnership is the membership body for organisations like the TSA that provide information, support or advice to their community through a support line. Helplines Partnership run the Helplines Standard – a nationally-recognised quality standard that demonstrates that an organisation offers a support line of the highest quality. After lots of hard work, the TSA received confirmation that we have received a positive Helplines Standard mark – underlining the strength of the service to best serve the TSC community.

Being awarded the Helplines Standard is an excellent way of ensuring that we're meeting the needs of the TSC community and everyone else who comes into contact with the TSA Support Line. We needed to demonstrate a wide range of things to receive the standard, such as the professionalism of our support team, robust safeguarding procedures, and meeting industry best practice.

With the Helplines Standard now secured for the TSA Support Line, we can be confident of continuing to improve and build upon what is already an excellent service, as we work to continue to provide support and information to the TSC community.

You can get in touch with our friendly TSA Support Line Advisers Monday – Friday, 9am – 5pm through email ([support@tuberous-sclerosis.org](mailto:support@tuberous-sclerosis.org)), telephone (**0808 801 0700**) and webchat.



# TSC Clinics Virtual Challenge

The TSC Clinics Virtual Challenge will return this **June**

**Together** we will go the distance as step-by-step we get closer to a cure!

Register your interest at:  
**tuberous-sclerosis.org/CVC**



## Incredible response to festive giving

**We received a great response to festive fundraising in 2021, including our festive greeting cards (featuring designs selected and made by you) selling out!**



The winter months can often be a challenging time for people's finances – especially for people who are experiencing the financial impact of living with TSC. However, the TSC community's response to fundraising opportunities for the TSA over last winter left us full of the festive spirit!

Thanks to your generous support, the festive season in 2021 raised the highest amount we've ever received for greeting card sales. This was in no small part thanks to our festive card design competition winner **Jasmine Ferguson**, with her brilliant design of robins with fairy lights illustrating winter perfectly (pictured here).

Not only was it a bumper year for card sales, but we also received fantastic support from you through additional donations, like swapping Christmas card giving to provide a gift to the TSA, and also your response to the Big Give Christmas Challenge (see **page 7**).

Thank you to everyone who got involved – the Elves are already hard at work to make sure winter 2022 is even more successful.

## Fundraising events in 2022: Get involved!

There are loads of different ways that you can fundraise for the TSA and make a huge difference to the lives of people affected by TSC – including taking part in some of the UK's biggest challenge events. Apply today to take on a challenge with a TSA place and be part of #TeamTSA!



### Great North Run

The UK's biggest half marathon is back to its iconic 'city to sea' route for 2022. If you fancy taking on the challenge on Sunday 11 September 2022, apply now for your place on our team.

### London Marathon

Be part of one of the most exciting global running events of the year – join the TCS London Marathon on Sunday 2 October 2022. We already have an amazing team of TSA runners in training who have been waiting since 2020 to take part, and you can apply to join them!



### Skydive

Take to the skies this year with TSA partners Skyline Events and experience the view from 10,000 feet in the ultimate adrenaline rush. A once in a lifetime experience with locations across the UK, it's a great way to raise vital funds for the TSA. Are you brave enough?

### London to Paris (Tour de France 2022)

This incredible cycle challenge connects two of the world's most chic capital cities. Soak up the Tour de France atmosphere on the Champs Elysees and tick it off your bucket list.



**Prefer taking on a local event or a different challenge for the TSA? Register your place with the event organisers and then let us know – we'll be sure to send a fundraising pack and a TSA t-shirt or running vest to wear!**

Visit **tuberous-sclerosis.org** to apply to any of these 2022 fundraising challenges, or email **fundraising@tuberous-sclerosis.org**



# TSA events calendar 2022

## The TSA has the most ambitious events calendar yet for 2022 – including the return of face-to-face events

The TSA understands the huge benefits of connecting the TSC community – including individuals and families affected by TSC and also professionals. For 2022, we're working even harder on a range of ways for the TSC community to come together.

The topics and themes covered in these events are very broad, including things such as:

- Specific medical topics related to TSC (such as learning difficulties or epilepsy)
- Non-medical ways that TSC can have an impact on individuals and families (such as financial problems or carer fatigue)
- Wellbeing and mental health topics (such as the importance of sleep)
- Updates from NHS TSC Clinics across the UK (such as how to get a referral or any changes to a service)

# Big Day is back, with a new look!

Big Day, our biggest event of the year, where we welcome everyone from the TSC community, is back for 2022 and taking place in Manchester, with a new style and feel.

Based on feedback from previous events and the new team structure at the TSA, there will now be fewer talks and set speakers at Big Day compared to previous years, but replaced with more chances for you to meet and speak with other people in the TSC community. There will no longer be creche facilities as part of Big Day, but children are welcome throughout the day.

If you want a relaxed face-to-face setting where you can grab a tea or coffee and say 'Hello' to others who understand the impact of TSC, Big Day is for you!

Be sure to keep an eye on all TSA channels for further updates on TSA events, including our monthly e-newsletters, social media and our website

TSA events						2022
JANUARY	FEBRUARY	MARCH	APRIL	MAY	JUNE	
<b>FINANCIAL WELLBEING</b> (with The Money Charity) <b>Wednesday 12 January</b> 6pm – 7pm		<b>BELFAST TSC CLINIC VIRTUAL UPDATE</b> <b>Thursday 10 March</b> 6pm – 7pm  <b>TSC AND THE KIDNEYS</b> (with Dr Nick Annear and Dr Chris Kingswood) <b>Wednesday 23 March</b> 6pm – 7pm	<b>TSC AND EPILEPSY</b> (with Dr Sam Amin) <b>Wednesday 6 April</b> 6pm – 7pm  <b>OUTLOOK 2022</b> <b>Saturday 23 April</b> Radisson Blu Hotel, Durham More details on our website	<b>A GUIDE TO RESPITE FOR CARERS IN THE TSC COMMUNITY</b> (with The Respite Association) <b>Wednesday 11 May</b> 6pm – 7pm  <b>GLOBAL TSC AWARENESS DAY</b> <b>Sunday 15 May</b>	<b>CARDIFF TSC CLINIC UPDATE</b> <b>Wednesday 15 June</b> 6pm – 7pm  <b>TSC AND CHILDREN AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS)</b> Date to be confirmed	
JULY	AUGUST	SEPTEMBER	OCTOBER	NOVEMBER	DECEMBER	
<b>TSC AND NEURODIVERSITY</b> (with The Brain Charity) <b>Wednesday 6 July</b> 6pm – 7pm  <b>LONDON-PARIS TOUR DE FRANCE</b> (with Skyline Promotions) <b>Wednesday 20 – Sunday 24 July</b>	<b>ST GEORGE'S TSC CLINIC UPDATE</b> <b>Wednesday 10 August</b> 6pm – 7pm	<b>GLASGOW TSC CLINIC UPDATE</b> <b>Wednesday 7 September</b> 6pm – 7pm  <b>GREAT NORTH RUN 2022</b> <b>Sunday 11 September</b>	<b>LONDON MARATHON 2022</b> <b>Sunday 2 October</b> <b>NEW LOOK BIG DAY 2022</b> <b>Saturday 8 October</b> (Venue to be confirmed Manchester) <b>TSC SKIN ISSUES AND EMOTIONAL WELLBEING</b> Date to be confirmed	<b>TSA ANNUAL GENERAL MEETING</b> <b>Wednesday 30 November</b>  <b>TSC AND MUSIC THERAPY</b> (with Nordoff Robins) <b>2, 9, 16, 23 November</b> 6pm – 7pm	<b>OUTLOOK FESTIVE SPECIAL 2022</b> Date to be confirmed	

# Financial resilience: Money and TSC

**Across the UK, everyday costs are slowly creeping up. Whether its household bills such as heating and electricity, groceries, or transport, we're all feeling the effects**

To help the TSC community negotiate this tricky time for finances, the TSA recently held the virtual event 'Financial resilience and TSC' with The Money Charity. At the event, financial wellbeing consultant Emma Waller (financial wellbeing consultant and co-author of Martin Lewis book 'Your Money Matters') provided lots of advice on financial resilience. But how do you become more financially resilient?

## Getting a grip on your budget

It's important to understand your own household's financial budget – grab a few recent bank statements and look at your outgoings against what you have coming in. Once you understand your financial obligations (things that must be paid every month, such as rent and bills) you can then make steps towards understanding where nonessential spending may be taking place. You may even find things that you're paying for that you no longer use, such as a long-forgotten subscription. However, for many people it is unfortunately a daily challenge to meet financial obligations even when budgeting for absolute necessities only.

You might find it handy to make a spreadsheet or use an app such as Yolt or Plum to track your budget. Sometimes, banks can offer free apps and other solutions to track finances.

## Boosting your savings, no matter how small

Saving money can often feel complex, daunting or unachievable. However, it can be as simple as having a digital or physical piggybank and dropping some spare change into it whenever you're able to do so. Remember that it doesn't matter whether you save pennies or pounds, and any savings that you manage to make should be celebrated.

You could even take on the '1p Savings Challenge', which is a manageable way of saving a really significant amount of money – On day 1 you save 1p, on day 2 you save 2p, and on you go for a full year. If you keep up the challenge, on the final day you'll add in £3.65 and will have saved £667.95!

If you'd rather have a way to save and not think too much about it, setting a standing order to take a certain amount out of your current account into a savings account every month could be an option.

The secret is that savings quickly add up, sometimes becoming an amount that can be used for an unexpected cost or for a well deserved treat. The key is consistency and being mindful of putting something away if you're ever able to do so.

## Make sure you're getting the best deals

Auto-renewing payments for things (such as broadband or gas) is often much easier, but might mean that you end up paying more. Be sure to check around for utilities and other bills to get the best deal possible, using sites such as [www.moneysavingexpert.com](http://www.moneysavingexpert.com).

Searching for alternatives can also be useful for other items, such as subscriptions to things like Spotify or Netflix. Maybe there's an alternative out there you could use instead of paying the subscription, such as YouTube or free digital radio?

## Checking and boosting your credit score

A credit score is a score assigned to you that different companies might use to try and decide whether or not to give you money ('credit') in some sort of financial agreement, such as a loan, mobile phone contract or credit card.



Your personal credit score is built from your credit history, with a higher number meaning a better score. A good credit score is important, as the better the score you have the more likely you are to be accepted for credit (or to be accepted for better rates).

Your credit score is personal to you, although things like joint accounts and mortgages in the name of a couple are taken into consideration. Ways that your credit score is rated and ways that it can be improved can often be confusing. Companies like Experian let you check your score for free, and help to paint a picture of how you might improve your score. Experian and similar sites are also useful to check if someone is illegally using your details to get credit.

## Getting help with your finances, for now and the future

Although payday loans, short-term loans, doorstep loans and use of an unauthorised overdraft may seem like a good quick fix, they're not recommended and could lead to financial problems quickly snowballing and getting out of control.

It can be challenging, but being up-front about any financial problems you're having with any organisations that you owe money to could be a good first step, although you might want to ask for third-part support to do this. If your finances are causing you concern, or if you feel that you need a bit of extra help and support, there are lots of organisations that you can turn to.

Depending on where you live in the UK, these organisations could help you to start your journey towards financial resilience:

- **Citizens Advice** ([www.citizensadvice.org.uk](http://www.citizensadvice.org.uk))
- **National Debt Helpline** ([www.nationaldebtline.org](http://www.nationaldebtline.org) or 0808 808 4000)
- **Step Change** ([www.stepchange.org](http://www.stepchange.org))
- **Unbiased** ([www.unbiased.co.uk](http://www.unbiased.co.uk) or 0800 020 9430)

## When things get too much: The TSA Support Fund

Hopefully with these helpful reminders your financial resilience will be improved. But, TSC can have a devastating impact on finances for whole families. When the financial burden of TSC becomes overwhelming, the TSA Support Fund may be able to help.

The TSA Support Fund can help to ease some of the financial burden that the TSC community may experience as a result of the condition. To find out more about the TSA Support Fund, contact the TSA Support Line (0808 801 0700 / [support@tuberous-sclerosis.org](mailto:support@tuberous-sclerosis.org)) or go to [tuberous-sclerosis.org/information-and-support/tsa-support-fund](http://tuberous-sclerosis.org/information-and-support/tsa-support-fund).



# How the TSA funds research

**The TSA is proud of our position at the front of research into TSC, so far funding £10 million into work to better understand the condition and kickstart the search for answers most important to you**

Our main aim is to drive research that gives people living with TSC and their families help for today and a cure for tomorrow. We're committed to funding research in-line with our research priorities, which are consistent with our five-year strategy to reach more people and drive more research.

The TSA follows rigorous steps in funding TSC research, to ensure that we maximise the potential of every penny used to better understanding all aspects of TSC. We give funding to different pieces of research through a process called 'grant rounds' – by looking into how TSA grant rounds work, you can better understand how the TSA decides which research will be given funding.

## Following best practice

To make sure that we fund the highest quality research projects possible, and that the research we fund has the best chance of making a real difference to people living with TSC and their families and carers, we follow guidelines set out by the Association of Medical Research Charities (AMRC). The AMRC ensures that member charities (like the TSA) fund high-quality research, by providing guidelines, training, and independent audits of their funding processes of member charities.

## Making sure we review potential research fairly

The TSA's research committee (RESCOM) is an independent team that reviews research funding applications as part of grant rounds. The people on the RESCOM team are a mixture of professionals with a scientific or medical background, who are experts in their field, and also people in the TSC community with a direct connection to the condition. Scientific and medical RESCOM members analyse research applications from a scientific point of view. RESCOM members from the TSC community provide a vital insight into the impact of living with TSC, meaning that the TSC community's voice is at the heart of TSA-funded research.

The role of RESCOM is to advise the TSA Board of Trustees when the charity has a funding round. RESCOM ensures that decisions on what research we fund is unbiased. RESCOM members use peer review (meaning that more than one expert looks at applications) in order to highlight the best research applications that the TSA has received. Based on the recommendations from RESCOM and the TSA's research priorities, the TSA's research team drafts a paper about the recommendations that goes to the TSA's Board of Trustees. The recommendations are then discussed and certified by the Board.

**Some of the major TSC breakthroughs that the TSA has funded include: The identification of the genes that cause TSC and what goes wrong in TSC cells, DNA testing for TSC, understanding what problems can occur with TSC (and when), and clinical trials of TSC medicines**

## The different stages of providing funding to researchers

There are three steps in a funding grant round: Pre-award, award and post-award.

The pre-award stage starts with an invitation to researchers to submit their research applications and proposals. Once all applications have been received and reviewed by the TSA, a recommendation is made by the charity's RESCOM on whether any of the research should be funded. This decision is based on the potential impact of the research and what the research hopes to achieve, as well as the amount of funding required compared to the amount of funding available. For every funding round, we publish full details of the process and timelines on our website and social media channels. We also publish guidance notes for applicants to help them complete the application form.

The award stage involves confirming that a piece of research will be funded by the TSA, agreeing the terms and conditions of the funding between the TSA, any other co-funders, and the researcher's institution (such as their university). Terms might include more information on deadlines or how research will be used to make a real difference in the TSC community.

The post-award stage begins when a successful applicant starts work on achieving the aims and outcomes of their research. During this phase, the TSA closely monitors the activities and outcomes of the projects through regular progress reports.

## Our most recent funding round

Our last major grant funding round took place in 2018. A number of research projects funded through this grant round are still in the post-award phase, and you can find out more about them on the TSA website: [tuberous-sclerosis.org/research/tsa-funded-research](https://tuberous-sclerosis.org/research/tsa-funded-research).

## Our current funding grant round: Focused on TSC-Associated Neuropsychiatric Disorders (TAND)

TSC-Associated Neuropsychiatric Disorders (TAND) is one of the least researched areas of TSA, despite affecting around 1 in 2 people who live with TSC and having a huge impact on the lives of individuals and families.

In 2019, we were delighted to co-fund the TANDem Project – research that is bringing together a worldwide team comprising of families affected by TSC, researchers and clinicians to provide scientific evidence for greater TAND intervention and treatment.

This year, decisions on who to award grants to will be made by our co-funders the TANDem project, with support provided by the research team at the TSA. The TSA is excited to be running a grant round within the TANDem team to continue our work in funding projects within this vital area. The funding opportunity will be open to TSC researchers across the world, and aligned with our priority areas for TAND. Applicants will be encouraged to apply for projects that reflect the TANDem Project. We'll share the successful applicants and their projects on our website, newsletters and the next issue of Scan. Watch this space!



**TANDem**  
Empowering families  
through technology

**None of this work in TSC research by the TSA would be possible without our generous supporters, as we receive no government funding.**

# Key opportunities for children and young people to get involved in TSC research

**A number of important pieces of TSC research are taking place right now, but they can be successful only if the TSC community gets involved**

## 'Early Development in Tuberous Sclerosis (EDiTS)' moves into its next phase

EDiTS has been running for five years and the team are continuing to investigate how early development is different in babies and young children with TSC compared to those without the condition.

The EDiTS team want to find out whether any differences that are found can predict later behaviour, such as communication and attention levels. It's hoped that findings will improve our understanding of the association between TSC and different behavioural outcomes, such as autism and ADHD. This in turn might help to put in place things to support children and families in the future that improve quality of life.

EDiTS has now completed the infant phase of the study, with just a few families left to visit in 2022 before they close this section of data collection. Now that the study is moving into the pre-school phase, the EDiTS researchers are looking for **children with TSC aged 3 – 5 years old** and their families to get involved.

The preschool phase of EDiTS uses a series of assessments to detect changes in preschool children, in ways that can be done in the family home (no matter where you are in the UK). The activities are fun and interactive, including a touchscreen tablet-based app called Pip and the Brain Explorers.

EDiTS is being led by Dr Charlotte Tye (Researcher and Lecturer at the Institute of Psychiatry, Psychology & Neuroscience at Kings College London). The study is taking place as a collaboration between King's College London, the Centre for Brain and Cognitive Development at Birkbeck, and the University of Birmingham. EDiTS is part-funded by the TSA and another UK charity, the Baily Thomas Charitable Fund.

If you're interested in being involved in EDiTS and making a real difference to our understanding of the development of TSC, contact the EDiTS team ([edits-study@kcl.ac.uk](mailto:edits-study@kcl.ac.uk)) or visit the TSA's website for more information: [tuberous-sclerosis.org/research/edits](https://tuberous-sclerosis.org/research/edits).



**There are lots of ways that you can help support the TSC community, whether its through fundraising, sharing your experiences or helping with campaigning. One of the most vital ways you can make a difference is by being part of TSC research**



**DR CHARLOTTE**  
(PRINCIPLE INVESTIGATOR, EDITS)



**DR JESS BROUGHTON**  
(CLINICAL PSYCHOLOGIST ACT IN TSC)



**ISOBEL BOWERS**  
(RESEARCH ASSISTANT, EDITS)



**ROWAN ARTHUR**  
(RESEARCH ASSISTANT, EDITS)



**DR ALEX MARSH**  
(CLINICAL PSYCHOLOGIST, ACT IN TSC)



**NATASHA LINDSAY**  
(RESEARCH ASSISTANT, EDITS)

## 'ACT in TSC': Building a meaningful life for young people with TSC

Acceptance and Commitment Therapy (ACT) is a psychological intervention that incorporates aspects of other well-known therapies, such as cognitive behaviour therapy (CBT) and mindfulness. ACT aims to help people build a rich and meaningful life, despite challenges and ongoing difficulties, by encouraging a person to be open and in contact with the present moment and engage in behaviours that are consistent with their life goals.

ACT in TSC, the first UK-based virtual psychotherapy trial for young people with TSC, is currently recruiting **children and young people aged between 11 – 24 years old** to get involved. The study will help to improve our knowledge about the types of psychological interventions that are effective for young people living with TSC, and the benefits of psychological therapy for this age group.

An important factor about ACT is that it encourages a person to engage with painful experiences rather than ignoring them, allowing the person to move towards acceptance. When it comes to people living with TSC, the way ACT works could have a big impact, with people who have TSC also having a higher likelihood of having physical or mental challenges.

ACT in TSC will take place remotely through video calls, with weekly sessions for up to 12 weeks. This means that participants won't have to travel anywhere to be part of the study. Each session will be with either Dr Alexander Marsh or Dr Jess Broughton (Clinical Psychologists, University of Bristol). Dr Marsh and Dr Broughton both have experience of working in paediatric neuropsychology and are excited to support young people with TSC.

To be part of ACT in TSC, contact the study co-ordinator Dr Jennifer Black ([Jennifer.black@uhbw.nhs.uk](mailto:Jennifer.black@uhbw.nhs.uk)) or visit the TSA website for more information: [tuberous-sclerosis.org/research/act-in-tsc](https://tuberous-sclerosis.org/research/act-in-tsc).



# Researcher in focus: Dr Kacper Rogala

**TSC research is possible only because of individuals dedicating their lives to unlocking the secrets of TSC. In this new ongoing feature, we meet the people behind the incredible TSC research taking place all around the world.**

Dr Kacper Rogala is a TSC researcher focused on developing new treatments and therapies for the condition. Dr Rogala is based at the Whitehead Institute MIT (Boston Massachusetts, USA). Dr Rogala's work into TSC is part-funded by the TSA.

## What was your background before becoming a TSC researcher?

"When studying at the University of Edinburgh, I came across the field of science called protein crystallography. I was drawn to it because, apart from sounding really cool, it was a very visual field of science where you can discover what proteins look like in three-dimensions (3D). Following this, my research master's degree at University College London was focused on mapping changes in human proteins.

My PhD at Oxford University looked at how structures inside our cells (called 'centrosomes') assemble from hundreds of individual proteins into a sophisticated molecular machine that makes sure our genetic material is divided equally between growing cells."

## What was your motivation for getting involved in TSC research?

"I feel that my involvement in TSC research was a progression that happened very naturally, out of my own curiosity of discovering how things work. My studies at Oxford sparked my fascination into how cells control the growth in the body. Mutations in the process of cell growth can lead to conditions like TSC.

At the moment, we have a broad understanding of how cell growth is controlled, but the details are missing. What motivates me as a TSC researcher is that my abilities to unearth detailed information about proteins is really useful in TSC. I feel like I can make a real difference to people living with TSC, which gives me a sense of purpose as a scientist."

## Why is your current TSA-funded research so important?

"Our cells have a sophisticated programme that controls whether it should grow or not. Information about the environment is sent to a decision-making protein called mTOR, and this information on the environment is used by the mTOR to decide whether to grow or not.

In TSC patients, the communication line between sensors, the environment and mTOR doesn't work as it should. This means that cells in TSC patients are more likely to grow when they shouldn't. To help with the treatment and management of TSC, we need to figure out how to fix the communication line between the body's environment sensors and mTOR. The tricky part is that we don't know how this communication between the environment sensors and mTOR works in the first place. This is where I come in as a protein chemist.

I'm working towards discovering the details of how mTOR receives the information from sensors. I do this by visualising proteins in 3D. Our goal is to create a medicine, that's safer and more effective than current therapies, which stops mTOR growing larger when there's a broken communication line between it and the environment sensors. This can only be achieved by first knowing how mTOR works and how it communicates with those sensors in the first place."



DR KACPER ROGALA

## What are your passions outside of research, in your spare time?

"I'm a certified ocean yacht master and I've been sailing since the age of 10. I sailed from Poland to Edinburgh, and then we crossed the North Sea, all the way to Norway – it was a real adventure! I've directed a number of short and full feature films, some of which were displayed in local cinemas in Krakow, Poland. For one of the short films produced in Scotland, we were nominated for a Bafta New Talent Award.

I also used to be an active handball player, including winning the UK National Championship in University Handball with Oxford, two years in a row."

## If you weren't a researcher, what do you think you'd be doing?

"There was a short period of time when I was actually seriously considering dropping everything and moving to Los Angeles in pursuit of a proper film-making career, so if I wasn't a scientist I'd be making movies."

## What do you hope we'll see in TSC research in years to come?

"I'd love to see a better understanding of what TSC genes are doing beyond their communication with mTOR. People with TSC experience many symptoms, which cannot be simply explained by faulty growth control alone. I'd love to see more researchers trying to figure this out."

## What's in store for you in the next couple of years?

"I'll be setting-up my own laboratory at Stanford University in California. This couldn't have happened without the generous support of the TSA and I'm forever thankful for the trust they've given me to carry out this project and develop it into something bigger."

## Do you have anything you'd like to say directly to the TSC community?

"You have a fierce ally in us scientists. We're a team of dedicated and passionate people, working hard behind the scenes, trying to materialise treatment ideas into a reality. We realise that time is precious which is why we strongly believe that by innovating, and by approaching the same problem from different angles, we have a better chance of succeeding at finding a cure for TSC. Thank you for supporting basic, fundamental research and discovery in TSC."

*You can watch the full interview with Dr Rogala on our website.*



# Fundraising thank yous

**Thank you to everyone who has been busy fundraising for the TSA to help improve lives in the TSC community. The TSA receives no government funding, so we can only be here thanks to your support**



Many of our community members have been getting active and raising vital funds. Here, we thank some of you!

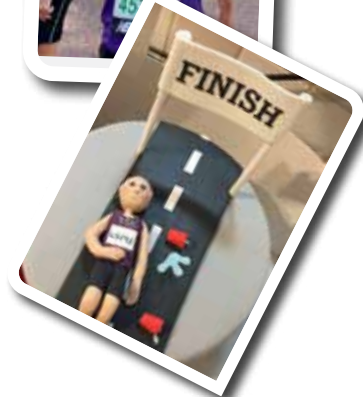
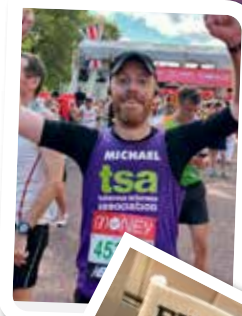
## Thank you to all who went the distance in 2021!

A massive 'Thank you' and 'Congratulations' to the incredible runners **Annemarie, Colin, Marlon** and **Michael** who took on the **London Marathon** for the TSA in 2021.

The hundreds of hours of hard training that our runners put in were all worth it, with an incredible **£20,500** raised to support the TSA and improve lives in the TSC community!

Our six-strong **Great North Run** team completed the half marathon in October 2021 (a year later than planned!) and raised a total of **£3,013** all going towards improving lives in the TSC community.

Thank you to **Daniel, Joanne, John, Joseph, Rosie** and **Sateesh**.



# Trusts and foundations

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

- A J & K M Barnett Charitable Trust
- Ardwick Trust
- Arnold Clark Community Fund
- D'Oyly Carte Charitable Trust
- Dunn Charitable Trust
- Esher House
- Gosling Foundation
- Harry-Krish Mootoosamy Foundation
- Hospital Saturday Fund
- Leach Fourteenth Trust
- Marsh Charitable Trust
- Rainford Trust
- Sir James Roll Charitable Trust
- Swann – Morton Foundation
- The Bartlett Taylor Charitable Trust
- The Michael and Anna Wix Charitable Trust
- The Rest-Harrow Trust
- William Openshaw Street Charitable Foundation

**Torie Appleyard** completed The London Landmarks Half Marathon – her first ever half marathon! Torie was inspired to put on her running shoes to show support for her daughter, Clara, who lives with TSC. Torie raised a whopping **£860!**



**Will Ash** ran the Votwo St Michael's Way Half Marathon in St. Ives and raised over **£660** in honour of his cousin's little boy Ezra, pictured! Brill!



**Andrew Kinninmonth** completed a mammoth cycle challenge fundraiser, covering the almost 1,000 miles from Land's End to John O'Groats in just nine days! Andrew was inspired by his sister Morag who lives with TSC, raising an incredible **£3,246!**



**Phillip Rogers**, a dedicated member of the TSA's Outlook group, took part in the Great East Swim and raised a wonderful **£275!**



**Alice Henery** finally got to complete her challenge of taking on both the Manchester Half and Full Marathon in October 2021, with almost two years between the first and second legs of the challenge due to covid cancellations. Alice raised an excellent **£570!**



**Mike Andrew** started his fundraising journey in pre-covid times and recently finished when he crossed the finish line at the Plymouth Half Marathon 2021, all to improve lives in the TSC community. Mike's sponsors included support from Yelverton Pals Golf Society, raising over **£2,000!**



Well done to **Callum, Graeme** and **Ciaran** who took on the massive challenge of conquering 'The Ben Lui Four' in a single day - the Munro mountains of Ben Lui, Beinn a'Chleibh, Ben Oss and Beinn Dhubhraig. Their hike took 11 hours across almost 30km, raising **£800** in honour of Lucy who lives with TSC.



Back in Scan winter 2021 we told you about the band of friends **Chris**,

**Jonty** and **Nige**, calling themselves 'Chasing Change', who planned to run 192 miles across the UK to raise money to help change the lives of people affected by TSC.

Well, they did it! After six days of running the equivalent of an ultra marathon every day back to back, the boys raising a whopping **£3,540** for the TSA – pictured is Jonty at the finish line celebrations!

**To find out more about this amazing challenge visit [tuberous-sclerosis.org/fundraisingchampions](https://tuberous-sclerosis.org/fundraisingchampions)**





## Thank you to everyone who has been holding events or using their own celebrations to benefit the TSA!



Thank you to **Julie Huntington**, who held a coffee morning at Whitchurch's Arts Café, in memory of **Zoë Bull**. The event raised a wonderful **£297**. Zoë's mum, **Jean Bull**, spoke to everyone at the event about TSC and about Zoë's wonderful book, which covers what life is like with TSC. The event even made the local paper!



**Harrow Bowls Club** held a charity day for the TSA! **Ian** and **Pat Gibbins** organised the full day event, which started with an afternoon of bowls and finished with an evening dinner and raffle that had a helicopter ride up for grabs! Their final total was over **£4,000**, made possible thanks to matched funding! Well done Harrow Bowls Club – you're flying high!



If you've been inspired to fundraise for the TSA this year, contact the TSA fundraising team on [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org) or 0300 222 5737 who can arrange for you to receive a copy of our **NEW** fundraising guide

**Sally Hankins** and her team at the vaccination centre at St Leonard's (Dorset) celebrated their last day of vaccinations in August by wearing colourful wigs, gathering a hair-raisingly fantastic **£254**!



A big 'Thank you!' to **Lucy** and **Pete Mills** and neighbour Mavis Roadhouse, who hosted an open garden event to fundraise for the TSA. The fantastic weather drew in lots of visitors, and it was a really successful afternoon. With some matched funding from Experian PLC, the event raised a brilliant **£600**!



**Richard Baxter** celebrated the Big 5-0 and raised **£469** for the TSA instead of receiving birthday gifts! Thank you and many happy returns!



**Linda Smith** has been busy fundraising again, asking for donations instead of gifts and also holding a raffle for her 65th birthday. Along with gifts made to the TSA at a family funeral, Linda has raised **£600**! But, she's not stopping there and is now busy planning a pub quiz!

## Corporate support

Thank you to our corporate partners for all of your support, and thank you to everyone who nominated us with employers or asked local or family businesses to consider supporting the TSA

**Hiscox London market operations team** have been busy again, with a 'survival of the fittest' challenge seeing team members take on health challenges including no alcohol, going vegetarian or running 100k over one month. Alongside a raffle, the challenge raised **£490**!



A massive 'Thank you' to **Gary Johnston** – pictured here with **Louise Fish**, TSA Chief Executive – for nominating us for a grant from his employer, **AkzoNobel**. Thanks to Gary, we've been awarded **£1,000** from The AkzoNobel Community Fund, helping us to improve lives in the TSC community. We want to also express our gratitude to the AkzoNobel team for supporting our work!

We're incredibly grateful to **Sir David Suchet CBE** for his continued support of the TSA. The huge generosity of Sir David and those who work with him is greatly appreciated by everyone at the TSA, raising over **£40,000** during the past three years. Sir David got 2022 off to an amazing start by making the final matinee performance of his show 'Poirot and Me' a charity performance to support the TSA. Thank you!



## Facebook fundraisers

Recently we've had a brilliant response to Facebook fundraising. Lots of you have used a birthday, anniversary or another celebration as a reason to fundraise for the TSA! A massive thank you to:

**Adam Bridge**  
**Kayleigh Burness**  
**Amy Dee Swartz**  
**Kelly-Ann Whitfield**  
**Annie Watt**  
**Lesly Guereca**  
**Brandon D Smith Sr.**  
**Lucy-anne Smith**  
**Chelsey Bunting**  
**Lynda O'Neill**  
**Deborah Gaskins**  
**Mary Dixie**  
**Elaine Pickup**

**Mega Arumugam**  
**Emma Drechsler**  
**Miranda Barness**  
**Emma Mace**  
**Mishalae Ching**  
**Evie Louise**  
**Paul Maywood**  
**Fi Wilson**  
**Paula Mapley**  
**Heatha Capeto Areias**  
**Rebekah Prosser**  
**Jeanne Seidl Martinez**  
**Rosie Howell**

**Jessica Alvarado-Cruz**  
**Samanthia Ruby**  
**Joanne Wood**  
**Sarah Norton**  
**John Raymond Ngabbu**  
**Sean McHugh**  
**Jolene Irvine**  
**Sky Alexandra Fay**  
**Karen Vennard**  
**Thea Louise Porter**  
**Katrina Hughes**  
**Tim Kimpton**

If you have a birthday, anniversary or another celebration coming up, you can set up a Facebook fundraiser for the TSA in just a couple of clicks!



# In loving memory

We've received many generous gifts over recent months in memory of loved ones. A special thank you to family and friends of those no longer with us, who choose to support the TSA during such difficult times



**Peter John Howe** passed away peacefully in December, aged 73. Peter was very close to his granddaughter, Jessica, who lives with TSC (pictured). Peter's family asked for donations to the TSA in lieu of flowers, with **£450** raised. From everyone at the TSA, thank you for your generosity.



**£660** was raised in memory of **Brian Rogers** who passed away in August. Brian asked for donations to the TSA in lieu of flowers, in honour of his grandson Ben, who lives with TSC. Thank you from everyone at the TSA to all of Brian's friends and family for their kind donations at this most difficult of times.



A special thank you to the family and friends of **Paul Lister** for the generous donations of **£172** made in his memory. Paul sadly passed away in November aged 51 following an illness over the last 12 months. Paul's mother, Val, commented: "Paul lived 46 years longer than we were originally told to expect by clinicians, showing how far medical knowledge has come over Paul's lifetime."



Everyone at the TSA would like to give a heartfelt thank you to the family and friends of the late **Hannah Emily Louisa Young**, who passed away in July last year. **£450** has been donated to the TSA in Hannah's memory. Hannah was a very special and adored daughter and sister, who will be greatly missed but always remembered. Our thoughts are with everyone close to Hannah.



Heartfelt condolences to the family and friends of the late **Marco Peter Papi**, who passed away in November, aged 41. Marco is described by his family as: "A teacher of life. All who ever knew him agree. Even though he had no verbal communication he taught so many so much. He spoke with his eyes and his resilience, compassion and fun always came through. Everyone admired and loved him, and took so much strength from him for their own problems. 'Legend' and 'unique' were some of the many lovely descriptions used to describe Marco."

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

# Driving discoveries in LAM

The recent International TSC and LAM Research Conference, titled 'Driving discoveries beyond boundaries', took place over three days and virtually welcomed TSC clinicians from across the world.

TSC can cause complications in the lungs, called 'lymphangioleiomyomatosis' (LAM). LAM occurs when there is an overgrowth of cells in the airways and in the lungs.

Co-organised by US groups TSC Alliance and the LAM Foundation, the LAM Research Conference focused on new and innovative TSC and LAM research. The TSA was in attendance, and we were delighted to see so many TSC-LAM researchers and clinicians join this important event.

Every day of the three-day conference kicked off with incredible TSC-LAM community speakers: Nicole Seefeldt, Ray Marco and Lesley Holmes, who all gave an inspiring account of their unique TSC and LAM journeys. Attendees noted the high importance of personal TSC experiences at professional conferences, with Professor Anna Jansen noting that these accounts help the professional community "to re-centre and re-focus, re-affirming the importance of the work that clinicians are undertaking. Hearing from people affected by TSC helps professionals to reflect on important issues that need to be addressed to better the lives of people living with TSC and LAM."

Each day, scientific presentations followed the community speakers. The first day was focused on cell biology, the chemical processes that go on inside cells, and how different cells talk to each other in TSC-LAM. On day two, delegates discussed how to predict and prevent the many different signs and symptoms of TSC-LAM, while day three looked at clinical and basic research for epilepsy and what this means for TSC-LAM patients. Each session at the conference was followed by topic-based discussions and exhibitions in the virtual hall.

The keynote address at the TSC and LAM Research Conference came from Daphne Koller, founder and CEO of Insitro - a drug discovery company utilising machine learning. Daphne's speech, titled 'Transforming drug discovery using digital biology', highlighted that digital biology (specifically machine learning) has emerged as a tool to allow scientists to make better predictions and therefore develop new medicines faster. Daphne's team are currently working on experiments in genes associated with TSC, but there is still lots of work to be done.

Throughout the conference, speakers and presenters emphasised how important it is for people in the TSC community to be involved in all steps of TSC research. Without the participation of the TSC community, the work being done on behalf of the TSC community would not be possible. The conference also stressed the importance of communication between different groups of professionals, with a lot of discussion around improving platforms and methods for professionals to work and learn together - including ways of sharing research resources and results on an international scale.

The next major TSC research conference, the 2022 World Tuberous Sclerosis Complex (TSC) Conference, will be co-hosted by TSC Alliance and Tuberous Sclerosis Complex International (TSCi) 28-31 July at the Hilton Anatole in Dallas, Texas.

Did you miss the last international research conference, which was organised by the TSA in June 2021? You can read about this exciting conference from the perspective of someone living with TSC on our website:

[tuberous-sclerosis.org/2020-conference-overview](https://tuberous-sclerosis.org/2020-conference-overview).



"Hearing from people affected by TSC helps professionals to reflect on important issues that need to be addressed to better the lives of people living with TSC and LAM."

Prof Anna Jansen





## TSA Support Line

 **Freephone**

**0808 801 0700**

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 **Email**

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