

# scan

AUGUST 2021

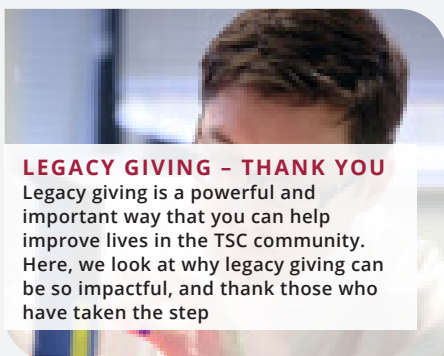
The magazine of the TSA



Looking to the future with hope

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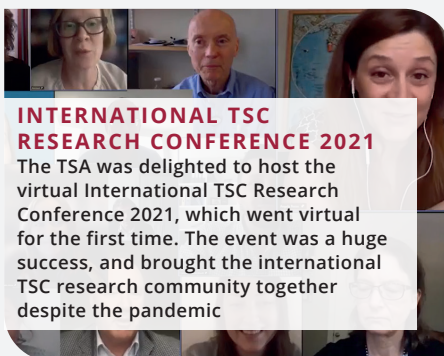
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## Head office

The Tuberous Sclerosis Association,  
Unit 56, 1 Emma Street, London, E2 9FP

Mike Dodson (Office Manager)

0300 222 5737

admin@tuberous-sclerosis.org

## Communications and Events

Luke Langlands (Head of Communications and Support)

comms@tuberous-sclerosis.org

## Fundraising

Mikaela Conlin-Hulme (Head of Income Generation)

Kathryn Worden (Fundraising Manager)

fundraising@tuberous-sclerosis.org

## Research

Pooja Takhar (Head of Research)

Bethan Vaughan (Research and Evidence Officer)

research@tuberous-sclerosis.org



LUKE LANGLANDS, EDITOR

## From the Editor

With the lighter nights and the warmth of summer comes a lot of hope. This year, the feeling of optimism is greatly emphasised, as the positive impact of covid-19 vaccinations, and the responsible return to a more familiar world, are beginning to be felt.

There's more reasons for hope in the TSC community, with lots of important and exciting next steps happening throughout support and information, research, fundraising and advocacy. Scan July 2021 focuses on this hope, and looking to the future with careful optimism. Recently, the TSA was proud to bring together the TSC professional community at the International TSC Research Conference 2021 (page 10), despite the hurdles that the pandemic brought. The event was a huge success, with hundreds of TSC professionals from across the globe in attendance, meaning that research breakthroughs in the diagnosis, treatment and management of TSC could continue to move forward.

As well as the international conference, this year's NHS TSC Clinics Education Meeting (page 13) was also a big success, with a record 85 TSC specialists attending virtually, to discuss the best ways that clinics can give the best care to people living with TSC.

Although these are quietly optimistic times, we know just how difficult TSC can be on daily life, which is why on pages 18 and 20 you'll find articles on the importance of self-care for TSC carers, and advice for those just starting their TSC journey following a new diagnosis. We're also continuing to work flat-out on medicine access and campaigning, with Louise (TSA Joint Chief Executive) discussing our upcoming plans in her foreword for this issue.

We recently said a fond farewell to Mega Arumugam from the TSA's Support and Information Services team, but also a warm 'Welcome' to our new Support Line Adviser, Rachel Harding. You can find out more about Rachel on page 17.

We very much hope that you enjoy this issue!

Luke Langlands, Editor

## Support and Information

Luke Langlands

(Head of Communications and Support)

Anna Gaunt

(Support Line Manager)

Rachel Harding

(Support Line Adviser)

The TSA Support Line is here for you Mon - Fri 9am - 5pm:  
Freephone: 0808 801 0700  
Email: support@tuberous-sclerosis.org

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/2NkZiwk>



# Joint CEO Foreword



**LOUISE FISH,**  
**JOINT CHIEF EXECUTIVE**



**SAMANTHA BARBER,**  
**JOINT CHIEF EXECUTIVE**

Everyone at the TSA is proud to have successfully delivered the International TSC Research Conference 2021. After a lot of hard work, we were delighted to host over 250 global clinical and research professionals who are working hard to learn more about TSC and improve treatment and care.

At the TSA we are always asking “What can we do next?”. With the international conference complete, our thoughts turn to how we can build upon what we learned at the event. The good news is that there are a lot of practical things for us to do!:

- We'll be offering our expertise to the US charity TSC Alliance in their amazing early work to develop a newborn screening test for TSC, so that babies living with TSC can be diagnosed earlier. You can find out more by watching Dr. Hope Northrup's (Director of Medical Genetics, University of Texas Health Center) keynote speech from the International TSC Research Conference 2021 at [tuberous-sclerosis.org/ITSCRC2021community](https://tuberous-sclerosis.org/ITSCRC2021community)
- We will share up-to-date information with the TSC community about emerging new treatments for TSC (see [page 7](#)). More information will be shared about our upcoming campaigns to ensure access to these treatments across England, Scotland, Wales and Northern Ireland - we'll be asking you to help us, so that your voice can be heard loud and clear by decision-makers
- We will explore how to support additional research into whether common medicines like metformin (a treatment for diabetes) can help with TSC. Using existing medicines in new ways is called 'drug repurposing', and we have spoken to the new NHS Medicines Repurposing Programme to ask for their advice on the next steps that we should take, so that the TSC community can benefit. We will let you know how we get on!

Alongside these exciting developments, the TSA continues to provide information and support to everyone who is affected by TSC. Our friendly and professional advisers on the TSA Support Line continue to respond to around 40 enquiries every month, with questions and concerns including those about covid-19 and TSC, carer support, and supporting families who have just received a new diagnosis of TSC - to help those new to TSC, we've introduced a new 'Welcome pack' for families who are starting their TSC journey.

Finally, we would like to wish the best of luck to Mega Arumugam who left the TSA in July, and to Samantha who is leaving at the end of August after working alongside Louise during the pandemic. Sam will remain an ally of the TSA in her ongoing role as Chief Executive of Gene People (formerly Genetic Disorders UK).

We will be keeping in touch!

Louise Fish and Samantha Barber  
**Joint Chief Executives (job-share)**



# Chair Foreward

When the TSA was established by three passionate and driven families back in 1977 they set out three charitable objectives for our work, which were: Support individuals and families affected by TSC; Encourage and support research into the causes and management of TSC; Provide education and information about TSC. These objectives remain as vital now as they did then, with the TSA still holding these aims in mind across everything that we do.

We were delighted with the virtual International TSC Research Conference 2021, which brought together TSC academics, clinicians and researchers from across the globe. The conference embodied all of the charitable objectives of the TSA, and we were proud to host it and drive forward TSC research into the diagnosis, treatment and management of the condition.

Each day of the conference opened with a speaker from the TSC community to remind delegates why it matters so much that the medical and research community continue to make improvements in treatment and care. I was able to share my own family's experience of living with TSC, alongside Jennifer Flinn, Eva Shoeters and Vicky Whittemore from the international TSC community.

Sir David Suchet CBE also spoke during the conference to thank delegates for their work. In his words:

*"Every clue that you find, every piece of evidence that you unearth, every breakthrough you discover, helps to solve the mystery of TSC and takes us another step towards a cure. Your incredible dedication gives my family hope for a better future for my grandson, and for everyone who lives with TSC."*

You can find out more about the International TSC Research Conference 2021 on **pages 10 – 12**. You can also find more information about the conference, as well as presentations from researchers to better understand why their pieces of research are so exciting, at [tuberous-sclerosis.org/ITSCRC2021community](https://tuberous-sclerosis.org/ITSCRC2021community). We also plan to give the TSC community the opportunity to ask questions to TSC experts about the research that was on display at the international conference – keep monitoring our different channels to find out more.

The incredible TSC research like that at the International TSC Research Conference 2021 can only happen due to the generosity of our donors. You can support the work of the TSA by visiting [tuberous-sclerosis.org/donate](https://tuberous-sclerosis.org/donate).

It was my pleasure to attend the conference and find out more about the research being led by the dedicated professionals who are striving to find out more about TSC and improve the lives of everyone affected by it. Their ongoing passion and hard work brings hope for the future.

Sanjay Sethi  
TSA Chair

“

*"Every clue that you find, every piece of evidence that you unearth, every breakthrough you discover, helps to solve the mystery of TSC and takes us another step towards a cure."*

**Sir David Suchet CBE**



**SANJAY SETHI, CHAIR**

# TSA passes AMRC's latest peer review audit

**The TSA is a proud member of the Association of Medical Research Charities (AMRC), a membership organisation dedicated to supporting medical research charities in their efforts to save and improve lives through research and innovation. We recently passed an AMRC peer review audit, confirming that our research funding processes are of the highest quality.**

The AMRC ensures that its member charities (like the TSA) fund the best research possible. They do this by developing guides, providing training, and encouraging best practice in medical research. Every five years, the AMRC carries out a comprehensive audit of each member organisation, to ensure that its funding processes comply with the key principles of peer review: Accountability, balance, independent decision making, rotation of scientific advisers, and impartiality. The AMRC audit also makes sure that every member organisation is keeping pace with best practice in research governance.

After a lot of hard work, the TSA's own audit by the AMRC was recently completed. Not only did we successfully pass the audit, but the AMRC also commented that the TSA's processes in funding research offered "...a really fantastic review and a great example of how a smaller AMRC research charity can still meet the requirements. It is clear that the recent review of AMRC guidelines and changes put in place and ratified by the Board was a very good piece of work." We even received a certificate of best practice from the AMRC!

## What is a peer review audit?

Peer review is the best method for medical research charities, like the TSA, to assess the quality of research funding applications they receive, in order to decide which research to then fund. During a peer review process, independent experts in the area of the proposed research give their feedback on research applications. This is usually done anonymously to enable open and constructive criticism. Peer review processes help maximise the impact of funding, allowing charities like the TSA to deliver changes that really matter to their communities, so that people affected by the condition being researched most benefit.



Receiving such positive feedback from the AMRC in their audit demonstrates the strength of the TSA's guidelines and regulations in research, which ultimately ensures that the research that we fund is of the highest quality and has the greatest impact in improving lives in the TSC community. The AMRC's comments are also important in enabling the TSA to raise money for research.

With a successful AMRC audit, the TSC community can be confident that every pound the TSA invests in research is spent on high quality research that is peer reviewed to world-class standards.

# Key next steps in access to TSC medicines

**The future for new and repurposed medicines to manage and treat different areas of TSC looks promising, with updates on UK approvals now given.**

The TSC research pipeline includes research into completely new treatments, plus using medicines already used for other conditions. We will keep the TSC community updated about the progress of these and other products, including our campaigning to ensure approvals, as they go through the UK processes for licensing and access.

## Everolimus for TSC-related epilepsy

The All Wales Medicines Strategy Group (AWMSG) is considering approval of everolimus (brand name Votubia) for TSC-related epilepsy. The TSA has emphasised to AWMSG the huge positive impact that greater access to everolimus in Wales would have to the TSC community. The decision is due to be made on 11 September 2021.

## Cannabidiol for TSC-related epilepsy

The Medicines and Healthcare products Regulatory Agency (MHRA), who is responsible for confirming if a medicine is safe and effective, is considering UK license approval for cannabidiol (brand name Epidiolex) for TSC-related epilepsy. The medicine has already received approval by the European Medicines Agency for use in the EU.

Once licensed for UK use, reviews on whether cannabidiol should be recommended for use will take place by the National Institute for Health & Care Excellence (NICE, for approval and use by NHS England) and the Scottish Medicines Consortium (SMC, for approval and use by NHS Scotland). We hope the bodies will reach decisions in early 2022.

## Cannabidiol - We need your help!

The TSA needs to speak to individuals living with TSC and their families who have experience of treatment with cannabidiol (Epidiolex), to better understand the positives and negatives of this new treatment. By speaking to us, you can help us in our work to campaign for access to this important medicine in the UK. Please get in touch with us at: [research@tuberous-sclerosis.org](mailto:research@tuberous-sclerosis.org) if you or someone you care for has taken this treatment:

- As part of a clinical trial using cannabidiol to treat TSC-related epilepsy
- Through a compassionate use programme
- For a secondary diagnosis of Lennox-Gastaut Syndrome

**Cannabidiol is not yet approved for TSC-related epilepsy in the UK. However, it is already approved for use in Lennox-Gastaut Syndrome (LSG), a severe form of epilepsy, in England and Scotland. If your loved one lives with severe epilepsy, you may wish to speak to their TSC Clinic or neurologist to see if a secondary diagnosis of LGS can be made**



**Your experience can help us to speak with a strong voice on behalf of the TSC community to inform decisions to be made about whether cannabidiol will be recommended for use across the UK.**



# Get staycation ready, while supporting the TSA!

We've got some great TSA merchandise available at our online store, so you can fly the TSA flag and help provide funds to support the TSA and our work the TSC community! Plus, use code 'SCANSUMMER' when ordering on our website before 31 August and get FREE shipping.



Stay hydrated during those sunny days

**WATER BOTTLE 400ML WITH TWO LID OPTIONS £8.50**



Long drives to the beach

**14OZ STAINLESS STEEL TRAVEL MUG £15.00**



Shield yourself from the sun

**SNAPBACK CAP £16.00**



Keeping you and others safe

**FACE MASK £7.50**  
(while stocks last)



Looking good when the sun's shining

**MEN'S GREEN TSA POLO SHIRT, S-2XL £21.00**



Keeping cool in the heat

**LADIES RED TSA VEST, XS -XL £16.00**

Check out these items and more at [tuberous-sclerosis.org/shop](https://tuberous-sclerosis.org/shop)



# The gift of a legacy: Thank you

**The TSA has been very fortunate over the years to have received legacy gifts. A legacy gift is when a person generously decides to give to us at the end of their lives, with the gift usually outlined in their will.**

Legacy gifts of all amounts are incredibly important to our work, with legacy gifts sustaining the TSA often over many years. For example, a large legacy gift kindly given to us in 1993 for research continues even now to fund potentially lifechanging TSC studies.

Last year, we received a staggering total of £50,000 from legacy giving. In what was a turbulent year, this support provided a safe haven and allowed the TSA to continue to operate. Thanks to this generosity, we were able to continue to guide everyone in the TSC community through a year like no other, ensuring that everyone who needed our support received it, and that our TSC community events could continue virtually, so that no-one was alone.

Without the generosity and selflessness of legacy donors, the TSA would have been in a very different position to where we now find ourselves.

**Thank you to all of the individuals and families who have already decided that they will give to the TSA through a legacy. We are extremely grateful.**

## Introducing our new partners:



More than half of UK adults don't have a will in place, despite the importance of having one. Having a will is the only way to ensure that your family and friends are provided for in the way that you wish for after you're gone. Plus, your will is also an opportunity to leave money or property to causes that you care about.

If you don't have a will in place or if your circumstances have changed since your last will, we've teamed up with [FreeWills.co.uk](https://freewills.co.uk) to offer a service to help you write your will completely for free and with no obligation to leave us a gift. We would be delighted if after making sure loved ones are looked after, you consider leaving the TSA a gift or a share of the assets that are left over.

Free Wills allows you to create your own bespoke and fully legal will for free and from the comfort of your own home, in as quickly as around 15 minutes. Free Wills also offers additional services such as will checking, printing and storage at a cost. To get started, please visit [freewills.co.uk/charity/tsa](https://freewills.co.uk/charity/tsa).

For complex arrangements such as trust creation it is advisable to seek individual legal advice. Please visit [tuberous-sclerosis.org/legacy](https://tuberous-sclerosis.org/legacy) for full details on leaving a gift in your will.

### Any questions?

**If you have any questions about legacy giving, or if you are already planning to kindly leave a legacy to the TSA, you can speak to us more by contacting Mikaela Conlin-Hulme (Head of Income Generation) at [mikaela.conlin-hulme@tuberous-sclerosis.org](mailto:mikaela.conlin-hulme@tuberous-sclerosis.org) / 0300 222 5737**



# International TSC Research Conference 2021: A Vision for the Future

**The annual International TSC Research Conference is a very important event for the TSC research community, giving TSC researchers and clinicians from around the world the opportunity to share their latest discoveries and plan new collaborations. The TSA was delighted to host this year's conference, which was held virtually for the first time.**



The International TSC Research Conference 2021 (ITSCRC2021) was originally planned to be face-to-face, but we were forced to postpone the meeting. The TSA and international TSC research committee were still determined to drive research forward, despite covid-19, and we agreed to host the event virtually through an online platform provided by the Royal College of Physicians between Thursday 17 – Saturday 19 June 2021.

After lots of hard work, the TSA was delighted with how the virtual ITSCRC2021 went. Around 250 TSC professional delegates joined ITSCRC2021 from 22 countries, all of whom are dedicating their lives to improving the lives of people affected by TSC. Attendees included:

- Healthcare professionals
- Academics
- Clinical and laboratory researchers
- Early career researchers (people on the start of their TSC research journey)
- PhD students and post-doctoral students
- TSC-focused organisations, including TSC Alliance (USA) and e-TSC (Europe-wide)

ITSCRC2021 featured 12 keynote speakers and 42 presenters. As part of the conference, we received 70 written overviews from attendees, outlining important TSC research that they are undertaking (called 'research abstracts').

The theme of ITSCRC2021 was 'A Vision for the future'. This theme focused on exploring how academics, researchers

and clinicians from across the globe are ambitiously driving new opportunities in TSC to advance their understanding, deliver innovation in clinical practice, and transform the lives of people living with TSC and their families.

The main way that things were presented at ITSCRC2021 was through all-attendee ('plenary') sessions, with presentations from keynote and community speakers. This was formed of research presentations of different lengths, including 'rapid-fire' presentations where speakers would need to discuss their research in just a few minutes – ensuring that content was varied and attendees heard about lots of different research. The conference also included a virtual exhibition stand of different TSC-focused groups, a networking area for delegates to further discuss key issues, and two industry-sponsored events for healthcare professionals and prescribers to attend.

ITSCRC2021 talks and presentations focused on six key areas of TSC across three days. These areas were chosen as they have been identified as the most important to people affected by TSC. This ensured that the research, networking and collaboration achieved through ITSCRC2021 would have as big an impact as possible on those who live with the impact of TSC globally. The key areas were:

- Early diagnosis
- Early risk assessment
- Basic science and pre-clinical work
- New and available therapies
- Prevention
- Social research





*The international TSC conference was a fantastic event, with the best experts in the field from all around the world. The event organisation was perfect. I was able to learn about the latest studies on TSC, and felt privileged for the opportunity to share my research thanks to the ECR award kindly given by Noema Pharma*

**Dr Angela Peron (Clinical Geneticist, University of Milan / University of Utah)**



ITSCRC2021 opened with a welcome message from Louise Fish, TSA Joint Chief Executive, followed by a special 'Thank you' message from the iconic Sir David Suchet CBE, which you can watch on the TSA's website. Our first keynote presentation came from Professor Julian Sampson (Clinical Geneticist, Cardiff University), who is known by many as being part of the international team that helped to identify of the TSC2 gene, as well as working as a member of the consortium that identified the TSC1 gene. Professor Sampson's presentation, *TSC Genetics: Past, present and future*, looked at how his early research is helping to shape future diagnostics and treatments.

We were committed to reminding attendees of the importance of TSC research, which is why we had a range of community speakers across all three days of the conference. Community members Sanjay Sethi (TSA Chair), Jennifer Flinn, Eva Schoeters and Vicky Whittemore all shared their personal experiences of how TSC has impacted on their lives and the lives of loved ones. The community presentations reminded delegates why it matters so much that the medical and research community continues to drive forward improvements in TSC treatment and care. We are very thankful to all community speakers at ITSCRC2021.

All TSC research is important, but an area of research presented at ITSCRC2021 that will be of particular interest to the TSC community is the TANDem Project, which is co-funded by the TSA. TAND stands for 'TSC-Associated Neuropsychiatric Disorders', which is an umbrella term for various mental health conditions seen in 90% of people who live with TSC, and TANDem is a mobile health project aiming to reduce TAND identification and treatment gaps. Dr Liesbeth de Waele (Paediatric Neurologist, UZ Leuven Belgium) is part of the TANDem project, and provided an update to ITSCRC2021 attendees.

Another highlight of the event was the final panel session, 'A vision for the future'. The session was led by Dr Xandra Breakefield (Professor of Neurology, Massachusetts General Hospital) who is investigating gene therapy as a new approach to treating TSC.

An 'Early Career Researcher' (ECR) is someone who has received their PhD or equivalent within the last eight years. As part of ITSCRC2021, we wanted to ensure that ECRs had the opportunity to share their exciting work, and could network effectively with the rest of the research community. As part of this, we were pleased to offer a conference bursary to six ECRs, courtesy of sponsorship from Noema Pharma.

Jessica Martin (King's College London ECR), was one of the attendees who received the ECR bursary. Jessica presented preliminary findings from the CoIN study, which is exploring the impact of covid-19 on parental mental health in households affected by TSC: "I thoroughly enjoyed hearing from researchers at the forefront of TSC research across multiple domains and sharing our research with an international and diverse audience. I would like to thank all of those involved in our research, especially the families for their participation."



*Despite being a virtual conference, I connected with so many people following my presentations, and felt truly inspired by the many talks across the three days. Thank you to the organisers and funders for hosting such an engaging and insightful event"*

**Dr Stacey Bissell (Research Fellow, University of Birmingham)**



*The selection of speakers, topics, and presentations was excellent and well worth my time to participate. I appreciate the efforts of the organisers to accommodate participant locations and timezones. The organisers did an excellent job of prioritising and balancing given the circumstances.*

**Conference attendee**

Encouraging ECRs to attend conferences like ITSCRC2021 enables these talented researchers to become further inspired by TSC research, and helps to achieve our goal of increasing the number of scientists and clinicians working in TSC research. In particular for ECRs, ITSCRC2021 fostered a culture of working collaboratively, and of sharing research findings and ideas. Helping to make the research community more productive, can accelerate the development of urgently needed treatments and measures for TSC.

By bringing together the international TSC research community at ITSCRC2021, it was possible to share and discuss research advances on how we can clinically manage challenging aspects of TSC, including diagnosis,

management and treatment. A major strength of our TSC research community has always been its ability and keenness to come together at an international level, which helps advance outcomes for those affected by TSC.

We were delighted with the flexibility and openness of attendees to embrace a virtual ITSCRC2021, and the end result. We are already looking forward to the World TSC Research Conference 2022, taking place in Dallas, USA.

**This year's conference was sponsored by GW Pharma and Nobel Pharma, with Noema Pharma sponsoring the registration of six early career researchers as part of the Noema Pharma Early Career Researchers Awards.**



*ITSCRC2021 was an outstanding success! Huge thanks to all of you and everyone on the organising committee for their work in making this happen! Many of the presentations were inspiring, including those by individuals with family members and loved ones affected by TSC!*

**David J. Kwiatkowski (Brigham and Women's Hospital, Boston US)**



# NHS TSC Clinics Education Meeting

**The TSA was delighted to host the virtual TSC Clinics Education Meeting 2021, an important opportunity for clinicians from NHS TSC Clinics across the UK to connect, network and learn.**

There are NHS TSC Clinics across the UK, all focused on diagnosing, managing and treating people living with TSC. These clinics vary in size and scope, but all include passionate and knowledgeable healthcare professionals who are experts in helping people affected by TSC.

Our work with clinics includes annual meetings for clinicians to meet, like the virtual TSC Clinics Education Meeting 2021, organised in partnership with St George's and Evelina London TSC Clinics. At the meeting, we welcomed TSC clinicians from across the UK, with a record 85 attendees joining the event.

Health and social care professionals at the TSC Clinics Education Meeting discussed a wide range of topics, with highlights including prenatal diagnosis, challenging behaviours, and neurodevelopment.

A special portion of the TSC Clinics Education

Meeting focused on how the TSA can continue to best support all NHS TSC clinics. The TSA is in regular communication with the different clinics across the UK, and aims to act as a central hub that connects all of the clinics. This encourages things like best practice, innovation and clinic updates to be shared across all NHS TSC Clinics. This is important, as it helps to ensure that the TSC community receives a sustainable, consistent and strong standard of care regardless of where in the UK someone lives.

The TSA is hoping to further boost its communications and ways of working with NHS TSC Clinics, so that the incredible TSC experts in these clinics can continue to do their very best to improve lives in the TSC community.

**There are 19 NHS TSC Clinics across England, Scotland, Wales and Northern Ireland. The TSA believes that everyone living with TSC should be referred to a TSC clinic, to ensure that they receive the care they deserve**





# Keeping the TSC community connected

**Throughout the year, we've been committed to making sure that the TSC community can continue to connect and be together. Thanks to the flexibility of the TSC community, and use of both modern and traditional communication methods, this has been a big success!**

## Regular virtual events

With at least one event a month (and often many more than that), our virtual events have given everyone the opportunity to see familiar faces, get key information on TSC, and make new friends. Our virtual events have covered a wide range of TSC-related topics, from managing challenging behaviours to questions about covid-19 vaccinations. With an average of around 300 people viewing recordings of every event we host, we are focused on continuing to deliver a useful series of virtual events, to reach as many people as possible.

## International TSC Research Conference 2021 roundup

**Have you accessed our community recordings from the International TSC Research Conference 2021? Head to [tuberous-sclerosis.org/ITSCRC2021community](https://tuberous-sclerosis.org/ITSCRC2021community) to see an overview of the International TSC Research Conference, with videos from TSC researchers especially for the community**

## Social media

With over 4,000 followers of our Facebook page alone, our social media pages have quickly become a key platform for the TSA and the TSC community. Over the last 12-18 months we have given greater focus to our Facebook and Twitter presence, so you can keep up-to-date with our work and keep in touch with other community members.

We also have further plans to improve our social media channels, so that they can be even more effective.

## Postal communications

Although we have focused a lot on digital, we are still championing traditional modes of communication too! We have been keeping in touch with you also through the post, including Scan, for those who prefer to read things on paper.

We recently released the first version of our new 'Welcome Packs', so that those new to the TSC community can get to grips with key info about living with the condition. The Welcome Pack includes an introduction guide to TSC, leaflets, and further information on how the TSA can help the TSC community. Further updates to the Welcome Pack are planned, with different versions planned for TSC health and social care professionals who get in touch with the TSA.

## Monthly email newsletter

Usually posted on the second Friday of every month, our monthly email newsletter is a bitesize overview of all-things TSC. If you don't read anything else about TSC, be sure to read this!

## TSA Support Line

Our TSA Support Line, and our small and friendly team of Support Line Advisers, have been answering lots of calls and emails from the TSC community on all-things TSC, whether to give specific information or even just to be a listening ear. We've also been helping lots of social and health professionals to better understand TSC, through our support line.

# TSA festive greeting card design 2021 competition

**Are you a budding artist, or are passionate about design? Enter our festive greeting card 2021 design competition, for a chance to have your work proudly displayed as a TSA card!**



Our greetings cards are always very popular, and now your own design could take pride of place amongst those that the TSA use in winter 2021. The competition is open to everyone of all ages in the TSC community in the UK. You can even submit more than one entry!

Whether you want to create a traditional snowy winter scene, something more modern, or anything else that is festive, design your card as you want it and enter it into the competition. Your entry could be a drawing, painting, photograph or even something designed digitally.

The winning entry will be printed and sold on our online shop, with all funds raised from the sale of the cards going towards supporting our work to improve the lives of people affected by TSC. The winning designer will also receive three packs of their printed card (with 10 cards in each), and a TSA hoodie!

To enter this year's festive greeting card competition, head to [tuberous-sclerosis.org/2021cardcomp](https://tuberous-sclerosis.org/2021cardcomp) for more information, an entry form and terms and conditions. Alternatively, contact our fundraising team on [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org) or 0300 222 5737 to find out more!

**Entries close at 12pm noon on Monday 23 August 2021. The winner will be selected by a judging panel and announced in September 2021.**



# tsa+ GAMING CHAMPION



## Be a summer TSA Gaming Champion

**Calling all gamers! Would you like to combine your passion for gaming with the chance to improve lives of people affected by TSC?**

Then become a TSA Gaming Champion – fundraise through a gaming challenge of your choice and make a difference to the TSC community. Maybe you'll choose a marathon session of a chosen game, organise a gaming tournament, or even a speedrun? Whatever you do, you'll be changing people's lives!

### HOW IT WORKS



Create your fundraising page on JustGiving



Set a date and time for your gaming event



Tell everyone about your challenge



Take on your challenge and improve lives



It's easy to get involved. Just think of a challenge, set-up your JustGiving fundraising page and get gaming! You'll also find loads of handy tips and ideas in our special TSA Gaming Champion fundraising guide, to keep you going.



**Head to [tuberous-sclerosis.org/gamingchampion](https://tuberous-sclerosis.org/gamingchampion) to find out more!**



# Changing faces

The TSA is saying a fond farewell to Mega Arumugam, an important member of our Support and Information Services team. But, we also say a warm welcome to Rachel Harding, the newest member of the TSA!



*As I move on to the next chapter in my professional life, I leave here knowing more than when I arrived. I am honoured to have worked with such a wonderful community. The knowledge and learning gained from being part of the TSA team has been so rewarding and inspirational. The nature of TSC makes every day on the TSA Support Line a unique experience, with no two calls ever being the same. As I bid my farewell, I am pleased to welcome our new and brilliant Support Line Adviser, Rachel Harding. Best wishes and every success to everyone in the TSC community.*

**Mega**



**MEGA ARUMUGAM**



**RACHEL HARDING**



*Hello everyone! My name is Rachel. I have joined the TSA as a Support Line Adviser and I am really looking forward to getting involved with the TSC Community.*

*I started my career with a large insurance company, where my role involved speaking to clients, and it was here that I learnt the value of listening. Even if I was unable to solve the problem that was presented, it was vital that the person felt heard and that their time was respected. I then retrained and worked in the outdoor activities industry, where I gravitated towards supporting people with special educational needs and disabilities, including people living with autism. This was a wonderful journey, and after several years I then began working on projects for organisations that help the most vulnerable groups in society. The skills gained from these roles will be helpful to the TSC Community.*

*More recently, I have been working as an Information Officer, where I took calls, emails, instant messages and texts from members of the public who were being abused. The TSA Support Line adviser role came up and after looking at the role, the website and social media I knew instantly that I wanted to be involved with this incredible charity.*

*Several years ago, I moved to North Wales while pregnant. This presented some interesting challenges, not least the language barrier, and due to having no support network I decided to set up my own community group which helped active parents stay active once their kids were born.*

*For fun I am studying a degree in Environmental Sciences and I also run, sew clothes and grow my own fruit and vegetables. I have a child and two dogs which keeps me busy. I am looking forward to meeting everyone!*

**Rachel**

# Carer self-care: Looking after yourself, as well as others

**There are an estimated 13.6 million unpaid carers in the UK, including many people in the TSC community who care for a loved one who lives with TSC. Being a carer for a loved one can often be an emotionally draining and exhausting challenge, leaving whole family units overwhelmed. If you care for someone who lives with TSC, it's important to remember to also care for yourself.**

A recent Carers UK survey highlighted the impact that caring can have on the wellbeing of carers: 1 in 3 carers said that they had suffered mental ill health as a result of caring, 3 in 5 carers confirmed physical ill health due to being a carer, and 8 in 10 carers said that they felt lonely or socially isolated.

It is common for carers of loved ones to find themselves so invested in their caring responsibilities that they have little or no ability to think or act upon anything else. This is understandable, as putting all of our energy and time towards supporting people we care about is often placed as a priority above our own wellbeing. But, self-care is also vital.

Self-care for carers helps to create meaningful and fulfilling lives, even during the most challenging of times. Carer burnout is not uncommon, and often only a natural reaction to the impact of caring. Taking even a very small amount of time to act upon your own social and emotional wellbeing can have many positive impacts, and is not selfish but rather a necessity to recharge your batteries, so that you can best care for your loved ones.



## Here are some tips on how you can continue in your caring role while maintaining your own emotional resilience:

### 1. Acknowledge and talk about your own feelings

Guilt, anger and depression are just some of the common emotions that we can experience when caring for someone becomes too much. It is normal to feel that you are not coping at times – these feelings should not be ignored, but instead acknowledged.

By being consciously aware of these negative emotions, you can come to terms with them and move forward in a way that is constructive and focused on acceptance. A recent TSA virtual session by Dr Jennifer Black (Clinical Psychologist, Bristol Royal Hospital for Children), discussed this through Acceptance and Commitment Therapy (ACT). You can watch the session at [tuberous-sclerosis.org/living-well](https://tuberous-sclerosis.org/living-well). It can also help to talk about your feelings with someone, whether a family member, another loved one, or even the TSA Support Line (**0808 801 0700 / support@tuberous-sclerosis.org**).

### 2. Ask for help

This can be an incredibly difficult step for carers to take, but asking for help can sometimes make all the difference. Whether it is financial, emotional or physical support, speaking to someone who may be able to help your situation could open up opportunities you had not considered previously. At the very least, telling an employer, GP, or the council can help to start a conversation about support for you as a carer.

### 3. Get some respite, even five minutes

Finding time for yourself might not always be possible, but ideally a schedule of regular respite breaks can be a big help. Whether it's a full day or even just five minutes, taking some time for yourself can help to 'refuel your carer tank'.

You might be able to access respite care through your local authority. Even if you don't think that council respite care would be suitable for you, it can sometimes be still worth having an initial chat with them.

### 4. Healthy living

A balanced diet and regular exercise affect how we feel physically and mentally. It can be difficult as a carer, but even a quick walk in the park, or grabbing some fresh fruit rather than a sugary snack, can have big benefits.

By living a healthier lifestyle, you might find that your energy levels and mood also pick-up, helping you to help yourself more and more.

### 5. Take steps for better sleep

Everyone feels better after a good sleep, and often much worse following a night of unrest. It might not be possible depending on your personal circumstances and the circumstances of your family, but taking steps to getting better sleep might benefit to you. Even a power nap during the day can be energy boosting, and help you to feel better and care for your loved one.

Over the last 18 months we have hosted two sleep-focused virtual sessions. You can watch them in full at [tuberous-sclerosis.org/sleep-problems](https://tuberous-sclerosis.org/sleep-problems).

**Being a carer in the TSC community can sometimes be extremely lonely and isolating, but remember that the TSA is here for you, as is the wider TSC community who understand the impact of TSC on daily life. Get in contact with the TSA Support Line, or join in the conversation on our Facebook page ([facebook.com/thetsauk](https://facebook.com/thetsauk))**

# Your first steps after a recent TSC diagnosis

**The road to understanding how TSC affects you or a loved one following a diagnosis can be confusing, frustrating and very difficult. The TSA is here for everyone at all stages of their TSC journey - including the opening days, weeks and months - when it can be difficult to know what the first steps should be. Although a new diagnosis is different for everyone, there are some common steps that can be useful.**

The words 'Tuberous Sclerosis Complex' can take time to work through – not only in understanding what TSC is and how it can affect people, but also the wide range of emotions you and those around you will undoubtedly feel. For example, grief is a common reaction, particularly for parents who receive a diagnosis for their child, with some possibly feeling that the lifestyle they had imagined for their son or daughter might now not happen. You may even feel guilt or anger, and wonder 'Why me?' or 'Why my child?'

People new to the TSC community also often have lots of questions, and 'information overloading' is a common and understandable reaction to a diagnosis. You may find yourself quickly becoming an expert in epilepsy, autism, kidney problems or any of the other issues that can affect someone living with TSC.

There is never a perfect way to respond to a new diagnosis, but the important thing to remember is that these emotions and responses are normal, and you are not alone. When you feel ready, these steps might come in handy for you and your loved ones:

## 1. Have a chat with the TSA's support line advisers

Through the TSA Support Line (**0808 801 0700 / [support@tuberous-sclerosis.org](mailto:support@tuberous-sclerosis.org)**) you can speak to a friendly and empathetic member of the TSA's support team. Whether you have a specific question or just want a listening ear, we're here for you. We will also offer to send a TSA Welcome Pack to you.

## 2. Do some research, but only if it is helping you move forward

The TSA's website and our support line are a wealth of information for you and your loved ones. Getting to know TSC better can help you feel in more control. But, don't feel burdened to become an expert, as this can feel overwhelming and not be helpful.

## 3. Focus on the person, not the condition

As challenging as a diagnosis can be, it is important to not compare the person diagnosed to their peers. Celebrate good days and acknowledge achievements, no matter how small they are.

## 4. Take it a day at a time

TSC affects everyone differently, and it can be difficult to know how TSC will impact on a person's life in the months and years ahead. By looking too far to the future, it can feel like you're on a never-ending rollercoaster. The most important day for you and your family is today.

## 5. Think about an NHS TSC Clinic referral

We suggest that everyone living with TSC gets a referral to an NHS TSC Clinic. The clinicians in TSC Clinics are experts in the condition, and can give medical recommendations in managing and treating the condition, so that the person living with TSC gets the best care possible.

**However you begin your TSC journey, do it at your own pace, and do not compare yourself to others.**

**Whatever your initial response to a new TSC diagnosis, remember that you are not powerless – improved information, advances in medical care and ongoing research allows us to continue to look to the future of diagnosis, treatment and management of TSC with hope.**



# London Marathon 2021

The London Marathon 2021 takes place on Sunday 3 October 2021, and we have some incredible runners covering the course in aid of the TSA.

Last year's in-person London Marathon was cancelled, meaning that 2021 is a bumper year, not only for the event but also for TSA runners, with seven TSA runners taking on the marathon alongside thousands of others around them. 50,000 virtual runners will also be challenging themselves to 26.2 miles, including three virtual runners on the TSA's team!

The team is already busy training for their individual events and has hit the ground running with their fundraising efforts. **Colin Hart** has already raised an incredible **£3,152**, making him the fundraising front runner!

We wish all of the TSA London Marathon runners 'Good luck' in their training and we look forward to hearing about their successes!



ANNEMARIE COTTON



DANIEL MARKS



MICHAEL DONNELLY



MARLON RASHO



COLIN HART



PAUL HARRISON



GRAHAM SALE

If you would like to be part of the 2022 team, register your interest now at [tuberous-sclerosis.org/LondonMarathon](https://tuberous-sclerosis.org/LondonMarathon)

## Facebook fundraisers

This year 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:

Alice Lawrie  
Aruna Bhatt  
Ashleigh Hayes  
Becky Saunders  
Beth Robinson  
Brian Thomson  
Carla Paramental Terry  
Chris Maidens  
Courtney Lyn Cramer-Stout  
Danielle Nicholson  
Dave Earnshaw  
Denise Kernaghan

Donna Finan  
Eamonn Lacey  
Hannah Hunter  
Helen Symonds  
John Godden  
Joyce Hunter  
Katie Eliot  
Katie Morris Taylor  
Katie Vaughan  
Liam Rose  
Lucy-Anne Smith  
Maria Panteloglou

Marilyn Dipple  
Mary Burns  
Mischa Smith  
Morag Dickson  
Natty Wilson  
Nicola Elliott  
Nina Shrum McMullen  
Paula Mapley  
Philip Rogers  
Ruth Evans  
Samantha Jayne Baldock  
Sarah Jane Mee

You can set up your own TSA Facebook fundraiser in just a couple of clicks from your Facebook profile, to raise vital funds for the TSA!

# Thanking all our Fantastic Fundraisers!

With the recent easing of lockdown restrictions, the TSC community has been busy getting their fundraising minds in gear and putting their plans into action. Thank you to all of our fantastic fundraisers, who are helping to improve lives in the TSC community.



**Emma Askew** went without chocolate in March, to raise funds for the TSA! Emma raised a choc-tastic **£50** for her daughter Amy and others who live with TSC. Brilliant work, and very 'sweet'!



**Luke Campbell** ran a mile every single day of May, in support of his cousin, Harvey, who lives with TSC. Luke and his supporters gathered an amazing **£2,027** and were even featured in their local newspaper!

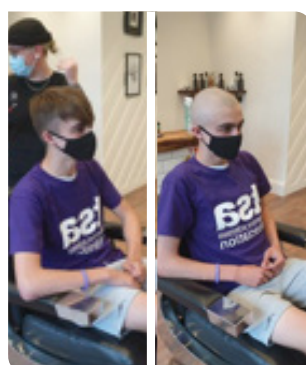
**Seren Griffiths** lives in the same town as Luke Campbell, and was so inspired by Luke that he took on his own mile a day challenge, this time in June. Seren hit a fantastic **£610** – a huge well done!



**Tom McGeoch** was inspired to walk from Oxwich Bay to Aberavon, having previously received enormous support from the TSC community. Tom raised a whopping **£1,455**!



**Sarah Mees** took on a 1 Million steps challenge in support of her son, Cody, who lives with TSC. Sarah and her supporters' hard work paid off, with an amazing **£386** raised!



16-year-old **Ronan O'Lenksie**, who recently had brain surgery for TSC-related epilepsy, had his head shaved to celebrate his new found post-surgery life and raise money to improve lives in the TSC community! A huge thank you and well done to Ronan, who achieved a hair-raising **£2,610**!



Manchester City Super Fan **Eddie Sparrow**, seen here with footballer Sergio Aguero, scored a wonderful **£460** by organising numerous football card events throughout the months of May and June. Eddie waits for hours and hours at the Manchester City training ground and the club's Etihad Campus to ensure that winners receive signed Manchester City memorabilia! Thank you, Eddie, for all your time and support

If you have been inspired by our fantastic fundraisers, please contact our fundraising team at [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org) and they will be happy to help!

# The pandemic didn't stop us, and it didn't stop you either!

**Covid-19 changed the world, but it's great to know that our community has continued to fundraise, all while sticking to local restrictions. Here, we thank some of you!**



**Tea & Scones for TSC 2021** fundraisers raised an amazing **£3,800**, gathering virtually and in-person (where able to do so) for a tea and pastry or something sweet, whilst acknowledging Global TSC Awareness Day on 15th May 2021. Our supporters included:



● **Sarah Best** and her family all got their aprons on and baked-up a fantastic **£410**! Thank you for all of your hard work!

● **Sharon Connolly**, her son Hugo and friends held a virtual raffle as part of their Tea & Scones event, raising a fantastic **£2,190**. Further support came from Sharon's employer Scott



Bader, who match funded part of the money raised!



● **Mamta Pattni** hosted an 'alternative' Tea & Scones party for a group of friends who enjoyed some fine dining and desserts created by Mamta herself! The party cooked-up a fantastic **£182**!

● **Nicola Daykin** and

her family organised a virtual Easter bonnet competition and a raffle on Facebook, raising an amazing **£890**! Egg-cellent work!



Our **TSC Clinics Virtual Challenge** participants, who challenged themselves to cover the equivalent distance between two chosen TSC clinics, raised a whopping **£3,100**!



● **Kelly Brown** walked 12 miles – The distance between the London TSC clinics St George's University Hospital and Royal Free hospital, gathering **£22**!

● **Wendy Lane** got her walking boots on and

covered 45 miles in 28 days, the distance between Central Manchester University Hospital and Liverpool's Alder Hey In The Park. Wendy raised a brilliant **£439**!



● **Barry Pearce** and **Adam Maddocks** ran four half marathons across every weekend in March, to support Barry's daughter who lives with TSC. This equalled 52.4



miles, the same distance as between Royal United Hospital Bath, and University Hospital of Wales, Cardiff. Barry and Adam's hard work raised a whopping **£776**!

● The TSA's own Joint Chief Executives **Louise Fish**

and **Sam Barber** took on the challenge as a team, cycling and walking 100 miles and raising an amazing **£1,896**! The distance was equivalent to between Leeds Royal Infirmary and The Royal Victoria Infirmary, Newcastle-upon-Tyne.

**Thank you to everyone who supported our amazing fundraisers and the TSA Community!**



# The huge impact of corporate support

**Corporate support plays a major role in the work of the TSA, with organisations choosing to help us in lots of different ways. Whether it is through a one-off event or with a year-long calendar of activities, we are very grateful to all of our corporate supporters.**

**Hiscox London Market Operations** organised a covid-friendly team challenge, splitting into three groups to cover a marathon distance across London, with some friendly competition on who could finish the fastest (and raise the most money)!

The route took the Hiscox teams from Twickenham and along the River Thames, all the way to Greenwich. Many blisters later, Team 2 were victorious, finishing in 7 hours and 33 minutes and raising over **£2,700!** Ellie said: "It feels great to support such a brilliant charity, and we look forward to doing more events in the future!"



We have also received a generous donation from **Softcat PLC**. At the end of 2020, the TSA was nominated

to receive **£750** following a highly competitive internal quiz for staff named 'University Challenge'. Twenty-eight teams across Softcat competed to come top of the leaderboard, and the 2nd placed team kindly nominated the TSA as their charity of choice thanks to TSA supporter **Tom Stafford**.

In 2021, to replace Softcat's annual charity May Ball, which could not go ahead due to the pandemic, the Softcat senior leadership team donated a whopping **£20,000** to the TSA!





We recently released a brand new corporate partnerships booklet, with lots of information for businesses, employers and employees about the huge benefits of partnering with the TSA. The pack includes info on corporate social responsibility, employee empowerment and making a real difference in the TSC community



## Over to you....

**You** can help us to continue our vital work, through your own organisation. There are lots of different ways that you can help - some as simple as throwing our name in the hat for charities your group may support!:

### You can nominate the TSA for your organisation's Charity of the Year

Does your workplace have a Charity of the Year scheme? Ask how you can nominate us, as a charity close to your heart.

We can provide details or help you with any applications, or we could even speak with your company directly. All you need to do is provide the passion!



### Match funding

Many businesses will agree to match your fundraising efforts for a cause, thereby doubling the money you give to improve lives in the TSC community. **Sharon Connolly's** employers **Scott Bader Company Ltd** did this, kindly donating **£1,000**. Ask in your company, and double your money! Don't worry about getting a perfect fundraising idea, as we can help you.



### Do you know local businesses who could support us?

Do you, a family member or a friend run a small business, and would like to support our work? A great way to do this is to set-up an agreed donation to the TSA, such as a small percentage on new business, or a percentage of every sale. This sounds tricky, but we can help to make it quick and easy through our partners Work for Good.

**For further details on corporate partnerships with the TSA please visit [tuberous-sclerosis.org/corporate-partnerships](https://tuberous-sclerosis.org/corporate-partnerships) and download our new fundraising pack. Alternatively, contact our fundraising team on [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org) or 0300 222 5737**

# Trust and foundations

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

- Baily Thomas Charitable Fund
- Beechwood Trust
- Hamilton Wallace Charitable Trust
- Ian Fleming Charitable Trust
- Jeans for Genes
- Meikle Foundation
- P F Charitable Trust
- R S Brownless Charitable Trust
- St James's Place Charitable Fund
- Swann – Morton Foundation
- The Michael and Anna Wix Charitable Trust
- The Rest-Harrow Trust

## Gone, but not forgotten

**The TSC community is made up of incredible individuals and families, who all understand the impact that the condition has on daily life. When someone affected by TSC is no longer with us, it is felt across the entire community.**

Although the lives of individuals in the TSC community may be very different, the connection that everyone shares in understanding TSC is unbreakable. The TSA was very saddened to hear of the recent passing of a very well loved and well known member of the TSC community.

Zoë Bull was a popular TSA volunteer and TSC community member, who lived with TSC and lymphangioleiomyomatosis (LAM). Zoë was known by many for her regular Outlook attendances, and her wonderful writing abilities.

In the words of Zoë's parents: "Zoë was loved by everyone and brought happiness to all. She endured many hospital visits and stays, many painful procedures and operations yet remained optimistic for the future. Zoë was finally overwhelmed with lymphoma and sadly passed away with her family around her on Easter Monday."

Before Zoë passed, she achieved her aim of writing a book, *'Rare: A journey of self-acceptance'*. *Rare* highlights Zoë's journey of self-acceptance in the face of living with TSC and LAM. Zoë's family have taken-up her torch, using Zoë's writing and work to highlight her journey, so that Zoë's life can be celebrated and others can learn from her. The book is available online at Amazon, Waterstones and other popular stores.

Find out more about Zoë, the remarkable woman that she was, and her book at [rareajourneyofselfacceptance.com](https://rareajourneyofselfacceptance.com).



## Rare: A Journey of Self-Acceptance

**By Zoë Bull**

Growing up, Zoë didn't want to have anything to do with her rare condition, Tuberous Sclerosis Complex (TSC). She just wanted to be the same as everyone else. But, when she suffered a life-threatening kidney bleed aged twenty, and multiple lung collapses a few years later, Zoë discovered she also had a second rare disease called LAM

**Through informative research and deep introspection, Zoë has written about her experiences with TSC and LAM, and how she has learnt to accept them in a way she never had imagined.**

*"This book captures the reality of a life touched by TSC and will be an encouragement to those who read it. Zoë has achieved so much, in spite of all that was stacked against her. I have read and written several scientific papers and book chapters on TSC in my professional capacity, however, Zoë's book has given me a deeper insight into TSC, from a different angle."*

**Dr Sam Amin, Paediatric Neurologist with a special interest in TSC**

Copies of Zoë's book can be purchased from: **Amazon.co.uk**, **Blackwells.co.uk**, **Bookdepository.com**, **Hive.co.uk**, and **Waterstones.com**

# Rare: A journey of self-acceptance

**Zoë Bull's posthumous book brilliantly recounts a young woman's path to self-discovery and acceptance of the impact of living with TSC and LAM.**

*Rare: A journey of self-acceptance* is an honest and open overview of Zoë's world. A world of overcoming the odds, and having the bravery to accept who we all are. Zoë's pragmatic viewpoints of living with TSC and LAM – including the struggles and worries of hospital visits, work towards seizure control, and the promise medicine trials – will reverberate throughout the TSC community and beyond.

Living with a rare disease can be an isolating and lonely experience, where it can often feel like very few people truly understand what it can mean to live with the condition. Zoë's book illustrates a world impacted by TSC and LAM, not only for her, but also for her loved ones and others in the TSC community. *Rare* reminds us all of the power of the TSC community, and the importance of facing the impact of TSC together.

In Zoë's short life, she achieved something that most of us will never reach: Fulfilling the pursuit of self-discovery and the ultimate goal of acceptance.



## TSA Support Line

 **Freephone**

**0808 801 0700**

Monday to Friday 9am - 5pm

 **Email**

**[support@tuberous-sclerosis.org](mailto:support@tuberous-sclerosis.org)**