

# scan

AUGUST 2020

The magazine of the TSA

**You're never alone with TSC**



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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 Engagement)

**Charlotte Strain** (Events and Communications Assistant)

✉ comms@tuberous-sclerosis.org

## Fundraising

**Mikaela Conlin-Hulme** (Head of Income Generation)

**Kathryn Harrison** (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

**It feels like a lifetime ago that we published our previous issue of Scan. In just a few months, the world now looks like a very different place to what it used to. But, one thing that hasn't changed is the TSA's commitment to improving the lives of people affected by TSC.**

At the TSA, the way that we work has been a little bit different to usual, with our focus being on helping you through the coronavirus pandemic. You can read more about what we've been doing in Louise's Chief Executive foreword on **page 4**.

Those of you who have attended one or more of the TSA's virtual meetings might now see me as a familiar face. As ongoing Chair for our virtual meetings, I've had the pleasure of meeting many of you recently, despite lockdown measures, in these sessions. If you were unable to make a session that you were interested in, don't worry, as all of our sessions have been recorded so that you can watch them when it is convenient to do so (see **pages 8 and 9** for a rundown).

I was also lucky to recently catch-up with Lauren McWhinnie, a community member and vlogger who is helping to raise awareness and understanding of what life with TSC can look like for some. At a time when we're all under great strain, Lauren's sunny outlook helps her to overcome life's hurdles. We can all learn from Lauren and you can read our interview with her on **page 16**.

On behalf of everyone at the TSA, it's been an honour to hopefully make 2020 a little bit easier for you. Let's stick together and take it one step at a time.

Keep safe,

**Luke Langlands**, Editor

## Support and Information

**Rachael Wyartt**

(Head of Support and Information)

**Julie Rainer**

(Information Officer)

**Anna Gaunt**

(Support Line Adviser)

**Mega Arumugam**

(Support Line Adviser)

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/2NkZiWk> or contact the TSA Support Line

# A word from your Chief Executive

## HOW WE'VE CONTINUED TO BE HERE FOR YOU DURING CORONAVIRUS

**We set new priorities during the coronavirus pandemic to provide you with effective information and support during a very difficult time.**

Coronavirus will continue to put pressure on everyone, personally and professionally, for some time. The TSA team and trustees have come together with three focused priorities to give you all the help we can in this challenging period.

### **Priority one: Providing information and support to the TSC community**

We took the broad UK Government guidance (which often changed daily) and worked with TSC specialists to give it a special TSC community focus. This was important, to help you to understand what matters most to people with TSC.

Our Support and Information Team have worked flat-out to be with you during this time. They have responded professionally to many individual questions and have been equally happy to be there when you have needed a listening ear. They have also been in touch with many of you to check on how you and your family have been coping, which has also helped us to shape how we can work best to help the community.

### **Priority two: Offering innovative ways for the TSC community to come together**

Face-to-face meetings and events have not been possible, but the virtual world has taken off! We have seized this opportunity and it has enabled the TSC community to meet, feel connected and know that they need not feel isolated.

We have offered an Outlook event, a series of virtual sessions on different TSC topics and also more online communications, including the launch of our 'TSC Chat' group on Facebook.

### **Priority three: Safeguarding the long-term survival of the charity**

Coronavirus has had a big financial impact on the TSA, with major events like the London Marathon postponed or cancelled and community fundraising activities being more difficult. The pressure on global financial markets has also cut the value and returns on our investments. Led by the Board of Trustees, we have taken steps to ensure the charity's long-term stability.

We took the very difficult decision to place some TSA staff onto the UK Government furlough scheme. Team members who were not furloughed and contracted full-time supported our efforts and voluntarily agreed to a temporary reduction in their working hours and salary. We also reached out to the TSC community through our Coronavirus Emergency Appeal and you responded magnificently! ([See page 22](#)).

The TSA and TSC community have faced the main coronavirus spike head-on, but our work doesn't stop here. The TSA team and trustees are working on support, information and guidance to help you to understand and make the best of the 'new normal'. There will undoubtedly be more significant challenges, but we know that we can overcome them together.

I'm proud of what the TSA has achieved during this time. Our non-furloughed staff have worked incredibly hard and without hesitation, and our furloughed staff have approached the situation with incredible patience.

Through great teamwork and the TSC community coming together, we will get through this. A huge thanks to you all.

Louise

[Louise.Fish@tuberous-sclerosis.org](mailto:Louise.Fish@tuberous-sclerosis.org)



LOUISE FISH, CHIEF EXECUTIVE



# A word from your Chair

## THE HEARTACHE OF THE LAST SIX MONTHS CAN BRING US TO A KINDER AND FAIRER WORLD

**I hope that this Scan finds you and your loved ones all safe, healthy and well. Many of us in the TSC community and beyond have been feeling overwhelmed, anxious and frustrated as a result of coronavirus. However, now might also be the tipping point which enables us to live in a world with more empathy.**

To say that the TSC community has been through a difficult time over the past few months is an understatement. Whether you have been shielding, caring for someone close to you, trying to understand complicated government advice, or simply been feeling inundated with information, it's been a year that none of us will forget.

I know that some of you will be shielding for some time to come – remember that we are here for you. The TSA's push to being more digitally focused and our desire to offer ways for the TSC community to meet with others virtually has hopefully made this a little bit easier for you. This new digital vision for the TSA has been a real success and we intend to continue with a 'digital first' focus even once covid-19 is behind us.



**SANJAY SETHI, CHAIR**

Being part of the TSC community is to share a deep bond of understanding with others. Whether you live with TSC yourself, or someone close to you does, it is this TSC family that can best understand the challenges that life has thrown at you, because they have experienced them too. The connection between TSC community members goes beyond the label 'Tuberous Sclerosis Complex' – it is a shared consciousness of sleepless nights, juggling multiple appointments with hospitals and schools, and navigating countless other challenges. As we say, although TSC can feel isolating when people outside of our community are unfamiliar with it, 'You're never alone'.

Although we all share a deep connection, we still also need to make sure that the TSA is reaching those outside of the immediate TSC community. In my last foreword, I encouraged everyone to ask those close to you to sign up to receive TSA information through our REACH campaign, to help us to engage with more people and to grow the charity. I want to thank the small number who responded to our call, but we need more, to do more – please continue to ask friends, family members and co-workers to register at [www.tuberous-sclerosis.org/iwanttohelp](http://www.tuberous-sclerosis.org/iwanttohelp).

During the last few months, as a result of the coronavirus pandemic, the wider world beyond our own community has experienced the same heightened emotions and difficult situations that we regularly do in the TSC community. As a result, the world feels more sympathetic, open and caring than before coronavirus hit, which gives me hope. This small chink of light at the end of the dark tunnel can only be a positive thing in our work to improve the lives of the TSC community.

Let's welcome this more empathetic society and celebrate the incredible response to our Coronavirus Emergency Appeal. Separately, we must commend the nonstop work of TSA staff and our Board of Trustees. In particular, I want to thank the staff who have stuck by the charity and reduced their salaries as the charity's income fell, and those who have been furloughed.

Through our work for you, as well as your support for us, we are going to get through this. Stay safe and remember that we're here for you.

Sanjay

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

# How the TSA Support Fund can help

**The TSA Support Fund is here to help everyone in the TSC community in their times of financial need, offering a lifeline when the cost implications of the condition become too great to carry alone.**

Through the TSA Support Line, individuals and families in the TSC community have reported an increase in various challenges during the coronavirus pandemic. These challenges have included financial worries as a result of changing routines whilst shielding or self-isolating.

One family who has been in contact with us is the Cooks. Gemma Cook, who lives with TSC, underwent surgery at the beginning of February 2020 and was recovering at home for seven weeks prior to the UK going into lockdown. This meant that the Cook family experienced the feelings of isolation and heightened stress and anxiety even before coronavirus became a part of everyone's lives.

Like many in the TSC community, the Cook family then received a shielding letter from the UK Government, recommending that the family should shield for an additional period of 12 further weeks to keep Gemma safe. This meant that Gemma and her family were facing a further period of prolonged isolation. Gemma's mum, Claire, was understandably concerned about what this could mean for Gemma's mental and physical wellbeing, as well as the impact on the family as a whole.

Gemma relaxes by watching television or playing video games. Unfortunately, just as the lockdown and Gemma's shielding period began, the television in her room broke. This could have had a significant impact on Gemma's stress and anxiety levels as her welcome distraction to shielding and coronavirus was lost. Gemma's challenging behaviours increased as a result.



**THE TSA SUPPORT FUND WAS ABLE TO HELP GEMMA COOK AND HER FAMILY**

The family was not in the position to buy another television, but Claire contacted the TSA. The TSA approved Claire's support fund application to provide Gemma with a replacement TV and Gemma was once again able to relax in her room. Video games and YouTube videos have given Gemma a creative outlet during lockdown and her challenging behaviours have improved. Gemma has even got involved in interactive online workouts with her school!

Contact the TSA Support Line to find out more about the TSA Support Fund, which can provide grants of up to £250: **0808 801 0700** / **support@tuberous-sclerosis.org**.

**For more information on accessing benefits and financial aid, visit the TSA website: <https://bit.ly/2Wj3jpV>**

**"The thought of being in lockdown for an indefinite period without entertainment and a distraction for Gemma was worrying – she would be lost without a TV. I was not in a financial position to buy another TV and although I was worried that it sounded silly to ask for a TV, I applied to the TSA Support Fund."**

**- Claire Cook**

# Tea & SCones for TSC 2020

On 15 May 2020 we celebrated Global TSC Awareness Day with Tea & SCones for TSC. This time, with a virtual twist!

Tea & SCones for TSC is all about getting together with others for a tea or coffee and some tasty treats, all to raise awareness of TSC. On Global TSC Awareness Day 2020 our social media pages were packed with pictures and films of you all marking the day in your homes. Here is just a small selection of some of your pictures!

TSA staff got involved too! Chief Executive Louise Fish and her little helpers spread the word in a video, while Mikaela Conlin-Hulme (Head of Income Generation) raised a scone with husband John to mark the day.



**You can do Tea & SCones for TSC at any time of the year, to help improve lives! Get more info here: <https://bit.ly/2OJllxB> and remember to send us some pictures too!**

## Restarting treatments

**Some people were asked to temporarily pause everolimus or sirolimus treatment as a result of coronavirus. Now, with the first peak of the pandemic over, NHS TSC Clinics feel more confident advising almost everyone to restart treatments.**

If you were taking everolimus or sirolimus prior to the outbreak and were then asked to pause treatment, you should now contact your doctor for advice on whether you should restart the medication.

Your doctor's advice may change depending on: The Government's assessment of the risk to the population from the virus; how many people in the UK have already caught the virus; and how the virus is affecting people. It is possible that lockdown and shielding – on either a national or local level – will be necessary again in a future outbreak. Your doctor's advice may also change if you are alerted by NHS 'track and trace' that you have been exposed to coronavirus or become ill, and their advice may be different based on the reason why you are taking everolimus or sirolimus.

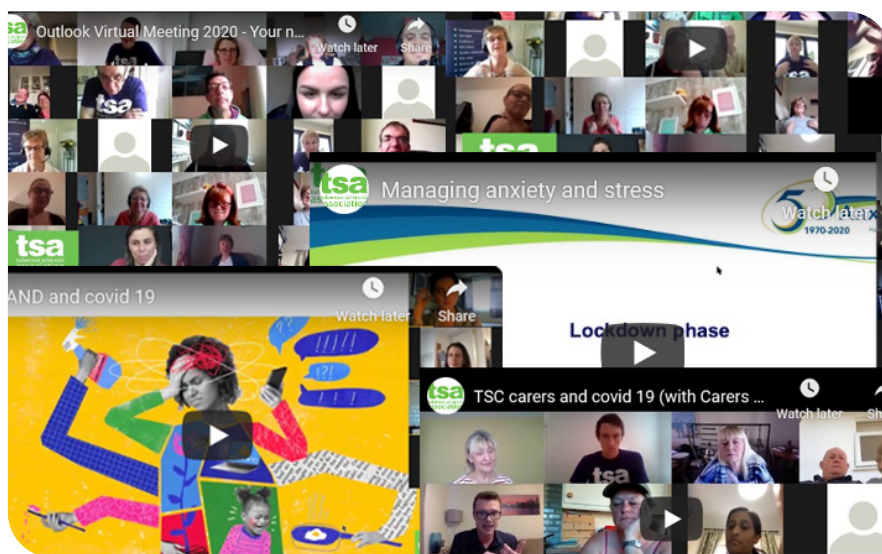
If you are taking everolimus or sirolimus for kidney angiomyolipomas (AMLs) or subependymal nodules (SEGAs), there may be less risk with you taking a break from treatment if you catch coronavirus or become ill. Your doctor may recommend that you stop taking the drug for a short period if you catch the virus or until you get better if you become ill.

If you are taking everolimus or sirolimus for refractory epilepsy or lymphangioleiomyomatosis (LAM) there may be more risk associated with you taking a break from treatment if you catch coronavirus or become ill. Your doctor will wish to discuss further with you, so that you can make an informed decision about whether to keep taking the drug or stop taking it, taking into account your medical history and the respective risks from epilepsy or LAM and coronavirus.



# Virtual Meetings Recap

Over the last few months, the TSA has been hosting a series of TSC-focused virtual sessions. This has meant that the TSC community has been able to come together, despite social isolation and shielding measures, while also learning about different TSC-related topics.



Here, we share a reminder of all of the virtual sessions we've hosted so far. Remember that you can catch-up on all of our talks and workshops in full on our website ([tuberous-sclerosis.org](https://tuberous-sclerosis.org)), Facebook page (<https://bit.ly/2WfgfwX>) and YouTube channel (<https://bit.ly/3j4ZApj>).

## Outlook 2020



The Outlook group, which welcomes adults mildly affected by TSC, is one of TSA's longest running events. Going virtual for the first time didn't stop this year from getting a bumper attendance! Attendees took part in a range of workshops and talks led by the TSA, including:

- A meet and greet by the new TSA support line advisers, Anna and Mega
- Discussions on the challenges and opportunities of being mildly affected by TSC
- A special Emotional Therapy Technique (EFT) practical session

**You can read more about EFT on page 13.**

## TAND and covid-19



TSC-Associated Neuropsychiatric Disorders (TAND) is one of the biggest challenges faced by the TSC community. In this session, we welcomed TAND experts Prof Petrus de Vries (Professor of Child & Adolescent Psychiatry, University of Cape Town) and Prof Anna Jansen (Head of Child Neurology, UZ Brussels) to discuss skills and ways to help manage TAND during the uncertainty of the coronavirus spread.

## TSC carer support (with Carers UK)



We welcomed Carers UK to the TSC community for a Q&A session all about the TSC carer community. Matthew Jones (Helplines and Advice Manager, Carers UK) talked us through key issues in caring that can be easily overlooked – especially at times of great upheaval like covid-19 – including how to access carer support and what support is available to help TSC carers.

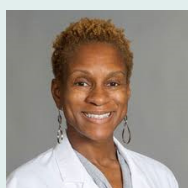
**You can read more advice from Carers UK on page 10.**

## Managing anxiety and stress (with Anxiety UK)



Managing anxiety and stress is always important, but particularly during this time for everyone in the TSC community and beyond. Dave Smithson (Operations Director, Anxiety UK) presented the TSC community with an overview of what exactly anxiety is and how we can learn to manage it.

**Read more advice from Anxiety UK on page 12.**



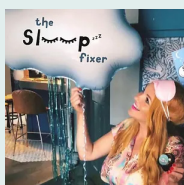
## Managing aggression and violent behaviours

A world leader in TSC behaviour, Dr Tanjala Gipson (TAND Clinic Director, Le Bonheur Children's Hospital, USA) discussed strategies to manage aggression and violent behaviours in TSC, with a focus on our transition back to the 'new normal' following relaxing of social distancing measures.

## Welsh Info Day



A record number of attendees came to the Welsh Info Day 2020! Dr Anurag Saxana (Cardiff TSC Clinic Lead) hosted a special Q&A session on accessing the Cardiff TSC Clinic, whilst Dr Elaine Dunlop (TSC Researcher and Lecturer, Cardiff University) discussed the amazing work that her and her team are doing for the TSC community.



## Strategies for better sleep

We heard from sleep practitioner Kerry Davies as she discussed the importance of sleep and how everyone in the TSC community can improve their chances of a good night's sleep in the face of anxieties surrounding coronavirus and the impact of TSC.



## Scottish Get Together

We welcomed TSC community members in Scotland to the first ever virtual Scottish Get Together! The TSA was delighted to welcome Dr Shelagh Joss (Glasgow TSC Clinic) to the meeting, who took the time to answer your TSC-related questions, as well as Emma Staughan (Scottish Association for Mental Health).

## Coming up: Northern Ireland Get Together

On **Saturday 12 September** we will invite the TSC community in Northern Ireland to gather virtually and discuss key issues. More info on the event, which will feature the Belfast TSC Clinic, will be shared soon.

# Supporting TSC carers

**Many people in the TSC community act as a carer for someone close to them. Matthew Jones (Helpline and Advice Manager, Carers UK) took time to share advice to TSC carers, to help them get through this very difficult time.**

The coronavirus outbreak has seen great change to our lives and brought with it unparalleled levels of anxiety and worry. This is especially true for the 6.5 million unpaid carers in the UK, and the estimated 4.5 million who have become unpaid carers as a result of the covid-19 pandemic.

Carers UK, the UK's only national membership charity for carers, is working to support unpaid carers and campaigns for lasting change. We've been hearing from carers about the difficulties caused by the pandemic, and have been providing information and guidance, whilst also representing the needs of carers to the UK Government and key decision-makers.

During the outbreak, I've been asked many times what my main advice is to unpaid carers, family carers and informal carers. At Carers UK, we are reminded daily that caring takes many different forms and won't look the same for everybody. In this article I have tried to include something for everyone, but if the information here doesn't feel right for your situation, get in touch with the TSA or us here at Carers UK so that we can talk to you.

## Stick to trusted sources of information

Social media and news speculation can add to rising anxiety levels, so focus on things like UK Government and NHS guidance, and content from groups like the TSA or Carers UK.

## Make a plan

Some of our most sought-after guidance has been around planning for emergencies. This might include:

- Confirming if there is trusted family or friends to help if you were ever unable to look after who you care for as you would do normally
- Checking which local services you could turn to for help
- Save down key contact details, medication (dosages and where they are kept), care arrangements and important details that the person you care for would want to be communicated

We have information about this on the Carers UK website at: [carersuk.org/help-and-advice/practical-support/planning-for-emergencies](https://carersuk.org/help-and-advice/practical-support/planning-for-emergencies).

## Ask questions

It may be the case that you are worried about care workers entering your home, or that the person you care for is in a



**MATTHEW JONES**  
(HELPLINE AND ADVICE MANAGER, CARERS UK)

**“During the outbreak, I've been asked many times what my main advice would be to unpaid carers, family carers and informal carers. At Carers UK, we are reminded daily that caring takes many different forms and won't look the same for everybody”**



**“ The coronavirus outbreak has seen great change to our lives and brought with it unparalleled levels of anxiety and worry. This is especially true for the estimated 6.5 million unpaid carers in the UK, and the estimated 4.5 million who have become unpaid carers as a result of the covid-19 pandemic ”**

residential setting and you're anxious that you can't visit as you would do usually. It is absolutely acceptable to approach care providers and ask them to explain to you the steps that they are taking to keep everybody safe, or how they can help you to stay in contact with the person you care for – this might include video technology or passing on a message from you. If you're having trouble getting answers, or if you're not sure what questions to ask, please contact the TSA or Carers UK.

### **Remember just how important you are as a carer**

Caring often means that your attention and focus is on the person that you care for. However, this doesn't mean that your needs disappear, and looking after your own wellbeing is really important. This isn't to make light of this topic, or to in any way suggest that approaching your own wellbeing as a carer is straightforward or easy, but I want to share some tips that other carers have spoken to us about that might help when it comes to your wellbeing:

- **Be kind to yourself – it's OK to have a bad day.** Contact your local carers' organisation to see how they are supporting carers in your area, or speak to your GP about how you are getting on and feeling. You could also see if local organisations can help with tasks to alleviate things at this time, such as collecting shopping and supplies, picking up prescriptions or other small but important tasks. You can find a directory of local carers service at [www.carersuk.org/help-and-advice/get-support/local-support](http://www.carersuk.org/help-and-advice/get-support/local-support)
- **Connect.** Are you able to stay in touch with friends and family? Are there any local groups offering check-in calls, or organisations offering ways to stay in touch? At Carers UK we run an online forum (<https://www.carersuk.org/forum>) where carers can connect. The TSA Support Line is offering regular postcards or calls to keep in touch if you are continuing shielding, particularly for families who are not online
- **Don't forget who you are and what makes you happy.** Even if this means allowing yourself just five minutes a day to do something like listen to your favourite music, read part of a book, draw, spend time in your garden, or even practice yoga and mindfulness

Hopefully, these reminders and suggestions can help you to get through this incredibly tough time, and will help to make the future look a little bit brighter. Try not to ever feel alone, as the TSA, Carers UK and lots of other organisations are here to help you, now and always.



### **TSA Support Line:**

0808 801 0700 / [support@tuberous-sclerosis.org](mailto:support@tuberous-sclerosis.org)  
(Monday – Friday, 9am – 5pm)

### **Carers UK helpline:**

0808 808 7777 (Monday – Friday, 9am – 6pm)  
Email: [advice@carersuk.org](mailto:advice@carersuk.org)

### **NHS Volunteer Responders:**

0808 196 3646 (Monday – Sunday, 8am – 8pm)

# Covid-19 and anxiety: Advice from Anxiety UK

**In a recent TSA virtual session, Dave Smithson (Operations Director at Anxiety UK) talked about different strategies for living well with anxiety. Here, Dave shares more tips and guidance with Scan readers as we look towards life after lockdown:**

You might be asking yourself “What can I do to manage this anxiety, so that I can start to contemplate and handle life as it was before lockdown?” Thankfully, there are resources and strategies to help address anxiety, as restrictions are lifted and we look towards a ‘new normal’ over the next few months.

Anxiety UK has resources and tools to support people at this time. This includes webinars, which can be watched on our YouTube channel (<https://www.youtube.com/user/AnxietyUKOfficial>), online anxiety management courses, and peer-led support groups (<https://www.anxietyuk.org.uk/get-help/coursesgroups>).

“We’ve all been through great change over the last few months, with news and reports leaving many of us feeling more anxious. Demand for our services at Anxiety UK has been extremely high during this time”



Try and get back into some form of routine. If you are able to do so, leaving the house for an hour or so a day to exercise and get some air can be a big help, allowing you to get used to the sights and sounds of the outside world again. If nothing else, your body will appreciate the exercise and it will help to get rid of excess adrenaline that your body might have.

Continue to observe social distancing. When outside of the house, keep your distance from people where possible. Take that extra 30 seconds to wait for someone to pass at a safe distance.

Don't feel the need to do everything in one big leap. It's OK to allow yourself time to slowly take little steps towards moving back into your pre-lockdown routines. For example, if you can work from home and don't feel confident returning to the office when it reopens, speak with your manager to let them know how you are feeling.

Finally, if you need some additional support to help you through this challenging period, Anxiety UK offers an extensive range of support services, including online anxiety management groups and 1:1 therapy services: <https://www.anxietyuk.org.uk/our-services/accessing-therapy>.

**For further information and support on all aspects of anxiety and coronavirus, visit the Anxiety UK #Coronanxiety webpage:** [www.anxietyuk.org.uk/coronanxiety-support-resources](http://www.anxietyuk.org.uk/coronanxiety-support-resources)

**For immediate support, access Anxiety UK's instant online therapy service or national helpline:** [www.anxietyuk.org.uk/tod](http://www.anxietyuk.org.uk/tod) / 03444 775 774

# What is... Emotional Freedom Technique?

**At the Outlook 2020 virtual meeting, Emotional Freedom Technique (EFT) practitioner Heather Carter hosted a practical session on EFT, which is an alternative treatment that can help reduce feelings of anxiety or stress. But how can you use EFT, and how might some people in the TSC community benefit? Here, we tap into the details of EFT.**



## EFT in a nutshell

EFT is like a form of emotional acupuncture without needles. It involves tapping different points of your body – such as your wrists, head or shoulders – in a rhythmic way to help regulate emotions and reduce any feelings of negativity. While tapping, people sometimes think of a specific feeling, thought or image.

## How can EFT help?

For some people, EFT has been found to be beneficial in reducing or relieving the intensity of negative emotions, such as anxiety, guilt or frustration. It has been found to be useful for things such as cravings and habits.

## Who can use EFT?

EFT can be practised by or on anyone, as it is a gentle and holistic coping strategy. Some people might find it very beneficial, whilst others find that other things are more useful.

**“EFT is like a form of emotional acupuncture without needles. It involves tapping different points of your body – such as your wrists, head or shoulders”**

## How do I do EFT?

1. First, it can help to acknowledge and tune in to the emotion or issue that you want to work on. You could try putting the emotion or issue into words
2. When you have the emotion or issue in mind, rate on a scale of 0 – 10 how strongly you are feeling its impact
3. Taking the emotion or issue that you have in mind, think of a positive statement or action in relation to it
4. Now, the EFT sequence can begin – make light tapping movements on different points around your body. You might want to try the top of your head, your forehead, wrists and sides of your hands (think of a karate chop). It can help to close your eyes or breathe deeply and slowly
5. After a few ‘rounds’, go back to your 0 – 10 scale, and see how strongly you are now experiencing the issue or emotion that you wanted to relieve, to see if it helped

## Where can I find resources on EFT?

The EFT workshop during Outlook 2020 can be viewed on the TSA’s website: <https://bit.ly/3esUekD>. Heather Carter can be contacted through her website ([www.heathercarter.co.uk](http://www.heathercarter.co.uk)) or [hello@heathercarter.co.uk](mailto:hello@heathercarter.co.uk).

Although many people find Emotional Freedom Technique (EFT) beneficial, it is still considered experimental and should never be used as a substitute for counselling, therapy or advice from a healthcare professional. If you have any concerns or doubts about using EFT, please contact your healthcare professional.



# Looking to the Future: Transitioning into the 'new normal'

**Across the UK, advice on shielding and social distancing is starting to ease as we transition to the 'new normal' following coronavirus. However, many people are understandably feeling apprehensive or have questions. Here, the TSA's Support Line Advisers, Anna and Mega, share some useful strategies for getting back into the outside world:**

After being told for so long to avoid social contact and to limit time outside, we all have mixed emotions as restrictions are relaxed. For example, you might be relieved that you are able to leave your house again after a prolonged period of isolation, but you may also be worried about the risks of coming into contact with other people again. Perhaps you're pleased with the possibility of accessing your support networks in your local area once more, but are worried about the impact that changing daily routines once again could have on a family member with additional needs.

Acknowledging that this time could be difficult helps to manage expectations for ourselves and those around us. Once expectations for how we will all cope are at a realistic level, we can give ourselves permission to instil positive change.

## Speak to the professionals

TSC affects everybody differently. Your care team, including doctors and those in social care, will be able to help guide you and provide individual advice on transitioning back into the wider world. Also, remember that the TSA is here for you too, whether as a listening ear or to provide you with specific information.

## Build up your routine once more

We know that for many people the biggest disruption and concern will be to integrate back into your former routines, which you are being asked to do after only just getting to grips with your current 'new' routine that was forced on you as a result of coronavirus.

Don't feel like you need to do everything at once. Take it slowly, or consider reintroducing old routines for different family members at different times, to make transition for the family unit as a whole easier.

It might also be beneficial to speak with all family members about how your routines will change, emphasising that change will come bit-by-bit and everyone's health, safety and wellbeing are paramount.

## Understand the situation by considering the pros and cons

It's important to get to grips with how re-integration with the wider world might impact on you and your family specifically. The good news is that, for the TSC community, making decisions about levels of risk in everyday situations is not unique to coronavirus.

Consider the opportunities and challenges of changes, such as allowing carers back into your home and returning to work or school. To stop this from becoming overwhelming, make things more realistic and manageable by taking different topics and dealing with them one-by-one:

“Acknowledging that this time could be difficult helps to manage expectations for ourselves and those around us”

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

Freephone: **0808 801 0700**  
Email: **support@tuberous-sclerosis.org**



“ Throughout this stage, remember that everyone will make different decisions based on what they think is best, and that is ok ”

1. Write down the different ways that your family's life changed as a result of the coronavirus outbreak. For example: "My child's school closed"
2. Then, for each point, write down what the current situation is for each by looking at reputable sources of information. For example: "The school has said that it will re-open fully in September"
3. Write down the pros and cons for the situation: "My child will re-enter education and my childcare problems will be eased, but I'm also concerned it might be too early and my child will be stressed"
4. Think about what you can do to influence and help the situation: "I will speak to my child's school about what measures they have in place to reduce the spread of coronavirus and re-integrate SEND students"
5. Once you've gone through different areas that will change, weigh up the points that are more manageable, and focus on them first. Throughout this stage, remember that everyone will make different decisions based on what they think is best, and that is ok

### Talk about how you're feeling

It is understandable to be affected by and worried about the challenges that coronavirus has brought to us, especially with the added complexity of TSC. Mindfully accept that this is natural and normal – our world was turned upside down, and it will take time for us to all heal.

Although feelings of anxiety or worry are expected, they should not be ignored. If you're comfortable doing so, open up to others. Whether this is to a professional (like a GP or counsellor), family members, or the TSA. You could even open up to yourself through a journal. A problem shared is often a problem halved. In practical terms, talking to a teacher or employer about any concerns you have about coming out of shielding may also help to put in place reasonable adjustments to make you feel more comfortable, such as a phased return to work.

Remember that the TSA is here for you and, with some sensible steps and planning, we can all reach the 'new normal' sensibly and safely.

# My life with TSC: Lauren McWhinnie



Lauren McWhinnie is a video blogger who shares open and honest films about her experiences of living with TSC. We caught up with Lauren to talk about her fantastic films, her reasons for vlogging and the power of laughter and togetherness to get through difficult times.



## Thanks for talking to us Lauren! Can you tell us a bit about how TSC affects you?

I'm 21 years old and I was diagnosed with TSC at 3 1/2 years old. Living with TSC has brought ups and downs, and has felt like a rollercoaster, with trying to juggle emotions and different scenarios. I have had two surgeries for TSC, the first being brain surgery back in 2010 – I was subsequently awarded the 'Spirit of Devon 2010' for my "bravery and Inspiration in everyday life".



LAUREN (RIGHT) WITH SISTER JODIE

## What was the inspiration behind setting up your vlog?

I set the vlog up from a viewpoint that TSC isn't a single diagnosis that fits all, but that TSC can affect people in different ways, with different possible complications and treatment options.

I also set it up to raise awareness of TSC and to reach others who are affected by TSC and related conditions. I want to help people feel more connected and reassured that they're not alone, by telling stories of my experiences.

My vlogs are an opportunity to teach others who may not know about TSC, which might help to give people living with TSC the right level of support at things like work placements.

The videos are also a fun way to boost my confidence, as I've always kept TSC private. I thought that the films would be a way I could speak openly about my condition and living with TSC. I hope that, in the future, when I attend hospital appointments or speak to the public alone, I'll now be able to open up more.

It's a bit of reassurance for me, to know that I'm not the only person living with TSC, as I'd never met anyone with TSC until the TSA Outlook event last year. I always wanted to hide my problems from others, even when things were

too much and kept piling on top of each other. It was only then when I realised that I needed help. Since college, I've been to see counsellors to help with my low self-esteem and anxiety.

## What have you enjoyed the most so far in making the videos?

Having my sister Jodie do them with me is great, as it has made us closer. I like to find the fun in each video and come up with a different theme for each week. However, some of the films weren't easy, but these are the ones I'm also most proud of. For example, the film about my brain surgery took a long time to film because myself and Jodie found it emotionally hard to film and talk about.

The films have also given me confidence to feel proud to be different. It's taught me that being different makes someone stand out from any crowd in a good way, which has been hard for me to accept as I got bullied through the majority of my school years.

## What have you been up to during lockdown, and do you have any future plans away from filming?

I joined the TSA's Outlook 2020 virtual meeting earlier in the year and I've been working on a counselling therapy course and a free epilepsy course. I've also been doing voluntary work for Epilepsy Action and Mind as an ambassador for both charities.

I'm studying Access to H.E. in Sports Science and completed a six-week project that I got from my tutor, receiving a Distinction grade. I hope to go to university next year to study a sports degree. This will involve moving away from home to live an independent and free life. I want to show and prove to myself and others that anything is possible when you put your mind to it.

## Do you have any tips on staying positive during tough times?

Find enjoyment in your passions. My way of coping is by writing quotes and memories down on paper, dancing to music, singing, art and baking, which are all therapeutic. I like to make people laugh and I like to be cheeky, which is how I make up for all the daily battles I face in my life.

## Is there anything you'd like to say directly to the TSC Community?

Never stop fighting for your dreams, even if TSC takes over – we're still in it together! We can be there to support each other to reach our goals and to not give up on life.

Whatever gets in my way, I always strive for gold, so that I can push through barriers and make sure that they don't stop me from achieving the best life possible.

# TSC research spotlight: Dr Charlotte Tye

**Dr Charlotte Tye (Kings College London) is a TSC researcher. Charlotte took some time to tell us about life as a researcher, her work for the TSC community and the ways that things changed under lockdown.**

## **Why did you decide to become a researcher, and how did you get involved in TSC-related research?**

I have always been interested in developmental disorders and wanted to find out more about how differences in brain development are related to behaviour, and how these differences could help to improve quality of life.

My first taste of research was during my undergraduate degree in psychology at the University of Bristol, which gave me an insight into analysing and interpreting data. I later completed my PhD at King's College London, which was focused on the overlap between autism and ADHD outside of TSC.

In 2013, I started working on the TSC 2000 Study, a large study of children and adolescents who were born in the early 2000s and live with TSC. This involved travelling across the UK to see families in their homes and was the point when the impact of behavioural difficulties in TSC, and the potential for TSC to improve our understanding of developmental disorders, became clear to me.

## **What TSC research are you involved in at the moment?**

My research focuses on gaining a better understanding of cognitive and behavioural difficulties that many people living with TSC face, and how these relate to brain manifestations, like tubers and epilepsy. The EDiTS Study ([www.edits-study.org](http://www.edits-study.org)), funded by a fellowship from the TSA, is investigating early brain and behavioural development of infants with TSC, to help identify features that may predict later difficulties.

After speaking with families, the impact that covid-19 is having on the TSC community became clear. That's why, along with a UK-wide network of experts, I launched the CoIN Study ([www.coinstudy.co.uk](http://www.coinstudy.co.uk)), an online study aiming to understand the impact of the pandemic on mental health and wellbeing in families of children with rare genetic and neurodevelopmental disorders, including TSC.



**“In 2013, I started working on the TSC 2000 Study, a large study of children and adolescents who were born in the early 2000s and live with TSC”**

**“It is striking how much progress has been made in TSC research in recent years – even during my time studying TSC, there have been huge strides in our understanding of molecular biology, as well as behaviour”**

### **What impact do you hope that the EDiTS study and CoIN study will have on improving the lives of people affected by TSC?**

We know that behavioural difficulties greatly impact upon quality of life in people affected by TSC. In the EDiTS Study, identifying early predictors of later behavioural problems will help inform early interventions.

Behavioural difficulties may be exacerbated during times of uncertainty. In the CoIN Study, it is therefore important to understand how the practical impact of covid-19 on everyday life is associated with child and parental mental health. A key part of the CoIN Study is to rapidly share results to the community, as well as to design and distribute tailored information and coping tips.

### **How important is patient involvement in TSC-related studies?**

Throughout my research career, a key element has been meeting with families affected by TSC. By meeting with families, it is possible to gain a strong understanding of the impact of TSC and its variability, and recognise the needs and priorities of families. I would really like to work more closely with families from the outset.

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

It is striking how much progress has been made in TSC research in recent years – even during my time studying TSC, there have been huge strides in our understanding of TSC-related molecular biology, as well as behaviour. From the perspective of cognitive and behavioural difficulties in TSC, I am hopeful that we will be able to target more specific interventions earlier, to improve long-term quality of life.

### **How has your working day changed as a result of covid-19?**

We welcomed a little boy last summer, and I returned to work after maternity leave one week into the lockdown – so we, like many others, have been juggling childcare and working at home during the past few months. I take my son for a walk every afternoon, which really helps to clear my mind after naptime or baby-bound video calls!

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

At university I was involved in a lot of fundraising and volunteering. I've always wanted to work with people, so I think I'd really enjoy working for a charity. I also love computing and analysis!

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

I love cooking and baking, although I'm not hugely creative and always follow a recipe! My son's first birthday is coming up, so I've tasked myself with my first birthday bake. I have also really enjoyed exploring the beautiful countryside here in Surrey over the past few months on our daily walks.

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

Thank you for the time and enthusiasm you've given to our studies – research like this would not be possible without your support. The TSC community is strong, and it's an honour to be part of it.

# Fundraising updates

**We hope that this issue of Scan finds you safe and well despite this turbulent time. This year has been unlike any other for the TSA, which we are sure is the same for you and your family.**

At this time of the year, we would normally be updating you on the amazing efforts of our London Marathon team and other community fundraisers who have been challenging

themselves at group events across the UK to improve the lives of people affected by TSC. However, this issue includes some very different thank you messages, celebrating the varied and ingenious ways that our community has been fundraising despite the country being in lockdown, as well as those who held virtual Tea & SCones for TSC get-togethers!

In this issue there's also a big "Thank you" to everyone who supported the TSA's Coronavirus Emergency Appeal in May. Thanks to the kindness and generosity of the appeal's supporters, the TSA can continue to provide support for people living with TSC and their families.

We are sad to say that the 2020 Prudential RideLondon – Surrey 100 event has also been cancelled, as has the Great North Run 2020. But, we are looking forward to the London Marathon, which is still taking place later in the year, and the 'virtual' RideLondon event. Plus, there are still many ways for you to support us post-lockdown!

As always, if you have any ideas or fundraising planned for the TSA please do let us know by contacting us at [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org) or by calling **0300 222 5737**. We'll then guide you and your fundraising at every step of the way, and will help in any way that we can.



**MIKAELA AND KATHRYN, TSA FUNDRAISING**

## **Mikaela and Kathryn** TSA fundraising

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

**Daytrippers Foundation** supported the TSA's Family Fun Day that was held back in March at the Blue Reef Aquarium in Portsmouth.

**The Bartlett Taylor Charitable Trust**

**The Rest-Harrow Trust**

**Joseph Strong Frazer Trust**

**Swann Morton Foundation**

**The Tregelles Trust**

**Bank of Scotland Foundation** is supporting the TSA by providing funding towards our virtual support sessions and maintaining our support line

**Daytrippers  
Foundation**

**BANK OF SCOTLAND  
Foundation**



# Fundraising Champions

**The Cotton family, including daughter Esme, were planning on tackling the Liverpool Spring 10k in aid of the TSA. Although the event was postponed due to coronavirus, it didn't stop the family from raising funds to help improve the lives of people affected by TSC! We spoke to Esme's mum, Annemarie, about the family's fundraising.**

## What inspired you to fundraise for the TSA and choose a running challenge?

Esme completed Couch to 5k last year and we're now regulars at our local Parkrun. We were so impressed, proud and surprised at our daughter becoming a regular runner that we decided to all run together for the TSA, to raise funds and awareness for people affected by TSC. We chose the Liverpool Spring 10k, but unfortunately it was postponed.

## What did you do when the Liverpool Spring 10k was postponed?

We were all really disappointed to find out that (quite understandably) the race had been postponed to October, but this felt a long way off and we wanted to do something to help the TSA sooner.

We decided to contact the friends and family that we would have asked to sponsor us for the Liverpool Spring 10k, asking them to directly donate to the TSA instead. Many people have been affected financially by the current coronavirus crisis, but some people are fortunate enough to not have had their income affected and we asked them to donate using money that they would have normally spent if lockdown wasn't happening, such as on travel costs, takeaway coffee or hair appointments.

## What motivates you to do all of this?

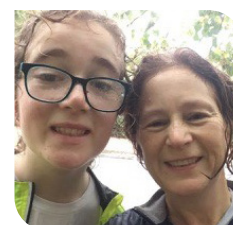
As a family, we know how important the TSA is and how vital fundraising is to keep the charity going.

Running is now a regular part of our family life and we run most days. Esme has a chart and colours in a square for each kilometre we run - we are hoping to fill the page before she goes back to school (as a result of covid-19). The positive side of Esme really liking a routine is that, once something is part of the routine, it is there to stay!

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

We found that asking people to donate money that they would have spent anyway was really powerful. We got a great response, with lots of donations being made.

The TSA were also helpful, I didn't know how to make an online donation page, but the TSA team were on-hand.



**Thank you to Esme, Jacob, Annemarie and Steven!**

<https://www.justgiving.com/fundraising/esmestsalockdownchallenge>



## Coronavirus emergency Appeal

Dear friends of the TSA,

Back in April, I wrote to you all asking if you were able to contribute to the TSA's Coronavirus Emergency Appeal. We looked to you, and you responded incredibly, with the appeal so far raising a jaw-dropping £16,000 to help the TSA to continue our work for everyone affected by TSC.

I am overjoyed to now thank each and every one of you who has supported our charity in this appeal to date. Your kind generosity has helped us to guide the TSC community and the TSA through a very difficult time, with the TSA's support and information services seeing a sharp increase in the number of people contacting our support line and accessing our resources.

We've been working with the TSC community through many different kinds of issues, such as transitioning from long periods of shielding or self-isolation, guidance around education for children with SEND, and managing TSC-related treatments during covid-19 to name just a few. The TSA has also remained committed to bringing the TSC community together despite social distancing, with regular virtual events allowing the TSC community to connect whilst also receiving expert guidance on a range of TSC-related issues.

We're proud to have been there for the community during this time, and to continue being here during the transition back to the 'new normal' and beyond.

We can provide support and information for people affected by TSC only because of the kindness and generosity of supporters like you. The Coronavirus Emergency Appeal is supporting the TSC community through a very difficult time and is ensuring that the TSA remains available for everyone who needs us.

If you would like to further support the appeal, or if you were unable to make a gift before but are now in a position to do so, please visit: [tuberous-sclerosis.org/donate](https://tuberous-sclerosis.org/donate).

Remember: **You are never alone with TSC. The TSA and fantastic TSC community are always here with you. Together, we can get through anything.**

Thank you once again.

With my warmest wishes,

Dr Chris Kingswood

President, Tuberous Sclerosis Association



# TSA Gaming Champion



## Now Loading!

Fundraising for the TSA through the power of video games.

Register your interest:

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



Registered with  
**FUNDRAISING  
REGULATOR**

## WHAT IF YOUR LASTING LEGACY COULD BE A CURE FOR TSC?

By leaving a gift in your will, you will further the search for a cure and make a lasting impact on the lives of people affected by TSC for generations to come.

After providing for those you care about in your Will, please consider leaving a gift to the Tuberous Sclerosis Association. Every gift is appreciated, no matter what size.



Please visit [www.tuberous-sclerosis.org/legacy](http://www.tuberous-sclerosis.org/legacy)

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**tsa**  
tuberous sclerosis  
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# Climbing the highest mountain together

**On Friday 15 May, TSC groups around the world celebrated Global TSC Awareness Day. At the TSA, we celebrated the day with a special Tea & SCones for TSC virtual event, while Equistone Partners Europe continued their team fundraising efforts for the TSA by 'climbing Mount Everest'...via the stairs!**

You might remember that earlier in the year we announced that Equistone Partners Europe had selected the TSA as their Charity of the Year - we were delighted!

The team at Equistone have been working hard all year to fundraise for the TSA, and didn't let working from home stop them from their mountainous fundraising efforts on Global TSC Awareness Day, with the team 'climbing' the equivalent height of Mount Everest via their staircases!

Climbing the 8,858m of Mount Everest, Equistone raised a staggering **£9,708** – and all in fancy dress too!

## EQUISTONE

The TSA's partnership with Equistone in 2020 has been fantastic. We look forward to seeing what Equistone will come up with for the TSA in the second half of 2020.



Equistone aren't the only ones taking on Mount Everest for the TSA, with 15-year-old Leo Gargett attempting the Mount Everest stair climb too! Leo is completing the challenge as part of his silver Duke of Edinburgh award and to increase awareness of TSC and to raise funds for the TSA as his mum, Vicky, lives with the condition.

As a solo challenger, Leo will need to get up and down the stairs 33 times every day for six months to reach the summit! Let's hope he's still smiling at the end of his challenge! You can follow his efforts on his JustGiving page: <https://www.justgiving.com/fundraising/leo-gargett> or via the TSA's social media.



# Fundraising thank yous

Send your event plans and post-event pictures to [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org) for a chance to feature in the next Scan or on our social media! Here are some of the amazing and ingenious ways people have been supporting the TSA since April.

## Community fundraising

Just before covid-19 impacted our lives, the brilliant **Jan Baynes, Anne Wells** and their family and friends got together for a quiz night, leading to **£100** towards their 2020 TSA fundraising goals!



THE QUIZ WINNERS RECEIVING THEIR PRIZES

Before lockdown and social distancing became part of our lives, the **Greaves family** held a fundraising night to improve the lives of people affected by TSC, which included magician Stevo who wowed everyone, raising **£400!**



THE GREAVES' EVENT WAS ENJOYED BY ALL!

**Clarissa Constable and family** have been busy fundraising by doing online raffles in celebration of daughter Olivia turning two years-old, with prizes including an Echo Dot, a hamper of sweets and a massive jar of jellybeans. In total they have raised **£973!**



CLARISSA'S DAUGHTER, OLIVIA

Esme Cotton inspired her uncle **Ron Firth** to fundraise for the TSA, holding a Virtual Grand National sweepstake which raised a wonderful **£148!**



THANK YOU RON

Well done to the brilliant eight-year-old **Francesca Brown**, who braved the scissors and had her long hair cut short to help improve the lives of people affected by TSC. Francesca's great idea has raised an amazing **£530!**



FRANCESCA BRAVED THE SCISSORS FOR THE TSC COMMUNITY!

**Kathleen Pye** was inspired by her son Vinnie and has been holding raffles, a football card sweepstake and collecting donations from family and friends, raising **£670!**



KATHLEEN AND VINNIE

**Chrissy Linford** got local businesses in Plymouth, including Thundercat Racing UK and Evolution Marine, involved in her #4LexiFund fundraiser, raising over **£1,000!** The fund, in aid of Lexi Dugdale, has seen a variety of activities taking place over the past year. This includes a virtual walk of the English Channel and back, hosting collections tins in local businesses and even a high speed boat race! Amazing!



CLAIRE WELCH, CHRISSEY LINFORD, JAMES DUGDALE AND LEXI DUGDALE

You could follow in Jan and Anne's footsteps - host a virtual quiz night and generate funds for people affected by TSC!



## 2.6 CHALLENGE FOR THE TSA

In April, many of you took on the 2.6 Challenge, organised by the London Marathon group, by thinking up different challenges linked to 2.6 or 26 to reflect the marathon distance!



THE DONNELLY FAMILY WITH TSA GEAR!

**Alex and Evie Donnelly** ran 2.6 miles and generated an amazing **£2,109**, which was then boosted by a generous donation from their parents' employers, giving a grand total of **£3,609**!

**Paul Maywood** hit **£95** by running the 2.6 Challenge, even going further by hitting 4.16 miles!



LONG-TIME TSA FUNDRAISER  
PAUL MAYWOOD

**Phillip Rogers** raised **£65** by hiking from Daisy Nook to Hartshead Pike in Tameside!

**Ariana Pothecary**, who has just turned 12, took on 2.6 miles with her dad and chose to help the TSA as her Auntie Amber, has TSC. Nice one Ariana!



ARIANA AND HER DAD, THANK YOU!

Even the TSA fundraising team got involved! **Kathryn Harrison** and her family raised **£260** by taking on different 2.6-themed tasks, including Kathryn's sister **Nicola** who moved 26 wheelbarrows of bark!



NICOLA GETTING STUCK IN!



KATHRYN HARRISON

We are sorry to say that the 2020 Prudential RideLondon – Surrey 100 and Great North Run have been cancelled. The TSA would like to thank our riders and runners for their efforts in training and fundraising: **Michael Hachar, Tim Swales, John Gladstone, Jamie Heselden, Emma Lupton, Louise Evans, Joe Nelson, Louise Fellows, Rosie Fellows, Jo Fellows** and **Daniel Marks**.



Our amazing Facebook fundraisers have raised over £5,800 in 2020 so far! How fantastic is that!? Thank you to recent fundraisers:

**Alice Titley**  
**Aruna Bhatt**  
**Hannah Mallekoote**  
**Izabela Dench**  
**Kendra King**

**Leyla Latif**  
**Nicola Elliott**  
**Samantha Jayne Baldock**  
**Tom Pinkerton**  
**Wendy Chamberlain**

**Nick Thornsak**  
**Fi Wilsom**  
**Roberta Tyler**

You can set up your own TSA Facebook fundraiser in just a couple of clicks from your Facebook profile to raise money for the TSA. Ask for donations for any personal challenges or for a birthday or special occasion!



## Looking for your own fundraising inspiration?

### Host a film marathon in your home

Get the popcorn and get ready and settle in for a 24-hour film marathon! Ask people to donate and select a film for your playlist – will they be nice or make you sit through some stinkers?!

### Hold a virtual quiz night

Bring people together and support a great cause! Quiz nights can be held virtually and you can ask participants to donate an entry fee to the TSA.

### Daily exercise

Set a weekly or monthly challenge! Could you do a marathon in a month? Or has Chrissy's fundraising in Plymouth inspired you to 'walk' the English Channel and back? You could log your mileage for any challenge using Strava linked to your JustGiving Page!

## Events

Lots of mass participation events have been cancelled or postponed, but that hasn't stopped #TeamTSA! Many of you are still training and fundraising hard, with some of you even taking on independent challenges!

**Carla Terry** wasn't put off when her planned event, the Hackney Half Marathon, was postponed. Instead, Carla decided to set her own 'Weymouth Half Marathon' route, running the 13.1 Miles around her hometown! Carla raised an incredible **£1,275** in honour of her nephew: "Ezra has been on new treatment and the tumour on his heart has so far got smaller – he's my hero!"



**WEYMOUTH HALF MARATHON  
'WINNER' CARLA!**



**GREAT WORK SUZANNE**

**Suzanne Rouse** set her own challenge of 100km throughout May! Suzanna not only smashed her challenge by hitting 124 km of walking and cycling by the 16th May but also raised a stunning **£1,555!**

In Suzanne's own words: "For the past 20 years I have had the pleasure of knowing Tara, a bright and kind young lady who has Tuberous Sclerosis Complex".

**Georgina Davenport** and her cousin **Natalie Davenport** took on the Cheshire Triathlon, raising money for the TSA in memory of Georgina's late sister, Jennifer. In total, they have raised **£585!** Georgina and Natalie would like to thank the generous TSC community members who donated to their cause!



**WELL DONE GEORGINA AND NATALIE!**

**Rebecca Mantell** is busy fundraising for the postponed Sheffield Half Marathon, which will now take place in



**DO IT FOR FREDDIE, REBECCA!**

September. Rebecca has already hit **£440!** Rebecca was inspired to take part by her 3-year-old nephew Freddie (left) who was diagnosed with TSC at 7 months: "Freddie is the most incredible, determined, funny, happy little boy who I am so proud of!"

**Have you been waiting for a local or national event to be rescheduled? You could do what Carla did and set your own date and route, even tracking your activity on JustGiving using Strava!**

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

*"We are all going through a time of change and uncertainty. However, with the TSA and the TSC community you should never feel alone."*

*Should you need our support, now or at any other time, we are here for you, whether it is just for a chat or to help you to better understand coronavirus or anything else TSC-related. You can reach us over the phone, email and (soon) webchat.*



*It might ease stresses or strains, and remind you that you're not alone.*

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