

scan

DECEMBER 2019

The magazine of the TSA



Big Day 2019



New website launched



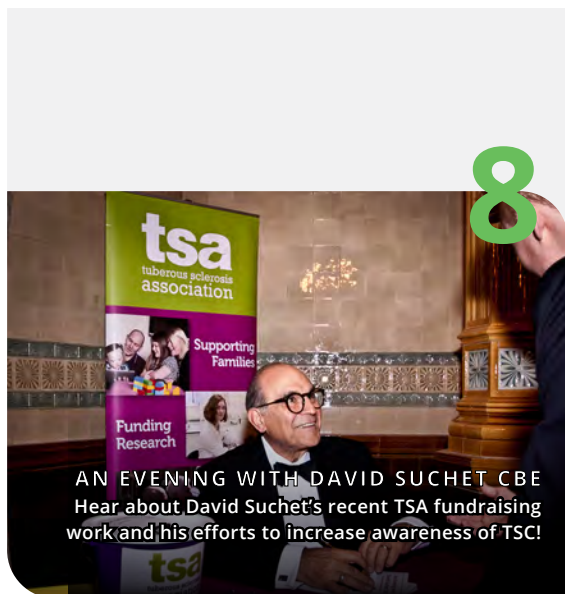
An evening with David Suchet CBE



TSA Annual General Meeting 2019



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LUKE LANGLANDS, EDITOR

From the Editor

Although the hope and excitement of a New Year beckons, everyone at the TSA is continuing to work hard up until the very last few days of 2019, with your final issue of Scan for the year showing just a glimpse of what we have been working on during the past few months!

This Scan focuses largely on the successful Big Day 2019. We wanted to ensure that those who were unable to make it to the day itself got the opportunity to hear about the event and from some of the fantastic speakers that made Big Day 2019 so special. To catch-up on what was discussed at Big Day 2019, start from **page 10**.

If you watch the BBC's *The One Show* or ITV's *This Morning*, read any number of different national newspapers or listen to BBC radio, you are likely to have caught David Suchet CBE discussing his new book *Behind The Lens: My Life*. David has made the wonderful step of using many of these media opportunities to raise awareness of TSC, turning the attention of the nation towards TSC and the impact that it can have. You can read more about David's awareness-raising on **page 8**.

You might have also seen that we have been busy with re-launching the TSA's website, with Tuberous-Sclerosis.org now more fitting of the growing and increasingly digitally-facing TSC community. A lot of hard work has gone into the launch of your new look website from everyone at the TSA. We hope you find it easier to navigate and packed with more up-to-date and relevant information compared to our old site.

As preparations for the festive period will be now well underway for many, don't forget our Christmas cards and other goodies, as well as our special TSA-branded snowflake baubles! Find out more in the fundraising sections of this edition of Scan.

Luke Langlands, Editor

Support and Information

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(Head of Support and Information)

Julie Rainer

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To access the TSA's support and information services, please contact Rachael Wyartt via **Rachael.Wyartt@tuberous-sclerosis.org / 0300 222 5737**.

Do you have feedback about changes to our support services from 2020? Make your voice heard - fill in our survey and take part in our virtual focus groups (see **page 13**)

Front cover and Big Day photography courtesy of **Mike Dodson / Vagabond Images**.

A word from your Chair

YOUR NEW CHAIR

I am proud to be your new Chair and look forward to representing the charity and helping the community.

Turning to this page of Scan, you may have expected to see the words of former TSA Chair, Martin Short. However, after a long tenure he has handed over the baton to me as the new Chair. Martin will continue to serve a critical function in the governance of the charity as Vice-Chair to make my transition into Chair easier. My deepest thanks go to Martin for his incredible work in leading and continuing to support the TSA. Over his time as Chair the charity has made huge strides in improving the lives of those affected by TSC.

For the benefit of those who were unable to make it to the Big Day 2019, we had a very informative day which we broadcast digitally. Hopefully those who could not attend in person were able to catch at least part of the day online. I am always struck by how much we can learn from people across the TSC community, from people living with TSC, their families, researchers and clinicians. The advice, experience and feedback of the community is invaluable to the TSA, and so I wish to reiterate the importance of us communicating with and supporting one another. It is the only way that we can be sure that we are doing everything that we can, within our means, to improve the lives of those affected by TSC.

As your Chair, I am committed to the TSA's new five-year strategy to REACH more people and drive more REseArCH, whilst working hard to balance the books.

With respect to REACHing more people, we have received a lot of feedback about the upcoming changes to our support services, which has understandably focused on the sad departure of our hard-working regional advisers. The TSA is moving from a large team of regional advisers to a smaller team of trained advisers who can be contacted regardless of where you live in the UK through a free and confidential support line. Looking ahead, the changes we are making will mean that our vital services continue to be accessible to everyone and are sustainable for the future. It is important that we maintain an open dialogue with those in the community that we serve, so I would very much urge you to engage in providing us with your feedback as and when you use the service so that we can continually monitor and improve it.

In response to the feedback we received at Big Day, the Scottish Get Together, Welsh Info Day and Outlook, we have extended the pilot phase of the support line to enable you to make your views known before its official launch – turn to **page 13** to read more about our support line survey (now open) and virtual focus groups. We would love to hear your views.

With respect to driving more REseArCH, I am excited that the UK will host the International TSC Research Conference 2020 where we will welcome leading clinicians and researchers from around the world to discuss the latest advances in medicine, science and technology that may benefit our understanding of this complex condition. With this and the TSA's new model of working in partnership and collaboration with other organisations, I believe there are exciting times ahead.

Finally, I wanted to highlight the Board's composition. The TSA's Board of Trustees consists of 12 members; 3 of which have TSC, and 10 of us have children or grandchildren with the condition. As such I consider us more than just custodians of the charity – we are stakeholders just like you. We are always looking to plug missing skill sets on the Board and recruitment is a continual process. I understand that being on the Board will not be practically possible for everyone, but I would ask that all of you make our voices resonate louder particularly on forthcoming campaigns and of course by fundraising to help us build on the TSA's vital work.

If you would ever like to talk to me about how we are doing, please get in touch: chair@tuberous-sclerosis.org.

With best wishes,

Sanjay



**SANJAY SETHI,
CHAIR**

A word from your Chief Executive

LOOKING BACK AT A DIFFICULT BUT SIGNIFICANT YEAR FOR THE TSA

This year has been one of change for the TSA. With the charity now focused on spending less whilst bringing in more income, difficult decisions were made about how we will deliver our services in the future.

Trustees and staff at the TSA are working hard to reduce expenditure, grow income and reshape the TSA, so that the charity can continue to support the TSC community for many years to come. You can find out more about why these changes are necessary on [page 14](#).

During 2019, we have reduced headcount at the TSA from a planned 21 members of staff to a much smaller team of 13 people. I would particularly like to acknowledge the loss of our regional advisor posts in 2019 – we have had to say goodbye to hardworking and valued members of staff, and I know that this loss has been keenly felt by trustees, myself, the TSA team who have lost valued colleagues, and the wider TSC community.

I would also like to thank our remaining 13 members of staff – some are new and some have been with us for a number of years. All of them are working incredibly hard to maintain and improve the services that we are passionate about providing to the TSC community, despite the lower headcount.

Despite these changes at the TSA, we have delivered a number of positive achievements for the TSC community in 2019. These include:

- Securing funding for everolimus for TSC-related epilepsy from April 2019
- Launching a new website packed with information about TSC and living with the condition
- Supporting the implementation of new UK clinical guidelines on TSC
- Maintaining our high-quality national events across the UK, including a boost by the incredible support for the charity by award-winning actor David Suchet CBE

The difficult decisions that have been made this year will help to ensure that the TSA can be here for the TSC community for many years to come. Over time, I believe that the TSA will be renewed, with greater resilience, courage and determination to support the TSC community as a result.

If you would like to speak to me about the changes taking place at the TSA, please get in touch: Louise.Fish@tuberous-sclerosis.org.

Very best wishes,

Louise



**LOUISE FISH,
CHIEF EXECUTIVE**

News

THE LATEST NEWS UPDATES FROM AROUND THE UK



Mandatory autism and learning disabilities training for nursing, health and social care workers

All nurses and other health and social care workers are to be given mandatory training on autism and learning disabilities after the death of teenager Oliver McGowan. Oliver McGowan, 18, died at Southmead Hospital, Bristol, in 2016 after being given a drug he was allergic to, despite staff being warned repeatedly from Oliver's parents.

The UK government has announced funding of £1.4m to develop and test the new training package, with training not currently mandatory and the quality of training varying across the UK.



United Response reports a rise in learning disability hate crimes

Research by learning disability charity United Response has found there were more than 6,000 reported cases of learning disability hate crimes across the UK in 2018-19, a rise of almost 12% compared to the previous year. United Response submitted Freedom of Information requests to 45 police forces across England and Wales, with the figures gathered by the charity also showing that fewer people were being charged or prosecuted for disability hate crimes across England and Wales.



New conference aims to improve mental health and wellbeing in Wales

Health and social care professionals from across Wales got together in Cardiff this October for the inaugural Together for Mental Health 2019 conference. Together For Mental Health is the Welsh Government's cross-portfolio strategic response to mental health, with the conference examining options for future improvements and innovation in Wales.



New NHS England taskforce to improve in-patient services for children with autism and learning disabilities

Secretary of State for Health, Matt Hancock, has announced that care for in-patients who have a learning disability and autism will be reviewed over the next 12 months. The taskforce forms part of the NHS Long Term Plan, which aims to improve patient wellbeing and includes an ambitious transformation of mental health, autism and learning disability services.



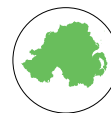
NHS Scotland urged to fund cannabis treatment for epilepsy

Campaigners in Scotland are pushing for greater uptake of cannabis-based treatments for people who live with treatment-resistant epilepsy. Cannabis-based drugs were reclassified last November in recognition of their therapeutic benefit for treating certain conditions and became available at NHS Scotland. Yet, some health boards are still not providing treatment with cannabis-based medicine.



Number of people on neurology waiting list in Northern Ireland doubles in four years

The number of people waiting for a first neurology out-patient appointment for conditions such as epilepsy has more than doubled in Northern Ireland in the past four years. In March 2015, there were 9,123 people waiting for a first appointment – by 2019, this figure rose to 19,376.



Of the people waiting for a first neurology appointment, 11,000 have been waiting for more than one year. The Department of Health has said that it is hoping to secure additional funding for more junior doctors in neurology to help reduce waiting times.

Fewer women receiving kidney transplants and dialysis, despite more women than men requiring these treatments

A European study suggests that more men than women receive either a kidney transplant or dialysis, even though more women are in need of these treatments compared to men. The research – which covers five decades' worth of data on chronic kidney disease, kidney replacement and dialysis – found that women consistently fall behind men in these treatments. Around 60% of men who need a kidney transplant or dialysis receive the treatment, compared to only around 40% of women.



Benefits freeze to end in 2020

The freeze in benefit payments, which has taken place since April 2016, will end from April 2020.



Since the benefit payment freeze, most benefits and tax credits for those of working-age have been kept at the same value, rather than going up every year in line with inflation. The last time the affected benefits rose was in April 2015.

A wide range of like-minded groups, including the Joseph Rowntree Foundation, have argued that the benefits freeze has been one of the biggest factors in worsening poverty levels among working families with children.

Working-age benefits, such as Universal Credit and Jobseeker's Allowance, will rise by 1.7% from April 2020. Other benefits that have been frozen but are now set to rise by inflation are: Employment and Support Allowance, Income Support, Housing Benefit, Child Tax Credits, Working Tax Credits and Child Benefit.

Disability benefits and carer's allowance, which have not been subject to the freeze, will also increase by 1.7% next year.

New TSA website launched

New website designed and launched with accessibility and ease-of-use at its heart

The TSA was delighted to unveil our brand new website! We've been working hard to make sure that our new digital home is befitting of our growing and increasingly digitally-facing members.

You'll find sections for a wide range of topics, including specialist areas for health and social care professionals.

The creation of the new TSA website has been a major project, with the entire website developed from the ground up. From initial drafts on paper to our future plans for more video and interactive content, the TSA website is one that any organisation would be proud of.

Why was a new TSA website needed?

Our previous website was becoming increasingly difficult to maintain, with the software used to host the website being very outdated, with navigation and keeping the site up-to-date bringing significant issues. Although a 'spring clean' of the previous site was considered, the time and resources needed to do this would be significant, with the launch of a newer, more modern and more accessible website being the better option.

Thank you to our website grant supporters

Developing the new TSA website and its upkeep for 12 months was funded in full thanks to kind grants by:

- P F Charitable Trust
- 29th May 1961 Charitable Trust
- Joseph Strong Frazer Trust
- British Association of Dermatologists
- Esher House Charitable Trust

An evening with David Suchet CBE

In September, we were delighted to hold the fundraising event 'An evening with David Suchet CBE', raising an incredible figure of over £14,000 to help improve the lives of people living with TSC!

Award-winning actor David Suchet CBE reflected on his stage and film career, including his early roles portraying an impressive catalogue of Shakespeare characters, twenty-five years of bringing Agatha Christie's iconic Poirot to life and the roles that he has enjoyed most since bidding farewell to the famous detective.

Taking place at the National Liberal Club in Westminster, London, the TSA welcomed 73 guests to the evening. As well as a black-tie dinner and hearing from David himself, a silent auction with executive prizes finished the great evening.

We would like to thank every single person who either attended 'An Evening with David Suchet CBE', or was kind enough to donate items for our silent auction.



New book by David Suchet CBE will help to raise funds for TSC research

As well as being generous enough to offer his time to help us fundraise, David has made the incredible step of donating profits from his new photobook *Behind the Lens: My Life* to help fund research into TSC!

Behind the Lens: My Life combines David's love of photography with his life journey, giving readers "an opportunity to really get to know me and the sort of person I am. Through my photographs, and the accompanying stories, you will see the world through my eyes."

Publicity for *Behind the Lens: My Life* has taken David across major TV shows, radio stations and newspapers such as *The One Show* (BBC One), *This Morning* (ITV) and *Steve Wright's Big Guests* (BBC Radio 2). David used these opportunities not only to discuss his photographic inspirations and his new book, but also to raise awareness of TSC.

We cannot thank David enough for his generosity and selflessness – be sure to pick up your copy of *Behind the Lens: My Life*, especially with Christmas approaching!



Family Fun Day 2019

THIS YEAR'S SOLD-OUT FAMILY FUN DAY WAS AT CHESTER ZOO, WHERE WE HAD A GREAT TIME GETTING TO KNOW MORE TSC FAMILIES AND SEEING SOME EXOTIC CREATURES!



The TSA's Family Fun Day is the perfect opportunity for families and children affected by TSC to get together for a great day out.

Family Fun Day 2019 did not disappoint, with a great turnout from the TSC community, which brightened us up on a rainy day!

Around 70 community members made it to the day itself, with demand for our subsidised tickets to Chester Zoo being very high – for future Family Fun Day events, we are going to work hard to make sure that as many people as possible can attend.

Family Fun Days in 2020

Family Fun Day 2020 planning is already well underway. We know that the TSC community love these days as much as we do, which is why we are looking at the possibility of hosting more than one Family Fun Day next year, so keep an eye out on our social media, website and future Scans for more info!

At the start of the day, TSA staff and community members made their way to the 'TSA HQ' in the zoo, a large indoor wooden hut perfect for sheltering from the rain and getting to know each other! Here, community members came and went, using the HQ as a base to meet with other families who understand the impact that TSC can have on the lives of individuals and whole families. Our HQ was also a great opportunity for the community to meet TSA team-members, both old and new, to chat about all of our work.

Although it was a wet and rainy day, there was still lots of wildlife on show! Many of us had a great time exploring the Tropical Realm, with its indoor areas keeping us toasty. Some braved the elements and went to other areas, with everything from insects to giraffes on offer at Chester Zoo!

Everyone left the Family Fun Day 2019 with lots of smiles, having come face-to-face with some fantastic creatures and having got to know fellow TSC community members!



Big Day 2019

BIG DAY 2019 TOOK PLACE IN NOTTINGHAM ON 2 NOVEMBER, WITH A BUSY AGENDA OF SPEAKERS AND WORKSHOPS FOCUSED ON LIVING WITH TSC, AS WELL AS LOTS OF CHANCES FOR THE COMMUNITY TO MEET AND GET TO KNOW ONE ANOTHER!

A hive of activity and discussions, Big Day 2019 lived up to the event's reputation for being an important opportunity for everyone in the TSC community - including individuals and families affected by TSC, researchers and clinicians - to connect and learn.

Big Day 2019 also achieved a fantastic turnout, despite having to compete against the Rugby World Cup final!

Big Day 2019 in numbers:



172 registered attendees from across the TSC community



18 talks and workshops



11 clinician one-to-ones



22 speakers, including community members, clinicians and external groups



4 different rooms



1 specialist creche for children with additional needs



Many attendees came to discuss TSA plans and projects achieved over the last year and plans for the future, or to attend talks from TSC specialist clinicians about their work, whilst others were keen to engage with the range of fantastic external charity speakers represented at Big Day 2019. Some people came to simply make new friends and meet familiar faces. Whatever a person's reason for coming to Big Day 2019, their needs were well catered for!

Session highlights: Meeting the TSA's new five-year strategy

The day started with Sanjay Sethi (Chair), Martin Short (Vice Chair) and Louise Fish (TSA Chief Executive) giving an overview of how the TSA is aiming to meet our new five-year strategy, including plans for the launch of a free and confidential support line in 2020. This session was an important one, allowing the TSA to discuss why the charity must now focus on reducing spending whilst also boosting income, in a way that was clear and transparent.

The TSA was delighted to host such a wide range of talks and workshops from external charities and groups at Big Day 2019, with each one invited because of their potential to help support the TSC community in different ways:

- Autism East Midlands
- Disability Rights UK
- Epilepsy Sparks
- Roald Dahl's Marvellous Children's Charity
- Sibbs

As well as external charities and groups, a wide range of specialist clinicians with a TSC focus were in attendance, kindly donating their time to talk with the TSC community about their work and research.

Session highlights: All about your new support services from 2020

The TSA is making changes to its support services from 2020, introducing a new 9am – 5pm support line. Big Day 2019 was an opportunity to talk about how the support services will change from next year, with Louise Fish (Chief Executive) and Rachael Wyarrt (Head of Support and Information) discussing the new service and what it might mean for community members.

A key aim this year was to offer attendees more scope to chat and get to know each other compared to previous years, as the chance to speak to other people who understand the impact of TSC is priceless. Many breaks and an extended lunch were included in the agenda, so that those at Big Day 2019 could make the most of the day and speak more together.

Session highlights: The UK TSC clinic network

Dr Chris Kingswood (Consultant Nephrologist, St George's University Hospital) and Dr Frances Elmslie (Consultant Clinical Geneticist, St George's University Hospital) gave an overview of UK NHS TSC clinics, including how to be referred to a clinic, what to expect at clinic appointments and what is planned in the near future for a more formal TSC clinic network across the UK.

The key themes of Big Day 2019 were autism and mental health in people living with TSC, with many sessions featuring these topics in their talks. The TSA was also committed to having a full and open discussion about how our new support services will operate from 2020 onwards, with multiple Q&A sessions and a presentation on how to access TSA support from next year.

Session highlights: Promoting positive behaviour in autism

Kevin Pakenham's (Autism East Midlands) workshop on the need to rethink our approach to autism and positive behaviour was inspirational, educational and relatable for many people at Big Day 2019. Encouraging people to take a step back and rethink how autism can impact a person's ability to receive information, Kevin demonstrated why unexpected behaviour in people living with autism can be reduced by relearning how we all interact with each other.

See you at Big Day 2021!

Big Day 2020 will make way for the TSC Research Conference 2020, with an opportunity for community members to come along to the research conference during a community-dedicated afternoon. However, Big Day is set to return in 2021!

TSA Big Day in pictures



OUR FAB TSA REGISTRATION TEAM ENJOYING
A WELL DESERVED CUP OF TEA!



AMAZING COMMUNITY SPEAKER
MARIE JAMES, SHARING THE TSC JOURNEY OF HER AND HER FAMILY



PROF JULIAN SAMPSON (CARDIFF UNIVERSITY)
- JUST ONE OF THE MANY SPEAKERS DURING BIG DAY 2019



TORIE ROBINSON (EPILEPSY SPARKS) DURING HER INSPIRATIONAL TALK

Survey and focus groups to get your views on upcoming TSA support line

The TSA has extended the period for TSC community members from across the UK to share their concerns and hopes ahead of the upcoming launch of the UK-wide TSA support line. Community members can share their feedback with the TSA through a support line survey, with virtual focus groups and a pilot of the support line to follow prior to the service's launch.

The TSA has heard mixed feedback about the upcoming launch of the support line. Regular users of our previous service feel understandably concerned and saddened about the departure of our regional advisers, whilst also feeling uncertain about how the support line will operate.

Having listened to all feedback, the TSA will now extend the support line pilot period, ensuring that we can listen to and field as many questions, concerns and opinions as possible.

The support line survey is now open and is available via: **tuberous-sclerosis.org/support-line-survey**.

Community members who fill out the survey will be invited to one of a number of virtual focus groups taking place in January 2020 to gather more feedback. Face-to-face focus groups had been planned originally – however, feedback has highlighted the need for us to be inclusive to all who live with TSC across the UK, particularly those in Scotland, Wales and Northern Ireland, leading us to switch to a virtual setting to gather the opinion of community members regardless of location.

The survey and virtual focus groups will help to provide a clearer picture of the thoughts and concerns of the TSC community around the support line, adding to the feedback already received. What we learn from the survey and focus groups will be used to inform the pilot of the support line in early 2020, giving the TSA a further opportunity to address any issues following people's initial experiences of the new service.

The TSA recognises that the changes taking place to our support services are disruptive to families across the TSC community, with the departure of our regional advisers and their long-term support being felt strongly. However, everyone at the TSA is committed to providing the community with a robust and effective support service for many years to come, with the support line being a very important part of this.

Revised timings for the preparation and launch of the support line are:

- **December 2019:** Support line survey open, participants invited to virtual focus groups
- **January 2020:** Virtual focus groups to take place
- **January – February 2020:** Support line pilot to take place
- **March – April 2020:** New support line launched

To take part in the survey, visit tuberous-sclerosis.org/support-line-survey

The survey should take no longer than 10 minutes to complete. If you would prefer to fill in the survey over the phone or via post, please contact Rachael Wyartt (Head of Support and Information) via Rachael.Wyartt@tuberous-sclerosis.org / 0300 222 5737.

TSA 2019 Annual General Meeting

The TSA's Annual General Meeting (AGM) for 2019 took place on 2 November 2019, on the morning of Big Day 2019. This year's AGM focused on why the TSA must now focus on balancing the books, the changes that are being made to help the TSA reduce its outgoings, and the TSA's new research strategy.

The 2019 AGM was very well attended – both in-person and also remotely, with an at-capacity room and over 600 people watching and participating in the AGM via live streaming on the TSA's Facebook page. The importance of community involvement in TSA work was emphasised by Sanjay Sethi (TSA Chair), who noted that whilst Big Day is well attended, it still amounts to only around 1% of the TSC community in the UK.

Formal voting-in of new Trustees and other AGM proceedings took place, including the presentation of the TSA's signed accounts for the previous financial year (2017 – 2018). In presenting the TSA's finances, Sanjay Sethi, Martin Short (Vice-Chair) and Louise Fish (Chief Executive) highlighted that, since 1993, when a generous legacy was left to the TSA, the charity has been able to invest more money into support services and into TSC research than we have raised every year. After 25 years of investment, and in a different financial climate, the TSA can no longer rely on the capital or income from this bequest. Therefore, the TSA team is working hard to reduce expenditure, grow income and reshape the TSA, so that the charity can continue to support the TSC community for many years to come.



SANJAY SETHI (CHAIR), MARTIN SHORT (VICE CHAIR) AND LOUISE FISH (CHIEF EXECUTIVE)

Some of the ways that the TSA is changing the way it works to reduce outgoings and increase income were discussed, including:

- Shifting from a regional support service to a UK-wide support line, including the reduction of staff from a projected 21 full and part-time team-members to the current 13 people
- Proactively working on new ways to raise donations and funds through individuals and organisations
- Driving more research into TSC through joint-funding with other likeminded organisations

Sanjay, Martin and Louise all highlighted the significant departure of the hard-working and hugely valued regional support advisers, with the loss of every adviser being felt keenly by Trustees, staff and the TSC community. Acknowledgements were also put forward to thank the staff that remain at the TSA, who are working tirelessly to maintain and improve services despite the lower headcount.

After discussing TSA finances and future plans, an in-depth question and answer session looked at some of the changes to come in more detail – in particular, the TSA's new UK-wide support line from 2020. Discussions focused on how people will use the new support line service and how the TSA has been preparing for its launch. It was reiterated by the TSA that the disruption and impact of transitioning to a support line was recognised and understood, with the loss of regional advisers understandably taking time to heal.

Closing the meeting, Sanjay, Martin and Louise emphasised the absolute commitment of themselves and the wider TSA team to ensuring that the charity will be operating and offering high-quality services for many years to come.

TSA discuss new 2020 support services during both AGM and Big Day 2019

As well as talking about changes to our support services as part of the 2019 AGM, Big Day 2019 was also a great opportunity to further discuss the new support services in more depth with attendees.

Three separate support line sessions took place at Big Day 2019, which were all focused on the new support line. These sessions looked specifically at how the new service will work and how the community will use the service.

Mental health and epilepsy:

My experience of Big Day 2019

Torie Robinson, founder of epilepsy group Epilepsy Sparks, kindly took the time to speak to community members during Big Day 2019 as our keynote guest speaker. Here, Torie talks about her first visit to Big Day and what she discussed.

It was wonderful to speak at the TSC event in Nottingham, to such a welcoming audience. My main purposes of the day were to empower those affected by epilepsy and mental illness through education, the realisation that they are not alone, and to highlight that there is help out there for them. People affected by epilepsy and/or mental illness need to know that they shouldn't feel any shame or guilt for being unwell. When anyone feels anxious, depressed, high, hears voices, sees things that aren't there (or anything else you can find in the Diagnostic and Statistical Manual of Mental Disorders) it's not through choice. Some of these things can sure feel awful at times, but they don't define a person and they can often be overcome or managed.

At Big Day 2019 I spoke of my own, very personal experiences regarding mental illness and epilepsy – from childhood through to present – with surgeries, medications, hospitals, therapists, and more. I spoke of the perceptions of others (both positive and negative) and what has and continues to help me cope when things aren't great. Prior to surgery I hadn't known that lots of great organisations to help people like us were out there, so I shared some of these with the audience at Big Day 2019, with names including (in addition to the TSA!): Mind, South London & Maudsley Trust, Epilepsy Research UK, Epilepsy Action, EpiCARE, the Samaritans, and more.

The Big Day 2019 audience was wonderful, and it was fantastic to meet such caring, positively uplifting people, including those with TSC, families and carers, TSA staff, and medical and science professionals. The air was buzzing and positively uplifting, conversations mixing education with laughter (which certainly goes against the stereotype of those affected by epilepsy and mental illness!)

For those affected by epilepsy and mental health issues: it's easy for me to type this right now but I want you to know that help is out there for you. Please try and remember this and have a back-up plan of useful telephone numbers ready for if and when you need them. You aren't as alone as you may feel and the more you understand your illness(es), the less alone, more confident and stronger you will feel long-term. You're amazing.

Torie Robinson

Epilepsy Sparks CEO

www.epilesysparks.com/torie-robinson



TORIEROBINSON
SPARKING DIALOGUE AND TRANSFORMATION

Charlotte Strain:

My first Big Day at the TSA

Big Day 2019 was the first time Charlotte Strain (Events and Communications Assistant) experienced the fun and hard work of helping to organise a Big Day event! Here, Charlotte looks back at her first Big Day at the TSA.



When I first joined the TSA in April 2019, I knew that I would be working hard to support people affected by TSC. I had also just moved to London from a small town in Northern Ireland, so it was an exciting challenge.

Over the past few months I have been busy juggling the day-to-day work of TSA communications alongside planning and preparation for Big Day 2019. Some of you may have met me in-person at Big Day 2019, or likely spoke to me over the phone if you rang up the office! Looking back, I'm pleased to say Big Day 2019 went very well!

Even in my first week, after learning about the TSA inside-out and our major projects to improve the lives of people living with TSC, talk and planning quickly moved to Big Day preparation! I was soon at Nottingham for a site visit of the Nottingham Belfry, the location of Big Day 2019, and tracking down potential external speakers for the day itself.

From that first week, it was full steam ahead with Big Day 2019, with just some tasks including contacting speakers and charities, allocating time slots, speaking to clinicians, writing event materials and booking people's tickets. In the run up to the event, excitement began to build, all while ensuring that other important work at the TSA wasn't allowed to slip.

Before we knew it, it was time to head back to the Nottingham Belfry to get ready for the event itself! I was excited and full of anticipation as the train pulled into the platform at Nottingham and reality set in! The night before was filled with setting up tables, putting up signage and making sure we were as organised as possible for the next day.

After an early night, the day itself was upon us – Big Day 2019! As people started to arrive it was great to know that all the hard work and energy we had put in had paid off. It was amazing to see so many of the TSC community chatting and laughing together,



between the sessions we had organised.

A session which really stands out was a meet-and-greet for the TSC Mums and Dads Facebook page - an independent and incredibly important online community. It was lovely for people who had only chatted online to finally connect in-person.

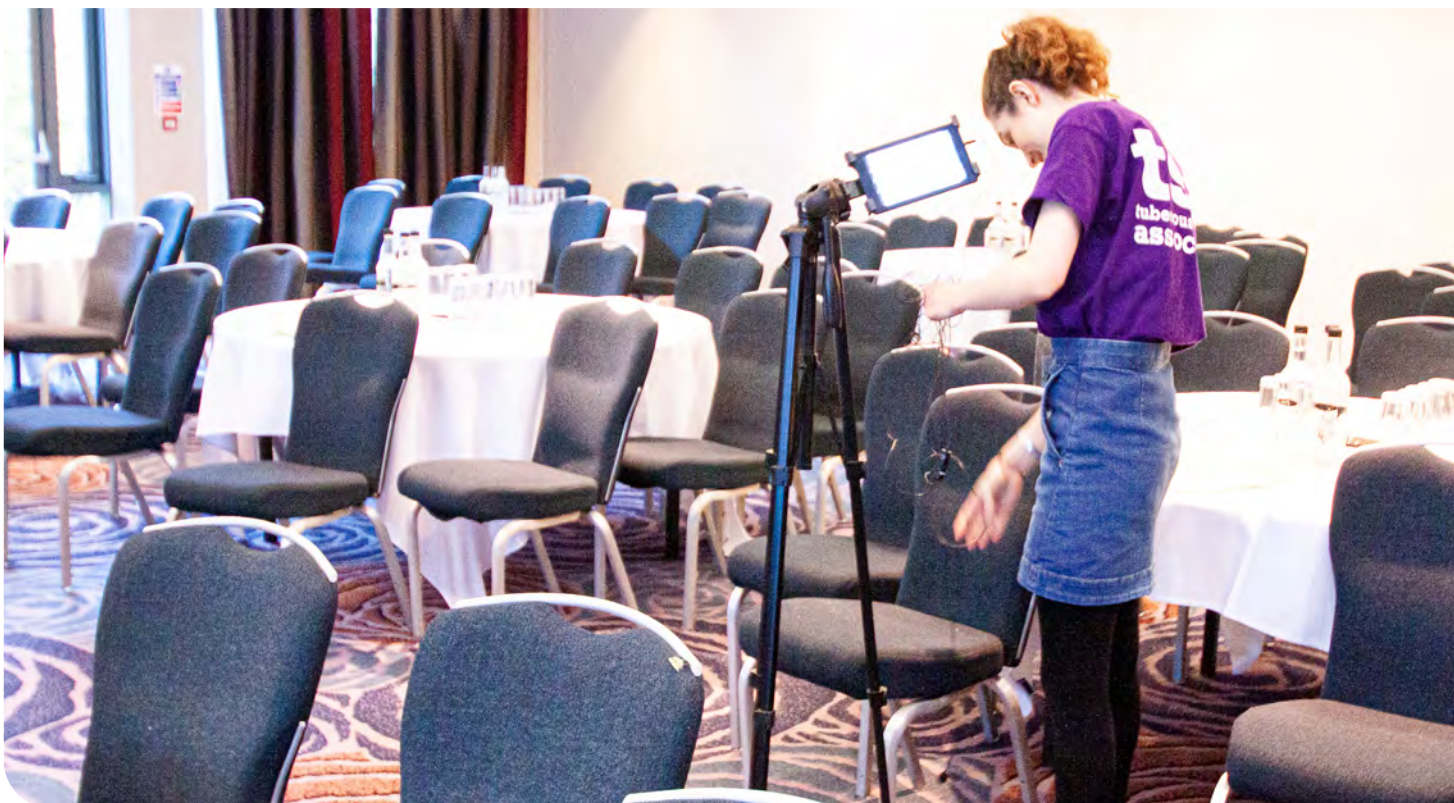
Another highlight of Big Day 2019 was to have so many amazing external speakers, such as Autism East Midlands and Roald Dahl's Marvellous Children's Charity, who spoke about their work and how the TSC community can benefit from accessing their services. There was also, of course,

the wonderful clinicians, who offered their time to come along and speak about a range of topics related to TSC.

Overall, the planning, preparation and execution of Big Day 2019 was a brilliant experience. The entire TSA team worked so hard for it to be a success, with their dedication paying off. However, we also couldn't have done it without the external speakers who came along or, of course, the fantastic TSC community.

Onwards and upwards to future TSA events!

- Charlotte



Get involved in the e-SNORE project

Sleep and its impact on waking hours is an important area of TSC research that might have a significant impact on improving people's day-to-day lives. Dr Stacey Bissell (Research fellow, University of Birmingham) is joint-leading the e-SNORE project, which is looking at this important problem. Stacey took the time to explain e-SNORE and how people can participate:

There is currently limited research on the impact that sleep problems in people living with TSC can have on either daytime behaviours (such as daytime sleepiness) or the potential relationships between sleep quality, seizure severity and physical health problems associated with pain.

Exploring Sleep in Neurodevelopmental disorders through Online and Remote Evaluation (e-SNORE) is a project that hopes to improve our understanding and management of sleep problems through two separate studies.



RESEARCH TEAM AT UNIVERSITY OF BIRMINGHAM



DR BISSELL (CENTRE-LEFT) AT BIG DAY 2019

e-SNORE is open to everyone in the UK caring for a child who is aged 4-15 years and lives with TSC. Parents and caregivers are not required to visit the University of Birmingham and there will be no home visits. Participants can choose to be a part of either or both studies, though more meaningful findings are expected if participants are in both.

Study one is an online behavioural questionnaire study, to be completed by parents and caregivers of children aged 4-15 years living with TSC. This study will explore behaviours such as autism characteristics, repetitive behaviours, impulsivity and overactivity.

Study two is a direct study of sleep characteristics in children aged 4-15 years living with TSC. This will involve children wearing an actiwatch (a small lightweight device that monitors movement) to measure daytime and night-time activity during a ten-day assessment period. Parents and caregivers are first invited to complete an online questionnaire (taking around 30 minutes to complete) which will measure health, sleep and behaviour. A telephone interview, which will take around 90 minutes to complete, will then follow, to discuss aspects relating to level of ability, history of epilepsy, and current sleep behaviours.

A mobile app will be used as part of study two, to record sleep activity and daytime behaviours during the ten-day assessment period. All aspects of this study are remote (equipment is sent in the post and questionnaires are completed online, over the phone, or via a mobile app).

Would you like to participate in the e-SNORE project? More information can be found via <https://tinyurl.com/vcrmczsz> (password: 'cerebra'). Alternatively, you can contact me (Stacey Bissell) on 0121 414 9775 or through S.L.Bissell@bham.ac.uk.



DR CAROLINE RICHARDS



PROF. CHRIS OLIVER



PROF. PETRUS DE VRIES



DR STACEY BISSELL



DR LUCY WILDE



DR CATHY HILL



DR ANDREW BAGSHAW

TSC research update: TSC databases

Dr Rosemary Ekong and her team at University College London are collecting as much consented information as possible about different changes in the genes that are responsible for TSC. This information is being stored in databases to help doctors better diagnose, manage and treat people living with the condition.

The TSC databases contain information about the changes that are found in the TSC1 and TSC2 genes, which are responsible for the development of TSC. The changes in TSC1 and TSC2 are found by testing the DNA of people living with TSC and their family members. By doing this, we can better understand what changes in either gene are actually as a result of TSC, which in turn can help us improve things like DNA testing for TSC.



DR ROSEMARY EKONG (UNIVERSITY COLLEGE LONDON)

The TSC databases now contains information on over 4,000 different changes to the TSC1 and TSC2 genes.

So far, Dr Ekong and her team have managed to arrange almost 80% of these thousands of changes into three different groups: if a change does cause TSC, if a change doesn't cause TSC, and if the impact of the change on TSC is as yet unknown.

The team at University College London find out whether a change can cause TSC through a range of methods, including family information, results from laboratory tests, changes in different groups of people, and special computer-based analysis.

Improved technology has also allowed the team at University College London to use advanced testing procedures, meaning that even more TSC changes are being found, including some that have never been seen before!

Dr Ekong and her team hope to find out whether the gene changes in the 'Unknown' group cause TSC or not. This would help to further our understanding of the causes of TSC and help doctors diagnose TSC more easily.

The ongoing hard work into the TSC1 and TSC2 databases will not only offer other researchers a valuable resource for their own work, but it could also offer an important tool in genetic testing and diagnosis of TSC.

Fundraising updates

Hi everyone,

We have certainly had a busy 2019 in fundraising, as you can see from the following pages and also previous Scan issues from this year. There is no limit to the inventive and incredible fundraising activities that the TSC community can come up with!

I'm pleased to confirm that we have launched new ways to give to the TSA, including direct debit and fundraising via Facebook and eBay. Many of you have already very generously used these new giving options, asking for birthday donations in lieu of gifts, or giving a percentage of profits from your eBay sales – thank you so much, this helps us to raise not only funds for people living with TSC, but also awareness of the condition!

In the lead up to Christmas, it is also worth noting we are part of several schemes that allow you to raise funds for the TSA while doing your shopping online, at no cost to you! Popular giving schemes include Amazon Smile, Easy Fundraising and Give As You Live! For more details please visit our website tuberous-sclerosis.org/donate.



Looking ahead to 2020, we want to encourage you to **'Set your own fundraising challenge for the TSA in 2020'**! This is a personal pledge to aim for a specific fundraising amount that you would like to raise for the TSA over the year.

Your personal fundraising challenge amount can be as high or low as you want and could be broken down into smaller challenges or events across the year to make it easier to hit. This could include a Tea & SCones get together, Dry January, or you could even take after Alfie, our fundraising champion for this issue, by selling excess produce or crafts!

If everyone who received this issue of Scan committed to a fundraising challenge of £150 over the next 12 months, we would be able to fund half of the TSA's running costs!

Are you ready and prepared to set your own fundraising challenge? If so, let us know your target by emailing fundraising@tuberous-sclerosis.org and we will add you to our fabulous 2020 challengers team, to make sure you are supported with ideas and inspiration on how to not only reach but smash your target (we can also provide you with a totaliser, so you can monitor your progress!)

Thank you to all fundraisers and donors for your continued support to the TSA. Without your generosity, the TSA would simply not be here for individuals and families affected by TSC.

We hope to fill the next year with even more fun ways that each and every one of you can take part in fundraising, all whilst spreading the word of the TSA's work!

Thank you, and Merry Christmas!

Mikaela, Tanya and Kathryn



MIKAELA, TANYA AND KATHRYN, TSA FUNDRAISING

Company and business support for people living with TSC

Help to raise the profile of TSC and boost funds for the TSA by speaking to local companies and businesses about how they can support people living with TSC!

Every year, the TSA benefits from generous corporations and thoughtful groups who take the incredibly kind step of supporting us. There are many ways that you and your organisation can get involved, with business involvement having the potential to make a huge difference to individuals, families and loved ones in the UK who live with the impact of a TSC diagnosis.

Here are just some of the ways a company could support the TSA!

Corporate donations

You could ask your business if they give charitable donations, or offer matched funding for employees who are fundraising.

Matched funding

1 + 1 = 2



Sponsorship

Could a local group sponsor a TSA event happening near them, such as the 2020 conference, Outlook, our events for every UK nation or our Family Fun Days?

Charity of the year

Does your business or employer have a 'Charity of the Year' scheme? If so, you could nominate the TSA (don't worry, we can help with the application form!)



Payroll giving

Payroll giving is a simple, effective and tax-efficient way to make regular donations directly from your salary, without paying tax on it. If your company offers payroll giving, ask for the TSA to be added to the advertised list of charities!

Collection tins

We can provide plastic or card collection tins to be placed on reception desks or counters – on average, every TSA collection tin raises an average of £60 a year!



Events

Looking for team-building opportunities? Taking part in a local event while fundraising for the TSA is a great way to bring colleagues together – don't take our word for it, check the John Lewis Logic Park team featured in this issue!

Get in touch with the TSA team to find out more about corporate giving:
fundraising@tuberous-sclerosis.org / 0300 222 573

Fundraising Champion

Ten year-old Alfie Budd from Buckinghamshire is this issue's Fundraising Champion. Alfie made his family very proud when he decided to sell homemade produce on his own stall and donate proceedings to the TSA!

So, Alfie, what fundraising have you been up to and what has the response been?

I decided to set up a stall to sell some local produce from my Grandad's allotment that was going to be spare, to raise some funds for the TSA in support of my Aunt Gemma, and raised £27.20.

I had a great response from locals – they were very generous when they knew it was for a good cause!

What motivates you to do all of this?

I thought it would be a good way to help my Aunt Gemma, who has TSC, as any money raised would mean more support to help Aunt Gemma and people like her.

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

Think about how you're going to raise money, work out a plan and just do it! You can speak to the TSA fundraising team, for help promoting what you are doing.

It is good to take pictures of what you do, so you can send these to the TSA, who can share your story - hopefully, others will then do their own fundraising.

I felt proud to receive a certificate from the TSA to thank me for my fundraising. I'm excited to be a fundraising champion!



The TSA cannot thank Alfie and his family enough for all of their support!

Catch a snowflake!

Support the TSA this Christmas with a festive donation of £25 or more and receive a limited edition 2019 TSA Snowflake. Display the TSA with pride on your Christmas tree!

Offer available while stocks last



tsa
tuberous sclerosis
association

www.tuberous-sclerosis.org/Christmas | fundraising@tuberous-sclerosis.org | Tel: 0300 222 5737
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Charity number 1039549 (England & Wales) SC042780 (Scotland)

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REGULATOR

Fundraising thank yous

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

COMMUNITY

Fiona Regan

A big Happy Birthday to Fiona, who held her 60th birthday celebrations at Ushaw College, Durham, with her friends from the Bethany Christian centre in Houghton-le-Spring. Enjoying a guided tour and afternoon tea, Fiona very kindly chose to raise funds for people affected by TSC, generating £450!



FIONA AND HER FAMILY AT HER BIRTHDAY!

Joanne

Murray cut an incredible 12 inches off her hair in honour of her cousin Tommy, raising a fantastic £380 and gaining a stunning new hairstyle!



JOANNE BEFORE THE CHOP!

JOHN LEWIS, LOGIC PARK (LEEDS)

We are very grateful to the John Lewis team at Logic Park, who have been fundraising year-round for the TSA! TSC is a cause close to Logic Park team-leader Jamie's heart, as his daughter lives with the condition.

In June, a 20-strong John Lewis partners team took on the 12km Total Warrior obstacle course, raising an epic £1,855.50. The event brought the whole team together, with John Lewis members running, cheering or supplying much needed snacks and drinks! Yet, the fundraising from John Lewis Logic Park has continued even beyond this, with TSC collection tins across the Logic Park site and Jamie and his partner taking on the London Marathon!

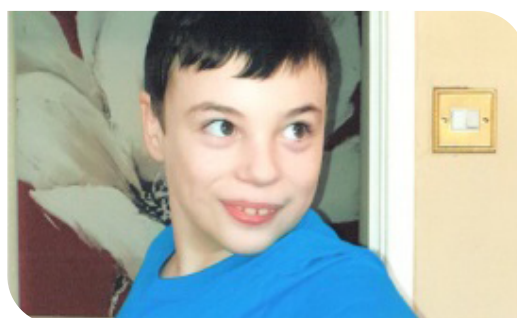
So far, the Logic Park team have raised £3,890.50! Amazing effort!

Jaybees Nursery hosted a coffee morning and football training session with Queen of the South Football Club, leading to £1,000 to help support people affected by TSC!



STUDENTS, STAFF AND THE QUEEN OF THE SOUTH FOOTBALLERS

Huge thanks to the **child benefit office** in Washington for raising a wonderful £243.36 in honour of Joshua Finley!



JOSHUA FINLEY

A massive thank you and congratulations to **Scott Simpson, Dan Collett** and **Mikee Clea**, who climbed an incredible 5,895 meters up Kilimanjaro in support of Scott's seven-year-old nephew, Charlie. They headed to the heights and raised over £5,000!



THE TEAM AT THE SUMMIT OF KILIMANJARO

A massive thank you to **Millie Whitaker**, who braved the rain to host a fab fundraising stall of homemade items, raising £80! Brill work Millie!



MILLIE AT HER STALL

A huge well done to the amazing **Charlie Gould** and his family for completing the Three Peaks Challenge, raising a brilliant £2,796! In the words of Charlie: "TSC will not stop me from doing anything!"



CHARLIE AT THE 'PEAK' OF THE CHALLENGE!



RYAN FINISHER PEAK DISTRICT CHALLENGE

Ryan Martin walked an amazing 50k in the Peak District challenge, raising £350 for little brother Juan – brilliant effort Ryan!

We are hugely grateful to **Claire Cracknell**, her team and the customers of **Life Chiropractic Clinics** in Basildon, Essex, who donated £150 from a TSA donation tin!



LINDA WITH ONE OF HER TINS!

Thanks go to **Linda Smith** for your continued support of having a donation tin placed at The White Horse (Downham Market) in support of son Ben!

If you could host a collection tin, please let the TSA team know!



CLAIRE OLIVER WITH PAUL, CERY'S AND GEORGE BARNES

Cerys Barnes supported her brother George by running the Brighton Music 5k for the second time, raising £125!

You can take on your local run for the TSA – just let us know what you are up to!



TEAM PHOTO OF BETHAN AND HER FRIENDS!

Bethan Whitelegg and friends completed the 25-mile Orwell walk in **Ipswich**, raising a brilliant £235!



MAVIS'S BEAUTIFUL GARDEN

Thank you to **Mavis Rhodehouse** who opened up her stunning garden to visitors, leading to donations of a whopping £275!



THE SPINATHON

Seafield Ocean Club in Northumberland held an exercise bike spinathon in support of Jack Gray, leading to a fantastic £500 to support people affected by TSC!

THANK YOU TO THE BRILLIANT SUPPORTERS WHO TOOK PART IN TEA & SCONES FOR TSC IN 2019, INCLUDING:

David Peacock, Alison Lingard, Coleg Gwent Independent Living skills department, Bobbie Tyler, Vicky Dyson, Angela Ironside, Ensors Chartered Accountants and Rebecca Rasho.

A scrumptious £4,918.78 was raised from Tea & Scones for TSC in 2019! To find out how to host your own Tea & Scones for TSC event please visit tuberous-sclerosis.org/get-involved/tea-scones-tsc/

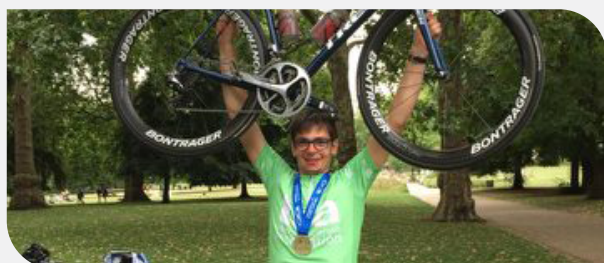


COLEG GWENT INDEPENDENT LIVING SKILLS DEPARTMENT

RIDE100 2019

Thank you to all of our fab #TeamTSA cyclists who took part in the Ride100 2019, who raising a jaw-dropping £9,483.04! (Gift Aid included)

- Tariq Farooqi
- Neil Edmonds
- David Cooke
- Nick Bunyard
- Grant Barnes
- Paul Barnes
- Elliot Parfitt
- Neil Henderson



ELLIOTT AT THE FINISH LINE!

GREAT NORTH RUN 2019

Thank you to all of our fab #TeamTSA runners at the Great North Run 2019, who between them gathered an unbelievable £10,132.87 to support people affected by TSC!

- Katie Plowman
- James Black
- Ken Welby
- Graeme Smith
- Daniel Marks
- Joe Nelson
- And our very own Mikaela Conlin-Hulme



MIKAELA AND KEN FLYING THE FLAG!

Secure your place for the Ride100 2020 or Great North Run 2020

Please get in contact via fundraising@tuberous-sclerosis.org or visit our website – places for both events are expected to go quickly!

TAKING TO THE SKY!



CLARISSA AND JAMIE ONCE THEY BOTH RETURNED IN ONE PIECE!

Clarissa Constable and **Jamie Richardson** took on a skydive to support the TSC community, raising over £2,000!



HEATHER IN THE AIR

Heather Skinner completed her parachute jump in October in support of her family, raising £455.16!

RUNNING TOWARDS VITAL SUPPORT, RESEARCH AND ADVOCACY

Kayley Stabler raised £768.57 taking on the Bournemouth Marathon Festival 10km, following the support she received after her TSC diagnosis. Well done Kayley!

Michael Donnelly ran the Windsor Half Marathon in support of 9-year-old son Alex, raising £960 so far!

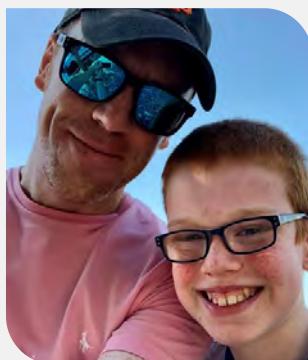
Zoe Mackenzie completed the Great Scottish Half Marathon, raising £201.01!

Jacob Horton took on the Chelmsford Half Marathon, generating £305 in donations!

Gary Johnston, a self-proclaimed 'non-runner', took on the Rough Runner 10km, gathering an amazing £1,111.25 for the TSC community! His words at the end were: "I may never run again!"

Victoria Collins and her sister Allyson ran the Cardiff Half Marathon, in support of daughter Jessica, raising a fantastic £690!

John Conlin-Hulme was inspired by his wife and took on the Leeds Abbey Dash 10k, raising £185!



MICHAEL AND SON ALEX



VICTORIA, HER SISTER ALLYSON AND JESSICA

NOT CONTENT WITH JUST ONE RUN...

Colin Miller took on two half marathons – Plymouth and Severn Bridge, in support of his friend's grandson who has TSC, raising a wonderful £461!

Scott Woodcock participated in three different 'Nuclear runs' from May to November and raised a whopping £740! What an effort!

GOING EVEN FURTHER

Graham Sale took part in Equinox 24 – an exhausting 24-hour race focused on how many 10k laps you can complete against the clock, generating a fantastic £207.50! All those laps were worth it Graham!



GRAHAM AT THE START LINE

Steve Wood raised £535 in support of daughter Millie by doing an Ironman! Could you do this incredible challenge? Get in touch to find out about Ironman challenges and similar events

FUNDRAISING THROUGH A PASSION

Martyn Baxter raised £791 plus £500 matched funding from his workplace for his cycle across Britain. Martin completed a jaw-dropping 980 miles, from Lands' End to John O'Groats, in support of his nephew Patrick with TSC!

Over the summer you may have seen **Will Cropper**, aged 11, and dad David, who completed the 170-mile Way of the Roses, cycling from coast to coast! This amazing effort raised £1,125 in support of Will's friend Sam. Will was also nominated for Young Fundraiser of the Year at the York Community Pride Awards, in recognition of his super effort!

Mike Andrew and **Terry Gibson** hosted a Golf day, held at Yelverton Golf Club. A brilliant £2,337 was generated, with Mike fundraising in support of granddaughter Lexi Dugdale. Fantastic work all!



MARTYN AT THE START OF HIS JOURNEY!



WILL AND DAVID AT THE FINISH POINT!

In memory

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

Everyone at the TSA would like to give a heartfelt thank you to the family and friends of the late Vanessa Platts, with £2,469 donated to the TSA in Vanessa's memory. Our thoughts are with everyone close to Vanessa at this difficult time. Vanessa's dedication to the TSA over many years is hugely appreciated by everyone at the charity and in the TSC community.

Trusts and foundations

Thank you to the following for their generous donations:

29th May 1961 Charitable Trust

AJ & K M Barnett Charitable Trust

Esher House Charitable Trust

Hospital Saturday Fund

Hugh Fraser Foundation

The Edward & Diana Hornby Charitable Trust

The Williams Serendipity Trust

New TSA merchandise

With the launch of our new website comes a new fantastic range of TSA merchandise!

From hoodies and t-shirts to homeware and Christmas goodies, there's lots of new ways to fly the TSA flag - whether at home, out-and-about, at the gym or even sthe office!

Visit the new TSA shop at Tuberous-Sclerosis.org/Shop

