

scan

FEB 2021

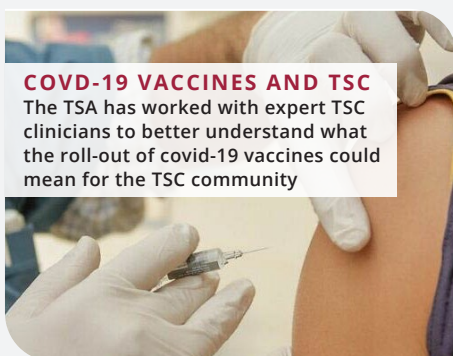
The magazine of the TSA

**A light that
shined through
a dark winter**



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LUKE LANGLANDS, EDITOR

From the Editor

We're almost through to the end of winter, and it's always darkest before the dawn. Everyone at the TSA is hoping that that we are able to move towards spring and summer with a feeling of positive change.

The TSA hasn't stopped over the last 12-18 months, despite us having to adapt to the realities of covid-19 (as you no doubt have also). We hope our work is helping to make things a little bit easier for you, during this very difficult time.

We're working with a clear roadmap of priorities for 2021, organised around support and information, fundraising, and research. Much of the work that we have planned for this year is outlined in this issue.

We've tried to cover lots of different things in this Scan, not only about covid-19, but on wider topics, too. On **page 10** you can see our ambitious plans to continue our very popular virtual events throughout the year, and on **page 12** we share updated information on living with TSC while being employed. Of course, we also say 'Thank you' to our amazing fundraisers on **page 18**, who have been working their socks off - while observing government restrictions - so that the TSA can continue with our work.

This Scan isn't just about providing information, as we also want to inspire you! On **page 22**, we're delighted to introduce you to Millie Power and her incredible story. Having been diagnosed with TSC when aged 11 months, Millie has gone on to fulfil her dream of working as a children's nurse, so that she can help children who are in a similar situation that she was once in.

So, grab a cuppa, settle in and welcome to your latest Scan!

Luke Langlands, Editor

Support and Information

Luke Langlands

(Head of Communications and Support)

Anna Gaunt

(TSA Support Line Manager)

Mega Arumugam

(TSA Support Line Manager)

The TSA Support Line is here for you, Monday - Friday 9am - 5pm:

Freephone: **0808 801 0700**

Email: **support@tuberous-sclerosis.org**

Have you used the new TSA Support Line? If so, we want to hear from you! Fill in our support line survey, so that we can continue to improve the service.

Visit <https://bit.ly/2NkZiww> or contact the TSA Support Line.

A word from your Chair

GETTING THROUGH THE PANDEMIC, AND LOOKING TO THE FUTURE

The start of 2021 has been incredibly difficult for everyone who is either living with TSC or caring for a loved one with TSC. Whether you have been home-schooling (as I have), caring for someone who is shielding, or been desperate to visit a loved one who lives in residential care, the covid-19 pandemic is one of the toughest challenges our community has ever faced.

However, you are not alone, and the TSA stands alongside you.

All of us who have lived through these difficult days and often sleepless nights are sharing similar feelings of pressure, frustration and confusion. While we have all been doing our best to hold things together, and look after ourselves and loved ones, we shouldn't forget that it's also 'ok to not be ok', too. We all have our limits and we need to be kind to ourselves as well as others – self-compassion and taking even a few minutes every day for ourselves can make a big difference to how we see the world.



SANJAY SETHI, CHAIR

Bringing in funds despite covid-19

We've been working on ways to continue to bring in income for the TSA, after covid-19 devastated the amount that we receive. We were delighted to host the fundraising event '*In Conversation with Sir David Suchet CBE*'. If you weren't able to make what was a fantastic night, you can get access to the recording by heading over to <https://bit.ly/3qMvRWi>.

Keeping TSC research on track

Alongside our work to support you during this year, our desire to better understand TSC isn't stopping. As part of this, the TSA is hosting the virtual International TSC Research Conference on 17 – 19 June 2021. The conference enables researchers from around the globe to come together and keep the incredible research that they are doing on track, despite the pandemic. While we grapple with the challenges that we're facing right now due to covid-19, it's reassuring to know that our incredible researchers and clinicians remain focused on finding solutions to the long-term challenges associated with TSC. On 20 June, immediately after the international conference, everyone at the TSA is looking forward to hosting a Community Education Afternoon, where researchers from the conference will share their work with the community, giving us all hope for the years ahead.

Supporting clinics and the development of new treatments

The TSA continues to work alongside the amazing NHS TSC clinics, to make sure you're getting the best care possible. We ensure that the views of people affected by TSC are considered in the development of promising new treatments for TSC. We anticipate that new treatments for TSC-related epilepsy and facial angiofibromas will be launched during 2021, with further new treatments for these conditions in Phase 2 trials - we will share more information on these as we have it.

Through the TSA's work for you, and your inspirational support for each other, we can work to get through this. Stay safe, look after yourself and your loved ones, and be mindful of the ongoing roll-out of vaccines, which is already well on its way to helping us to a brighter near future.

Sanjay

Chair@tuberous-sclerosis.org

A word from your Joint Chief Executives

WE KEPT A LIGHT SHINING THROUGH THIS DARK WINTER

The 'new normal' we were living in over summer sadly gave way to a second wave of covid-19. At the TSA, we've been determined to keep a steady light shining, as we await the upcoming green shoots of spring to return, and its hopes of a brighter future.

Bringing everyone together

We continue to provide help for today through our popular series of virtual events, giving us all the opportunity to still connect while we can't meet in person. We've got a great calendar lined up for this year, with many of you attending a wide range of events we've already hosted in 2021. This included the amazing 'In Conversation with Sir David Suchet CBE', which was just the tonic we needed to help raise all of our spirits, right at a time when it has been most needed.

Of course, 2021 will also include our flagship events, including Outlook and our special get together events for community members living in Scotland, Wales and Northern Ireland. Head to **page 10** for more info on our plans for events in 2021.

Reaching out

As always, our hand remains outreached for you to grab. One of the main ways that this can happen is through the TSA Support Line.

We recently sent postcards across the UK to remind everyone that the TSA Support Line is here to help. If you're feeling lonely, or you have questions about covid-19 or anything else about TSC, our friendly and caring support line advisers are here to help. Freephone 0808 801 0700 Monday to Friday 9am – 5pm*, email support@tuberous-sclerosis.org or write to 'Freepost TSA'.

To make the TSA Support Line even more accessible, this year we are also planning on introducing web chat functionality and also translation services.

Sharing information

Our goal is to make sure that everyone in the TSC community has access to timely, important and useful information about TSC. This includes the often fast-changing, complicated and overwhelming covid-19 advice and guidance from governments across the four nations. We will continue to share up-to-date information through the TSA's website (tuberous-sclerosis.org), Facebook ([thetsauk](https://www.facebook.com/thetsauk)) and Twitter ([@UKTSA](https://twitter.com/UKTSA)). If you have questions around things like TSC and covid-19, when you can visit a loved one living in residential care, or how fast you are likely to be vaccinated (if you have not yet been), we're here to make things clearer.

We remain grateful for the incredible support of the TSC community during this challenging time, and we continue to be here for you, and we will get through this together.

Louise and Sam

Joint Chief Executives



LOUISE FISH,
JOINT CHIEF EXECUTIVE



SAMANTHA BARBER,
JOINT CHIEF EXECUTIVE



This could be YOU in 2021

Take the
leap and get
fundraising
for us!

Whether it's a skydive,
bake sale, run or
anything else you can
think of, fundraise for
the TSA and help us
to improve lives in the
TSC community.

Note: Always follow local
guidelines and guidance on
restrictions in your local area.



Registered with
**FUNDRAISING
REGULATOR**

tssa
tuberous sclerosis
association

NHS TSC Clinic updates

Updates from some of the NHS TSC Clinics across the UK

Addenbrooke's Hospital (Cambridge)

Children's clinic

The clinic was quick to change clinic appointments to be as remote as possible and have been able to maintain all normal activities, with the continuation of existing treatments being made a priority, along with addressing issues around social isolation for families who normally greatly benefit from specialist schooling.

Dr Alasdair Parker, Consultant Pediatric Neurologist
Tel: 01223 216 662

Email: alsadair.parker@addenbrookes.nhs.uk

Adult's clinic

A multidisciplinary adult TSC service has been launched. Any referrals to this clinic should be made by your GP (ideally with all relevant background information) to Dr Anke Hensiek.

Dr Anke Hensiek
Tel: 01223 217 603
Email: ahensiek@nhs.net

Bath Supraregional TSC Service (Royal United Hospital)

Bath Supraregional TSC Service has continued to operate fully since the pandemic started, adapting by holding regular clinics through either phone, video or face-to-face – depending on the needs of those we see. Care of the community remains paramount, and the clinic remains available Monday – Friday by phone or email.

Ms Charlotte Reed, Administrator
Tel: 01225 821 545
Email: charlottereed1@nhs.net

St George's Hospital (London)

The clinic is now located at Queen Mary's Roehampton and we are aiming to have all appointments virtual.

Ms Lydia Israel, TSC Nurse Specialist
Tel: 020 8725 1688
Email: TSCreferrals@stgeorges.nhs.uk

Newcastle TSC Clinic (Royal Victoria Infirmary, Newcastle-upon-Tyne)

The clinic has continued to come together throughout the covid-19 pandemic by meeting virtually. A major focus has been supporting patients with everolimus dosing changes and advice for vaccinations.

Professor John Sayer, Professor of Renal Medicine
Email: john.sayer1@nhs.net

Belfast TSC Clinic (Belfast City Hospital, NI)

The clinic has remained active throughout the pandemic, with appointments carried out over the phone. Radiological scans also continued, though there is some backlog. Those that we see at the clinic who had tested positive for covid-19 have all made a full recovery, including those on mTOR inhibitors.

The pandemic has led to dramatic changes in the way the service is run, and the clinic is very keen for patients to be involved in any long-term changes. As part of this, a questionnaire was sent to community members at the clinic, and we are still keen to hear any ideas and suggestions from anyone who has not yet contributed.

The clinic hopes to offer an improved TSC service for Northern Ireland soon, providing a mixture of telephone and face-to-face appointments.

Dr Deirdre Donnelly
Tel: 020 9504 7240
Email: jennifer.hand@belfasttrust.hscni.net

You can find details of your local NHS TSC Clinic, and information on how to be referred to an NHS TSC Clinic, by visiting the TSA's website.

Covid-19 vaccines and TSC

The TSA has worked with TSC clinicians in the NHS to better understand covid-19 vaccines and what their roll-out means for the TSC community. We've also been answering lots of questions on the TSA Support Line about covid-19 vaccines from people who haven't had one yet. Here, we share some answers to some of the common questions we've been receiving.

Is it safe to receive a covid-19 vaccine if you live with TSC?

The TSA is not aware of any evidence suggesting that covid-19 vaccines are unsafe for those living with TSC. If you are offered any covid-19 vaccine, it is important that you have it.

Can I catch covid-19 from a vaccine, and do I need to be vaccinated if I have already had covid-19?

You cannot catch covid-19 from a vaccine. If you have already had covid-19, you should still get the vaccine, as it may be possible to get the virus more than once.

Will having the covid-19 vaccine mean that I need to alter any TSC treatments that I am receiving?

If you are being treated with mTORs for AMLs or SEGAs, you may wish to speak to your clinician about whether to stop taking the medicine for a week before and a week after being vaccinated. **However, if you are offered a vaccine at short notice you should still take it, and not delay.**

If you are taking mTORs for LAM or epilepsy, then it is probably better not to take a break from treatment. No changes to treatments should be made without first discussing the issue with your clinician.

Will children be vaccinated against covid-19?

Covid-19 vaccines are not routinely recommended for children under 16. However, it is advised that children at very high risk of exposure and serious outcomes should be offered vaccination, including older children with severe neuro-disabilities who regularly spend time in specialised residential care settings for children with complex needs.



What are the covid-19 vaccine priority groups?

The Joint Committee on Vaccination and Immunisation (JCVI) has listed the different groups of people who should be prioritised to receive a covid-19 vaccine first. These are:

- **GROUP 1.** Residents in a care home for older adults and their carers
- **GROUP 2.** All those 80 years of age and over. Frontline health and social care workers
- **GROUP 3.** All those 75 years of age and over
- **GROUP 4.** All those 70 years of age and over. Clinically extremely vulnerable individuals
- **GROUP 5.** All those 65 years of age and over
- **GROUP 6.** All those 16 years to 64 years who have underlying health conditions that put them at higher risk of serious disease and mortality, or are on their GP's Learning Disability Register. In addition, those in receipt of a carer's allowance, or those who are the main carer of an elderly or disabled person whose welfare may be at risk if the carer falls ill



- **GROUP 7.** All those 60 years of age and over
- **GROUP 8.** All those 55 years of age and over
- **GROUP 9.** All those 50 years of age and over

Which priority groups are people who are affected by TSC in?

People living by TSC will be in different groups depending on how TSC affects them or their loved ones. The TSA has worked hard to understand which individuals will be in which groups:

- Those who live with TSC and are in **care homes for the elderly** are likely to be in **GROUP 1**
- Those who live with TSC and are '**clinically extremely vulnerable**' to covid-19 are likely to be in **GROUP 4**. You will have received a letter from your GP or clinician if you are 'clinically extremely vulnerable'. If you have not received a letter and think you should be in this group, talk to your GP or clinician
- Those who live with TSC that are either **on their GP's Learning Disabilities Register** or **have one of the following conditions** are likely to be in **GROUP 6**:

- Chronic respiratory conditions (such as LAM)
- Chronic kidney disease (such as AMLs of kidney cysts)
- Chronic neurological conditions (such as epilepsy)
- Immunosuppression due to treatment with mTORs
- Severe mental illness
- Severe or profound learning disabilities

- **Carers for people who live with TSC** are likely to be in **GROUP 6** if:
 - The carer is in receipt of a carer's allowance
 - The welfare of the person that they care for might be at risk if the carer falls ill

- **Younger adults who live with TSC and are in residential care** are likely to be vaccinated along with fellow residents if vaccination of everyone living in the care setting is recommended

You must speak to your GP or TSC clinician before you make any decisions about whether to stop treatment before or after vaccination. If you are offered the vaccine, do not delay in getting it.

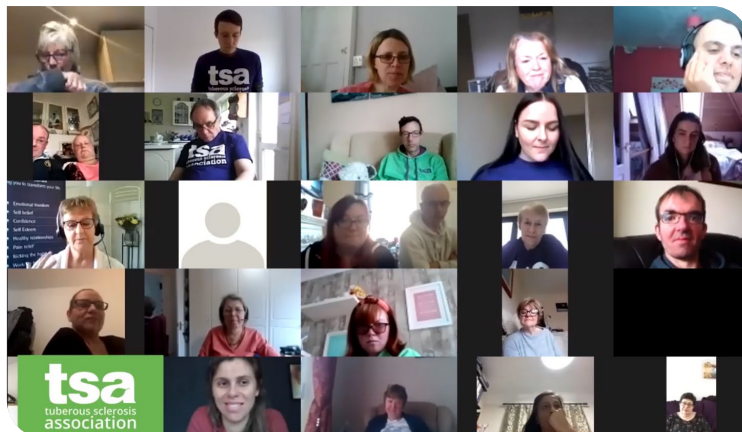
The TSA knows just how confusing and frustrating covid-19 guidance can be. We are continuing to work hard to make it easier for the TSC community to navigate guidelines, rules and recommendations so that we can make your lives easier. Continue to check our website and social media pages for ongoing updates, or contact the TSA Support Line.

TSA events

Everyone at the TSA is looking forward to the day that we can all finally meet again face-to-face. In the meantime, we're determined to still give everyone the opportunity to connect, engage and learn together through virtual sessions.

After introducing virtual events in 2020 for the first time, the response from the TSC community was very positive, with an amazing **560** sign-ups for events over the year, and a staggering **7,947** views of virtual event recordings on our website and social media pages!

We're aiming to host at least one virtual event every month during 2021 - the event could be a chance to check-in with each other, perhaps an update on some exciting new research or even a workshop around a specific TSC topic.



Some of our upcoming events



Epidiolex (cannabidiol) and TSC (8 March)

Dr Sam Amin (Consultant Paediatric Neurologist, University of Bristol) will discuss Epidiolex (cannabidiol) and its potential use in TSC-related epilepsy, as well as highlighting two further TSC-related epilepsy treatments undergoing clinical trials.



Outlook 2021 (17th April)

If you're an adult mildly affected by TSC, come along to Outlook to connect with others who understand the impact that TSC can have on day-to-day lives. There will be plenty of opportunities to make new friends, learn more about the work of the TSA and listen or take part in some great workshops.



Northern Ireland Get Together (13 March)

The TSA, along with the Belfast TSC Clinic, will open our virtual doors to the TSC community in Northern Ireland, as we discuss key issues focused on TSC and living in Northern Ireland, and offer opportunities to hear from the Belfast TSC clinic.



We also look forward to confirming dates for the Scottish Get Together and Welsh Get Together for later in the year, as well as many more events planned for the middle and second-half of 2021.

We've already hosted some great events this year...

- Women's Health, Menopause and TSC (13 January)
- Covid-19 vaccines and TSC: Q&A (8 February)
- In Conversation with Sir David Suchet CBE (18 February)

...and we can't wait to welcome you to many more!

Head to our website to book your place at any of our events, and remember that we try to share recordings of every session, in case you can't make it on the day!

It's always darkest before the dawn

2020 was a tough year for all of us, and so far 2021 has also proven difficult. However, there can be reasons to be thankful, even in these times.

Despite the hurdles we are all having to overcome, many in the TSC Community are finding joy in the little victories, discovering new talents or holding onto hope for the future.

Alice Lawrie:

"I'm thankful for having my full-time job that, although hectic at times, gives me a routine. I'm also grateful for Zoom, which allows us to continue to run our Brownie unit."

Rachael Davies:

"I'm thankful for having my first vaccine in December so we can make steps to returning to some form of normality."

Katie Eliot:

"I'm currently working on my Level 3 Counselling Skills course, and I am looking forward to hopefully starting my BA (Hons) in Counselling in September."

Lauren McWhinnie:

"I am grateful to have family and friends close by, whether that's at home or virtually – just knowing there's someone at the end of the line makes me feel at ease. Knowing there are vaccines to protect the vulnerable, including me, gives me hope. I am hoping for a summer to celebrate this year! In September, I hope I'll be accepted to study Access to H.E. in Sports Studies."

Luke Langlands:

"I've been learning to speak Polish for a few years now, but having more free time during evenings and weekends in 2020 meant that I could really immerse myself in the language."

Welcome to your new Joint Chief Executive

Samantha Barber recently joined the TSA as our Joint Chief Executive. Sam brings a wealth of experience to the TSA from many different charity roles and is enthusiastic about working to improve lives in the TSC community.

"Hi everyone! My name is Sam, and I'm delighted to be acting as Joint Chief Executive for the TSA. Everyone in the TSC community has made me feel incredibly welcome, and it's a pleasure to be here and working towards our mission of providing help for today and a cure for tomorrow."

I've previously worked in lots of different senior and leadership roles in the social, voluntary and charity sectors, and my main focus at the TSA has been to help bring in income and boost fundraising, so that the charity can

continue to be here for the TSC community. My role as Chief Executive is a job-share, alongside Louise Fish.

I am passionate about inclusion, equality and support for everyone, and I want to do my best to continue the great work of the TSA for this lovely community – this includes taking part in the NHS TSC Clinics Virtual Challenge (see [page 20](#)) as part of a significant birthday milestone (no, I'm not telling you what milestone it is!)

If you ever have any questions or ideas for me, drop me a line at Samantha.Barber@tuberous-sclerosis.org."



TSC and employment



We've received lots of enquiries on the TSA Support Line about seeking employment or having a job when living with TSC.

Whether you're currently employed, looking for a new job or thinking about starting work, here we address some of the questions and concerns that you might have if you wonder how living with TSC might impact your working life.

Can having TSC stop me getting a job?

There may be some jobs that you find more difficult, depending on how the condition affects you. TSC impacts on everyone very differently. This means that some people who live with TSC find that the condition means that they are unable to work altogether, while many others have successful and meaningful careers. However, it is unlawful for an employer to use TSC as a reason not to employ you, unless there is a health and safety concern. For example, if you have TSC-related epilepsy, a job working at heights could put you and others at risk in the workplace.

Should I tell someone interviewing me that I live with TSC?

You might be worried that a potential employer will judge you differently if you tell them that you live with TSC in an application form or during an interview.

However, under the Equality Act, it is unlawful for employers to ask questions about your health before offering you a job, except in a minority of cases such as for jobs in the armed forces.

Ultimately, it is a personal decision whether to tell an interviewer or not that you live with TSC.

Should I tell my employer that I live with TSC?

There is no legal requirement to tell your employer that you live with TSC. However, talking to an employer about how TSC affects you might be helpful. Your employer can only be aware of your needs and consider reasonable adjustments at work for you if they are aware that you live with TSC. But, it is a personal choice.

If you do decide to speak to your employer about your TSC, you might find it useful to refer them to our new publications '*TSC and employment: A guide for employers*' and '*TSC: A letter for employers*' – these are both available on our website, or you can contact our support line to get access to these.

Similarly, it is a personal decision whether to decide to tell co-workers that you live with TSC, or to choose not to tell them. However, you might find that talking to them about how TSC affects you helps to encourage an understanding and supportive working environment.

What are my rights as an employee?

If you are considered to have a disability under the Equality Act (England, Wales, Scotland) or Disability Discrimination Act (Northern Ireland), your employer has a legal duty to make reasonable adjustments for you.

You might live with TSC and not consider yourself to have a disability - this is ok. If this is the case, you may still qualify for protection under the Equality Act or Disability Discrimination Act. According to the acts, a disability is a physical or mental impairment which has a substantial, adverse and long-term effect on a person's ability to carry out day-to-day activities (for example, if you have TSC-related epilepsy this might be considered substantial and adverse). Even if your epilepsy is controlled by medication, treatment and management of a condition is rarely considered when determining if somebody has a disability.

What reasonable adjustments can I expect an employer to make if I am disabled under the Equality Act or Disability Discrimination Act?

Reasonable adjustments are things that your employer can do to help you at work. These might include:

- Changes to your working hours
- Allowing you time to go to medical appointments
- Providing adapted or different equipment
- Offering additional training
- Offering mentoring
- Arranging a regular 'check in' with you

The adjustments must be considered 'reasonable' to both you and your employer. For help with any costs associated with reasonable adjustments, your employer may be able to access funding through the government 'Access to work' scheme.

Employment support available for people living with TSC

There are lots of places to access support. The TSA Support Line's advisers can listen to any worries you may have about living and working with TSC, and offer support, information and signposting to other organisations that may be able to help. Get in touch 9am-5pm, Monday-Friday by freephone (0808 801 0700) or email (support@tuberous-sclerosis.org).

Other organisations who offer support include:

- **AbilityNet:** abilitynet.org.uk – Offer adaptive technology to make using technology easier
- **Acas:** acas.org.uk – Free, impartial and confidential advice about disputes in the workplace
- **Citizens Advice:** citizensadvice.org.uk – Free information services for people across the UK, including for issues related to employer and disability rights
- **Disability Law Service:** dls.org.uk – Free advice and representation for disabled people on specific areas of law, including disability discrimination, employment and welfare
- **Specialist Employability Support from Jobcentre Plus:** gov.uk/contact-jobcentre-plus – Intensive support and training to help disabled people into work



Know Your Rights: Social and residential care provision

We know that lots of you have questions and concerns about the long-term impact of covid-19 on care provision for loved ones in social and residential care.

At the TSA, we're working hard to try and give the TSC community clarity on issues around care provision, as we know how confusing and frustrating this time is for many. Our work includes providing information on the measures and assessment processes that care providers need to put in place during these times.

Visiting your loved one

It may still be some time before we are back to being able to have residential care visits like we used to have, so it is reasonable to expect some clear plans for until then. Decisions regarding visits in residential care homes should involve you, your loved one, the care provider and other relevant professionals such as clinicians, where appropriate.

It is important to be part of the conversation with your loved one's care provider in understanding the steps towards residential care visits. This might include:

- **A clear understanding and 'road map' towards restarting residential care visits**
- **Ways to keep in touch while usual visits are not possible, such as outdoor or 'screened' visits**
- **Consensus on effective ways to re-introduce and discuss visits with your loved one, so that your loved one is well prepared**

Changes in your loved one's care

A care package should not be changed without a Needs Assessment or Support Plan Review, and you should be informed of any changes that are made. To challenge any reduction in support, request written copies of the completed Needs Assessment Plan and the latest Care and Support Plan. If the changes mean that your loved one is no longer receiving the essential care that they were initially assessed as needing, there is a strong argument that this could breach human rights law. It is recommended that you keep a paper trail of any conversations regarding care provisions, by using post or email.

Have further questions?

Check UK government guidelines on care support during the pandemic (<http://bit.ly/2MvnxLr>), or contact the TSA Support Line to discuss more.

Key questions if your loved one's care provision has changed:

- **Have you carried out a needs assessment or support plan review?**
- **Why was my loved one's family not informed of the changes being made?**
- **Has my loved one's level of care been reduced to below what he was previously receiving?**
- **Will my loved one's care provision revert to its previous levels, following the pandemic?**
- **Can you please demonstrate that the essential care my loved one needs is still being provided?**



tsc+ GAMING CHAMPION

BECOME A GAMING CHAMPION

Organise or take part in a gaming challenge and help improve lives in the TSC community

Calling all gamers! Would you like to combine your passion for gaming with the chance to improve the 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.



Registered with
**FUNDRAISING
REGULATOR**

Head to
<https://tuberous-sclerosis.org/get-involved/gaming-champion/>
to find out more!

TSC research pipeline: How new TSC medicines are made

It is an exciting time for TSC research, with lots of potential treatments on the horizon. But, what are the steps to approving a new TSC medicine in the UK?

We often hear that a new medicine is at a certain stage in its steps towards being made available to the public, which can include things like when a medicine is in a phase of clinical trials, or at the stage when the company developing the medicine is seeking regulatory approval. It is easy to be confused about what this all means, and with the TSC research pipeline currently looking very positive, we want to try and make the journey of developing new medicines clearer.



The TSA is continuing its commitment to be a leader in funding TSC-focused research, ensuring that we not only provide help today but also work towards a cure for tomorrow. We do this by working closely with TSC experts in the UK and beyond.

The steps to developing a new TSC medicine

The journey of a new treatment, from a researcher having an initial idea to the medicine being available for use, can be long and winding. However, this ensures that medicines are safe and effective.

Pre-discovery

Researchers work to understand TSC better, by using existing knowledge and data

Drug discovery

Researchers find something, like a gene or a protein, that has potential to be used to help with TSC. This could be the start of a new medicine

Pre-clinical testing

The component found in drug discovery that could be a new medicine is checked for safety and effectiveness. This is done by running computer tests, and tests on single cells outside of the body

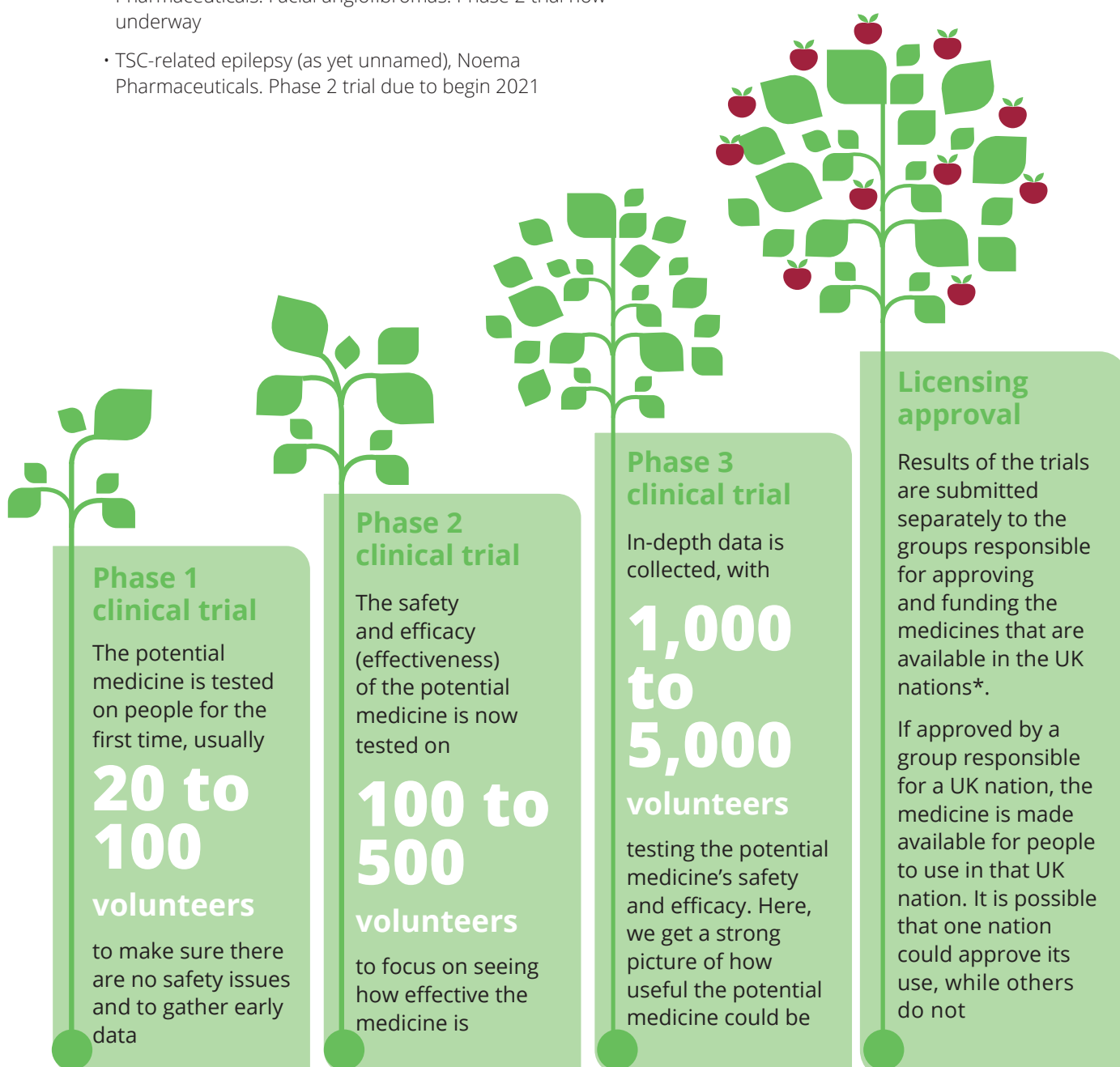
What stage of development are some of the potential TSC medicines that are being researched?

- Epidiolex (cannabidiol), GW Pharmaceuticals. TSC-related epilepsy. Stage 3 clinical trials compete. Licensing submission expected in 2021
- Topical sirolimus cream, Nobel Pharmaceuticals. Facial angiofibromas. Stage 3 clinical trials compete. Licensing submission expected in 2021
- Ganaxolone, Marinus Pharmaceuticals. TSC-related epilepsy. Phase 2 trial now underway in the United States
- TMB-002 (topical sirolimus cream), Timber Pharmaceuticals. Facial angiofibromas. Phase 2 trial now underway
- TSC-related epilepsy (as yet unnamed), Noema Pharmaceuticals. Phase 2 trial due to begin 2021

Could existing medicines be used differently for TSC?

There is also research taking place to see if existing medicines could be used in different ways to help with TSC:

- Research suggests that using vigabatrin earlier than we do at the moment can help to reduce the number of seizures in infants who live with TSC-related epilepsy
- Metformin, a medicine used in type-2 diabetes, has been shown to be beneficial in TSC-related epilepsy, by reducing seizures frequency and the size of SEGAs



*Medicines and Healthcare products Regulatory Agency (MHRA). The MHRA says whether a medicine is safe and effective and can be considered for use in the UK. Then, NHS England, the Scottish Medicines Consortium, the Welsh Specialised Services Team and the Department of Health, Social and Public Safety (Northern Ireland) decide whether to fund a medicine or not in their respective UK nations.

Fundraising thank yous

Even a pandemic hasn't stopped our dedicated fundraisers! Thank you to everyone who has raised funds for the TSA since the last issue of Scan. Send event plans and post-event pictures to fundraising@tuberous-sclerosis.org for a chance to feature in the next Scan or our social media pages

Community fundraising

Thank you to everyone who attended 'In Conversation with Sir David Suchet' - you can see the recording by going to <https://bit.ly/3qMvRWi>.

Back in December, **John Chamley** ran a virtual Christmas Quiz and brought in a sparkling **£290.00!**

John Godden was the first to take on the TSA Gaming Champion challenge, testing his gaming ability, and bringing in a brilliant **£25.00!**

Despite the main London Marathon 2020 being postponed, **Marlon Rasho** ran the virtual marathon in aid of the TSA. All the prep paid off, and he gathered an amazing **£3,701.25!**

Another athlete, **Nicola Daykin**, challenged herself to the Great North Run virtual event, completing 40 runs in 78 Days, clocking up an incredible 300 miles, and raising a fabulous **£775.00!** Nicola took on the challenge in honour of her son, who lives with TSC.

Jonathan and Matthew Plant collected a marvellous **£821.13** by cycling the Ride Prudential Virtual London-Surrey 53, in two mammoth laps of a course near Strathaven. Well done and thanks to both of you!

Facebook fundraisers

WOW! In 2020, our fantastic **Facebook fundraisers** raised well over **£10,000.00** in vital funds for the TSA! With more than 230 fundraisers taking to Facebook and asking for donations on their birthdays and other significant events during the year, there are simply too many people to list here. Everyone at the TSA send each and every one of you our heartfelt thanks.

Let's see if we can make 2021 even better - you can set up your own Facebook fundraiser in just a couple of clicks from your Facebook profile to bring in money for the TSA. You could ask for donations for your birthday or other special occasion, or any personal challenges you are doing!

Corporates

A massive thanks to Equistone, who completed a full year of fundraising for the TSA in December. More about their activities and achievements in the next issue of Scan.

Thank you to **GW Pharmaceuticals** and **PlusUltra Pharma** for sponsoring the International TSC Research Symposium 2020 and for also awarding the TSA grants following our covid-19 Emergency Appeal.

Thank you also to **C Lomax Ltd** and **Munro Properties** for your kind donations.

Trusts and Foundations

We would like to thank the following Trusts and Foundations for their generous support:

Anglo American Foundation
Douglas Heath Eves Charitable Trust
Dunn Charitable Trust
Hamer Trust
Thomas Sivewright Catto Charitable Settlement

JTH Charitable Trust
The Lorimer Trust
Meikle Foundation
The Michael and Anna Wix Charitable Trust
The Sir James Knott Trust

Coast-to-coast in aid of TSC



JONTY BROWN, 30, FROM HARROGATE

SAM JONES, 29, FROM BOURNEMOUTH

CHRIS WILKINSON, 28, FROM BRISTOL

On 21 August 2021, keen runners Chris, Jonty and Sam will embark on a 192-mile journey, all to raise money for three chosen charities, including the TSA

Starting on the west coast of Cumbria, in the village of St Bees, the trio will run an average of 28.5 miles a day for 7 consecutive days, finishing on the east coast, at Robin Hood Bay.

The boys have each chosen a charity close to their hearts. Chris' older brother, Rob, lives with TSC, and Chris was kind enough to take the amazing step of choosing the TSA as his charity for the challenge.

We look forward to telling you more about the boys as they prepare for and then take on their mammoth challenge, and you can also read their own stories on their website: www.chasingchange.co.uk.

Good luck to the trio! Keep checking our social media pages, website and the next issue of Scan to see how they get on.

You can support Chris, Jonty and Sam's challenge, head to <https://uk.virginmoneygiving.com/CHASINGCHANGE>

No Cost Fundraising

Did you know that there are ways to raise funds for the TSA without even leaving your home or spending anything extra? Here are three ways that you help improve the lives of people with TSC when doing your online shop!



Amazon Smile is a scheme which enables Amazon customers to donate to a charity of their choice every time they shop, at no extra cost to you! To choose the TSA, visit <https://smile.amazon.co.uk/ch/1039549-0>.



Shop at your favourite stores online with Give as you Live, and they'll donate to us – at no extra cost to you! There are thousands of top retailers - head to <https://www.giveasyoulive.com> and search for Tuberous Sclerosis Association.



On EasyFundraising, there are yet more popular retailers that will give donations to the TSA when you shop, at no cost to you. Visit <https://www.easyfundraising.org.uk> - it only takes a minute!

TSC Clinics Virtual Challenge

We're pleased to introduce our new TSC Clinics Virtual Challenge, an exciting way for us to all get involved in fundraising together!

The TSC community has amazing fundraisers and givers, all ready to help support the TSA, but it's been incredibly difficult to hold and take part in community events over the last year or so. This has meant that much-needed income for the TSA has reduced significantly, despite us knowing that there are lots of people out there ready to get stuck in with some challenges if offered the right opportunity. To help with this, the TSA team got our heads together and created the TSC Clinics Virtual Challenge!

What is the TSC Clinics Virtual Challenge?

We want to celebrate the incredible work of the TSC clinics that are all across the UK, while encouraging greater giving. To do this, we are asking you to locally walk, run, cycle, swim (or anything else) the equivalent distance between two different NHS TSC clinics of your choice. You could choose a smaller distance, like Birmingham Children's Hospital to Birmingham Queen Elizabeth Hospital (4.4 miles) or even something huge, like Queen Elizabeth University Hospital Glasgow to Belfast Royal Victoria Hospital Belfast (144 miles!)

It doesn't matter if you do the distance in one go, or tick off the miles in bitesize chunks over a number of days - it all counts!

You could even take on the challenge as a team, with the miles adding up to a set target number.

Louise and Sam are getting involved too!

Louise Fish and Samantha Barber (Joint Chief Executives) are also going to be pounding the pavement as part of the TSC Clinics Virtual Challenge. Sam said: "I want take part in the challenge to do my part to help the TSA continue its work for the TSC community. By leading from the front, I hope that Louise and I can show the importance of fundraising for the TSA." Louise also commented: "With so many fundraising opportunities being cancelled in 2020, I'm excited to help the TSC community have a chance of fundraising that is in our own control, and can also be done while socially distancing."



What you need to do

- 1. Decide who is taking part**
- are you going solo, or tackling it as a team?
- 2. How will you complete the challenge? Will you walk, run, swim, roll!?**
- 3. Choose your clinic-to-clinic distance**
- 4. Set a date and time for the challenge**
- 5. Set-up a JustGiving page and get fundraising!**
Don't forget to tell the TSA about your plans, so we can help you at every step of the way:
fundraising@tuberous-sclerosis.org

CHOOSE YOUR TSC CLINICS VIRTUAL CHALLENGE DISTANCE

On the map below we've highlighted a few TSC Clinic distances that you might want to choose, to get you thinking. But, you could choose any distance and any clinics you want!



NHS TSC CLINICS IN THE UK

To help you to decide which clinics to use to set your distance, we've listed all of the NHS TSC clinics that are currently operating across the UK:

Addenbrooke's Hospital (Cambridge)	Birmingham Children's Hospital	Queen Elizabeth Hospital (Birmingham)	Royal United Hospital (Bath)	Sheffield Northern General Hospital	Truro outreach clinic (via Royal United Hospital Bath)
Alder Hey in the Park Children's NHS Foundation (Liverpool)	Evelina London Children's Hospital (London)	Queen Elizabeth University Hospital (Glasgow)	Royal Victoria Infirmary (Newcastle)	St George's University Hospital (London)	University Hospital of Wales (Cardiff)
Belfast City Hospital	Leeds General Infirmary	Royal Free Hospital (London)	Saint Mary's Hospital (Manchester)	The Royal Liverpool Hospital	York District Hospital

Millie's story

Millie Power was diagnosed with Tuberous Sclerosis Complex when she was 11 months old. Millie's experience of TSC and her desire to better understand the condition led her to wanting to pursue a profession in healthcare. Millie spoke to Scan about what it was like growing up with TSC, having surgery, and achieving her life ambition of becoming a children's nurse.



My name is Millie Power. I'm 27 years old, and I live in Petts Wood, Orpington, with my fiancé. I was diagnosed with Tuberous Sclerosis Complex after I first started having tonic clonic seizures. Receiving my diagnosis of TSC was a complete surprise to my parents, as nobody in my family had the condition. This made it difficult for me growing up at times as, whenever I was ill, I knew that no-one around me fully understood what I was going through.

I always wanted to understand my condition more, as it felt so out of control. Due to this and some memorable nurses, I decided to become a children's nurse. I have an interest in neurology and neurosurgery, so when I qualified in 2015 I began working on a neurology and neurosurgical children's ward at Great Ormond Street Hospital.

How Tuberous Sclerosis Complex affects me

Since I was diagnosed with TSC it has mainly affected me through epilepsy and having regular seizures. Once I was started on medication as a baby, I gradually stopped having tonic clonic seizures, but continued to have regular focal seizures every week. Now that I am older and about to get married, I am realising that TSC affected me as a child more than I ever realised at the time. I am now going through lots of tests and doctor appointments to try and find my Tuberous Sclerosis Complex gene error. So far, they have been unable to find where it is in me, and this is definitely affecting my mental health. As we all know, anyone with TSC can pass the condition on to their children, and that is hard to come to terms with.

“This can be a tough, difficult journey and sometimes it can feel impossible, but I want everyone to know you are all strong, amazing individuals”

TSC: My inspiration for nursing

My diagnosis of TSC and epilepsy is definitely what led to me wanting to become a children's nurse. My mum also inspired me, as she was a nurse her whole working life, and she is also a strong woman who I looked up to. My parents tell me stories of how, when I was first diagnosed with Tuberous Sclerosis Complex, medical professionals apologised to my parents, and they began treating me differently. It was my mum who stood up and said that they should “treat the symptoms Millie shows, not define her as a condition.” I will never understand exactly what my parents went through when receiving my diagnosis and adapting to life because of it, but I will forever be thankful to them

for being strong, and for treating me no differently to my other siblings. It is because of their encouragement I became the nurse that I am today.

I decided I wanted to specialise in neurology and neurosurgery when I was a teenager. I had grown up with no-one fully understanding how lonely and upsetting epilepsy can make you feel, and I knew that if I had even just one person who understood, it would have made life more manageable for me. It was because of this I decided that my dream was to be that person for other children and young people with epilepsy and Tuberous Sclerosis Complex.

My experiences of surgery

In July 2020, I went through epilepsy surgery and it is safe to say that it has changed my life for the better. When I was a child, my parents and I were never made aware that surgery could be an option. I used to be at work looking after patients, thinking “it's a shame surgery isn't an option for me”. Then, in 2019, I moved to a different neurologist who organised further testing for me (including things like EEG at home, and neuropsychologists). They found that all my seizures were coming from a specific area of my brain. This led to me meeting a neurosurgeon in October 2019, who suggested having a temporal lobectomy. The build-up to meeting the surgeon was very emotional - my biggest worries were how it would affect me and my career. I had a wonderful partner and my dream job, what if this would be affected by surgery?

At this point I was having 2-4 seizures a week. I walked into the meeting with my surgeon with lots of questions and if I'm honest I was planning to say “Thanks, but no thanks”, as I was so worried about what I could lose. However, my surgeon made me feel so safe, and reassured me that it wouldn't affect my ability to be a nurse. For the first time in my life I felt myself putting what I wanted first - suddenly the life I had always dreamt of could become a possibility.

The feelings I felt before and after surgery have been very mixed. First, I have felt happiness and hope for one of the first times in my TSC and epilepsy journey - I finally felt like it could be possible to not have to plan



my life around epilepsy. This has also shown me that epilepsy is a big part of my identity. Without epilepsy I may not have become a nurse. It made me think "Who am I without epilepsy?" This is something I am struggling with post-surgery - I am not someone who hates epilepsy. In fact, what I've done with it and in spite of it are some of my biggest achievements in life. However, it is hard to process the idea that I feel lost without seizures. It was seizures that made me feel down, exhausted and angry, but epilepsy has made me who I am. I am proud to be someone with epilepsy!

My recovery from surgery

I am lucky enough to be writing this having had a really positive recovery from surgery. The beginning of my recovery was spent sleeping a lot. I wasn't able to bend down or do any day-to-day activities (like cooking or washing) for around 6-8 weeks. To help me stay positive and help my mental health I started doing yoga at home in the morning. I found it helped me get into a positive mind space. In no way has my recovery been perfect - the area of my brain that was removed helps control mood and speech memory, and I have really struggled with anxiety during my recovery. My seizures mainly came at night before I went to sleep, so I now find myself getting anxious every night before bed. After years of having seizures it is hard to not still expect one to come. Due to this anxiety around sleep I now listen to a meditation app each night, otherwise I find I don't sleep well at all.

At the beginning of my recovery, I would get emotional very easily, and sometimes it would come out of nowhere, which was hard to process and explain. I also forget some

"I had grown up with no-one fully understanding how lonely and upsetting epilepsy can make you feel, and I knew that if I had even just one person who understood, it would have made life more manageable for me"

words. The difficulty is that you don't know what you've forgotten until you trying to think of it! I still sometimes feel that the word is on the tip of my tongue, but I just can't find it sometimes. All these side-effects will improve over time, but as I begin to feel more like my old self, they are becoming frustrating. I am still quite tired at times and need to rest after some activities, but my recovery is definitely going in the right direction. The best part of my recovery is that I can currently say that since surgery I have been seizure-free. This is a sentence that I never thought I would ever be able to say in my life, and that has been the best gift of all.

Roadblocks and moments of celebration

Throughout my nursing training and career there have definitely been a few roadblocks, but also many moments of celebration. As a student nurse I remember initially struggling with shift patterns, as I worked both days and nights as well as long shifts. While I was getting used to this way of working it definitely increased my seizures, but as it was my dream job, and as I always got an aura before my seizure, I was able to ensure that my patients and I were always safe. Throughout my career I have been able to find what type of shift pattern works for me to decrease the number of seizures that I have. I am not yet back at work after surgery, but hopefully this will be less of a roadblock now I have had surgery.

There have been so many moments of celebration through my career. The main moments that I will always celebrate are the times when I have related to a patient's situation and they have opened up to me and asked for support. Throughout my student and

“Through growing up with TSC and going through surgery, the biggest lesson I have learnt is it's ok to not be ok.”

nursing career I have heard stories from patients who struggle with things like their diagnosis or taking medication, and when I tell them about my condition, they feel able to open up and talk to me. This has also led to me being able to direct families to the TSA and epilepsy charities. A personal celebratory moment was first stepping into Great Ormond Street as a qualified nurse. Growing up it was suggested to me by teachers and some doctors that I wouldn't be able to become a nurse because of my condition, but I am proof that it's important to follow your dreams. I felt proud just qualifying as a nurse – knowing I had achieved my dream job meant the world to me.

Explaining Tuberous Sclerosis Complex to people without the condition

I think one of the hardest things to explain to people who don't live with TSC is how it affects every part of your life, even if it's not visible. It's hard to comprehend that I have a condition that has the potential to get worse, and as you get older there are more worries to add to the pile. As someone who is mildly affected with TSC it is harder for people to understand that those risks are always there. People have always seen my only issue as epilepsy and seizures, but as I get older my worries include how I can safely have children without passing on TSC, or if the condition will spread further to other organs. These things are sometimes a really big struggle, on top of everyday adult worries.



Looking forward

It has been six months since my surgery and I am still seizure-free, which is such an exciting feeling. Throughout my recovery I have grown so much as a person and I am learning who I am without seizures. This is such an exciting feeling and for the first time in my life nothing feels impossible. I never realised how much seizures controlled my day-to-day life, whereas now I feel like I have been able to take some of that control back. I will be returning to work soon as a paediatric nurse. My hope is that if my seizures stay controlled, I can finally focus on my dreams of getting a promotion and of one day being a Specialist Epilepsy Nurse for children, helping children who were like me.

I am getting married in September 2021, so I am very excited to start a new adventure with my

partner. As part of our journey for starting a family I have recently agreed for DNA samples of mine to be sent away, to try and distinguish which TSC gene is affected for me. My hope is that, with an answer to this, we can ensure I don't pass on this condition to my children.

A message to the Tuberous Sclerosis Complex community

As someone who was diagnosed with TSC at a very young age and does not have another family member with the condition, I want everyone to know that you are not alone. This can be a tough, difficult journey and sometimes it can feel impossible, but I want everyone to know you are all strong, amazing individuals. Whether it is you who has TSC or if it is a loved one, you are all incredible.

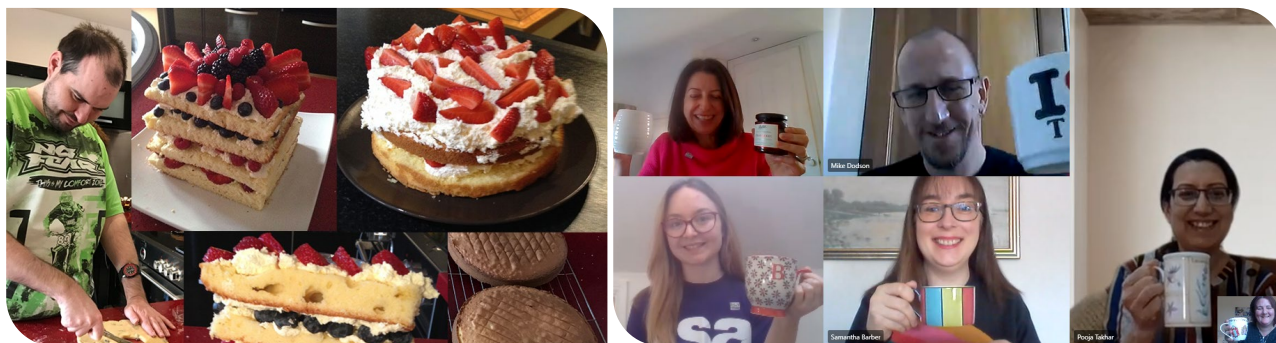
Through growing up with TSC and going through surgery, the biggest lesson I have learnt is it's ok to not be ok. It is easy to think you have to push on and keep going because that's what people expect, and you want to act as 'normal' as possible, but it's important to accept we are all different, and that for that we are amazing.

Virtual Tea & SCones for TSC 2021



It will soon be spring and that means only one thing: Tea & SCones for TSC! Get your oven gloves ready and the kettle boiling as we organise a big TSC community tea party

Tea & SCones for TSC, our flagship event focused on baking (or just grabbing a biscuit) and having a brew, all to raise funds to help improve lives in the TSC community, went virtual last year for the first time. It was such a great success that for 2021, at a time when we're all keen to connect with others, we're doing it again!



Saturday 15 May 2021 is TSC Global Awareness Day, and we want you to mark the occasion by getting family, friends and colleagues involved in a Tea & SCones for TSC virtual event. But remember that you can do a Tea & SCones event at any time, so don't worry if you can't make that day. Let's get Tea & SCones for TSC happening all around the world!



Why Tea & SCones for TSC is so important

The money that you raise through fundraising opportunities like Tea & SCones for TSC helps us to improve the lives of people affected by TSC. This includes funding things like direct support, research, campaigning and advocacy. Your fundraising efforts are vital, to help us to continue our work.

How to get involved in Tea & SCones for TSC 2021

1. Choose the day and time that you're hosting your event and register at tuberous-sclerosis.org/tea&scones2021
2. Let loved ones know what you're doing, and get them involved! You can tell them why you're doing it too – to help the TSA continue our work to improve the lives of people in the TSC community
3. Get fundraising! There are lots of ways to do this, like opening a page on JustGiving or starting a Facebook Fundraiser
4. On the big day, grab your baked goods (or even just a cuppa) and gather everyone virtually – whether that is through a phonecall, Zoom, WhatsApp or another similar platform

Remember to post pictures of your event on the TSA's Facebook and Twitter pages, so we can spread the cheer and celebrate your hard work! Be sure to also let us know your plans by emailing fundraising@tuberous-sclerosis.org





TSC Research Volunteer Network

SUPPORTING PATIENT AND PUBLIC INVOLVEMENT IN RESEARCH

Are you affected by TSC? Join the TSC Research Volunteer Network to have an important voice in influencing research that the TSA prioritises and funds

There is growing evidence which suggests that involving people who are directly affected by a condition in research can have a positive impact on those living with the condition – this is called 'Patient and Public Involvement' (PPI). The TSA knows first-hand just how vital this can be, and we want you to get involved with the TSC Research Volunteer Network.

The TSC Research Volunteer Network encourages more conversations between researchers and the TSC community. By involving more people from the TSC community in our research priorities, the TSA can be sure that it is focusing research on what matters most to the TSC community.

Joining the TSC Research Volunteer Network is not about being an active participant in clinical trials or answering lots of surveys (although these things are still very important outside of the network). Instead, members of the TSC Research Volunteer Network will be asked if they would like to do things like:

- Telling researchers about their personal experiences of TSC
- Identifying important research questions that the TSA should be trying to answer
- Suggesting ideas for new research projects
- Reviewing funding applications for research, that the TSA has received
- Reviewing community-friendly summaries of research applications, and projects that are currently funded
- Talking at TSC research events about how TSC affects you on a daily basis, and how research might help to improve your quality of life



We want to ensure that the community is at the heart of research into TSC, and we want to do that by actively involving you in the research that is carried out. That way, instead of funding research 'for' or 'about' the TSC community, we can say that the research we fund is undertaken 'with' or 'by' the community, which is much more meaningful. We believe that this won't just mean that the community's voice is heard, but that the actual research that is carried out will have greater benefit in improving lives affected by TSC.

We aren't the only charity looking to our community to help, as it is now seen by many funders as an essential part of the process of how research is carried out. Many funders will now only accept funding applications only if a charity can clearly show how the researcher has and will involve their community at every stage of their research.

If you'd like to know more about the TSC Research Volunteer Network, visit tuberous-sclerosis.org/research/tsc-research-volunteer-network or email research@tuberous-sclerosis.org.

International TSC Research Symposium 2020 – Pushing TSC research forward

LAST YEAR, WE POSTPONED THE INTERNATIONAL TSC RESEARCH CONFERENCE TO 2021, DUE TO COVID-19. TO HELP BRIDGE THE GAP, IN NOVEMBER 2020 WE HOSTED AN EXCITING VIRTUAL SYMPOSIUM.

The TSC International Research Conference is held annually to bring together academics, healthcare professionals, industry representatives and the TSC community from around the world. The conference gives everyone the chance to share their knowledge and experience, and to learn about new and exciting developments in TSC research. The conference in 2020 was due to take place from 12 - 14 November. However, due to the covid-19 pandemic, we were forced to postpone it to 17 - 19 June 2021, with **the Community Research Event - where we will invite the TSC community to join us virtually - to take place on 20 June 2021.**

To fill this gap, the TSA were delighted hosted a half day research symposium on 13 November 2020, together with the TS Alliance (USA) and the LAM Foundation. A total of 141 delegates from 14 different countries attended the symposium. The organising committee structured the symposium into these three sessions, which all featured distinguished TSC researchers from around the world:

- 1. Early learning on covid-19 and TSC**
- 2. Emerging research on the physical aspects of TSC**
- 3. Emerging research on the TAND aspects of TSC**

The symposium was chaired by Professor Andrew Tee (Cardiff University) and Dr Chris Kingswood (St George's University). The first session of the day began with Jennifer Fujikawa, who lives with TSC and LAM. Jennifer spoke about her experience of TSC, as well as her experience of contracting covid-19. Jennifer helped to give the researchers a direct insight into what life is like when managing TSC daily, along with moderate-to-severe LAM. Thankfully, Jennifer did not experience any major covid-19 symptoms, and she remains full of positivity!

Next, Dr Angela Peron (San Paolo University Hospital, Milan) presented data from an Italian study which looked at people who live with TSC and also caught covid-19. This talk was followed by Dr Nishant Gupta (University of Cincinnati), who discussed his research into use of mTOR inhibitors in covid-19, and the implications this research would have for people who live with TSC-LAM.

The second session included presentations from Professor Simon Johnson (University of Nottingham), presenting new insights into lung damage in TSC-LAM, and Professor John Bissler (University of Tennessee), who walked us through TSC renal cysts, cellular composition and the timing of therapy.

Professor Mustafa Sahin (Harvard Medical School) began the final session with a presentation on emerging research on TAND-related biomarkers and treatments. TAND stands for 'TSC-Associated Neuropsychiatric Disorders' - an umbrella term for various mental health conditions that are seen in 90% of people who live with TSC. Dr Charlotte Tye (King's College London) presented her latest research on characterising the cognitive development and behavioural profile of infants with TSC. Finally, Professor Petrus de Vries (University of Cape Town), Professor Anna Jansen (UZ Brussel), Dr Stephanie Vanclooster and Dr Tosca Heunis (Vrije Universiteit

Brussel) gave an update on ongoing work into their TANDem app.

By bringing together our international research community, we were able to share and discuss research advances on how we can clinically manage challenging aspects of TSC. A critical strength within our TSC research community has always been their ability to come together at an international level, which helps advance future treatment and management of TSC.

Overall, the conference was a huge success, and an excellent taster of things to come at the International TSC Research Conference in June 2021!

The symposium was made possible by its sponsors, GW Pharmaceuticals and Plus Ultra Pharma UK Ltd (an affiliated company of Nobel Pharma Co, Ltd, Japan).



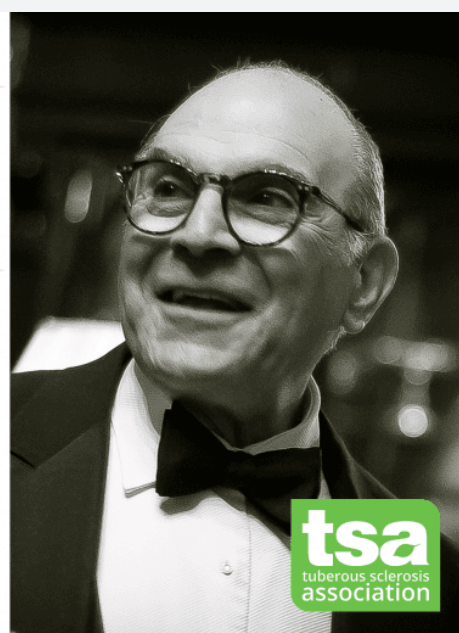
In conversation with: Sir David Suchet CBE

To rewatch this unique event head to
<https://bit.ly/3qMvRWi>



Fundraising event in aid of the Tuberous Sclerosis Association (Charity number 1039549 (England & Wales) SC042780 (Scotland)). The Tuberous Sclerosis Association, Unit 56, 1 Emma Street, London, E2 9FP

As this is a fundraising event, attendees are encouraged, where possible, to kindly give additional donations during checkout or via tuberous-sclerosis.org/donate



An update from the CoIN Study team



The CoIN Study aims to assess the impact of covid-19 on the wellbeing of families of children with rare neurodevelopmental and genetic disorders, such as TSC. Recently, the CoIN team spoke to participants for an update on their experiences.

Since May 2020, families have been taking part in CoIN. As part of this, the families involved in the study have been filling out monthly surveys, answering questions about things like family life and relationships, access to healthcare and education, overall health and wellbeing, child behaviour and coping during the covid-19 pandemic. The information collected from the CoIN study will be used to identify and develop better support for families of children with rare neurological disorders in the future.

Now almost one year since it began, CoIN researchers invited members of the CoIN study community to talk about their experiences so far, with some interesting findings.

Taking part in CoIN

Participants said that the CoIN study is easy to follow and most found the length of the surveys agreeable (an important factor, as it ensures that participating does not impact on people's lives too much). One parent said that being involved in CoIN helped them "understand what they were feeling", while another said that they could now "reflect on how their family was coping". These responses will be further analysed and used to improve the final study.

Parent concerns

CoIN researchers asked parents how stressed they had felt over the previous week, and what was causing this stress. The results showed that the future outlook for their children, as well as their children's overall wellbeing, education and behaviour were the main causes for worry. The parents of children with neurogenetic disorders reported their child's future to be the main cause of concern.

Child behaviour

The behaviour of children in the participating families was assessed using a questionnaire. The findings show that during 2020 most of the children in participating families experienced significant difficulties in positive social behaviours. Almost half of the children were greatly impacted by these difficulties, to the extent that they could cause significant stress or harm to either themselves or their families. This provides evidence that children with rare neurological disorders and their families need extra support during unprecedented times, such as the covid-19 pandemic.

Parent mental health

The mental health of parents in the study was assessed using something called the 'Depression, anxiety and stress scale'. It was found that most of the parents scored on the 'normal' range for depression, anxiety and stress. However, around one in five parents scored in the 'severe' or 'extremely severe' categories for stress or depression.

There are other studies exploring similar things to CoIN during the covid-19 pandemic, but for the broader population. When comparing CoIN with these studies, we can see that specific changes during the pandemic have had a more significant impact on parents of children with rare neurological disorders when compared with adults in the general population.

Further study

The CoIN study will continue, taking these initial findings and considering them in a final analysis once the study is completed. When the study is complete, focus groups and workshops will be held with parents who have been involved to discuss the findings in greater depth, and to better understand how professionals can use the findings to make the biggest difference to communities like those affected by TSC.

More information

You can read more about the CoIN Study on the TSA website, or at coinstudy.co.uk.

Acceptance and Commitment Therapy trial to start soon

It is hoped that ACT, a type of talking therapy that encourages people to embrace their thoughts and feelings, could benefit the TSC community.

University Hospitals Bristol & Weston NHS Foundation Trust will soon open recruitment for an upcoming study looking at the effects of Acceptance and Commitment Therapy (ACT) in reducing distress and improving quality of life in people living with TSC.

It is hoped that ACT, a type of talking therapy that encourages people to embrace their thoughts and feelings, could benefit the TSC community. Researchers Dr Sam Amin (Consultant Paediatric Neurologist) and Dr Jennifer Black (Clinical Psychologist) will look into this further through the new study, inviting participants to regular video calls to try ACT for themselves.

Further information will be shared soon. Keep checking the TSA website and social media pages, or contact with Dr Black: Jennifer.black@uhbw.nhs.uk.



During coronavirus and beyond: **We're here for you**

"There has been a lot of people contacting the TSA Support Line over the last few months. This has included people asking a wide range of questions or enquiries, or even just giving us a quick ring to say 'Hello' and to let us know how they are getting on. We're really pleased about this, as it means that more people can get the right information, or feel that they aren't alone at this time.

The TSA Support Line isn't here just for people who live with TSC. We are here for EVERYONE in the TSC community - including you! Mums, dads, grandparents, siblings, TSC professionals, friends, employers, carers and even teachers are just some of the people we have helped over the last few months.



So, don't forget, that we are here for YOU, too!

*Best wishes,
Mega and Anna
TSA Support Line Advisers"*



TSA Support Line

 **Freephone**

0808 801 0700

Monday to Friday 9am - 5pm

 **Email**

support@tuberous-sclerosis.org