TSA BIGDAY 2019

EVENT GUIDE

Saturday 2 November 2019, Nottingham Belfry Hotel

tsa
tuberous sclerosis
association

We are excited to welcome you to the **Tuberous Sclerosis Association (TSA) Big Day 2019**. This year is set to be our biggest yet, with a fantastic lineup of researchers, external speakers and updates from the TSA!

Today you can expect:

- Networking sessions to allow you to connect with old friends and new faces
- An excellent range of external speakers covering TSC-related topics
- Updates from NHS TSC clinics, including access to everolimus for epilepsy
- More information about the TSA's new support line, which will launch in January 2020

Welcome from the TSA Board

Welcome to Big Day 2019!

SANJAY SETHI,
CHAIR

MARTIN SHORT,
VICE CHAIR

You join us at a time of change for the TSA. Our mission is to provide help for today and a cure for tomorrow. Since 1993, when a generous legacy was left to the TSA, we have been able to invest more money into our support services and into TSC research than we have raised every year. After 25 years of investment, and in a different financial climate, we can no longer rely on the capital or income from this bequest. We have to reduce our expenditure, grow our income and reshape the TSA, so that we can continue to support the TSC community for many years to come.

In light of this, 2019 has already brought significant changes to the way we work:

- **Reaching more people.** We are moving from a large team of regional advisers to a smaller team of trained advisers who can be contacted regardless of wherever you live in the UK, through a free and confidential support line. This is not an easy change, but it means that our vital services continue to be accessible to everyone and sustainable for the future.
- **Driving more research.** We no longer have large reserves to spend on new research by ourselves. Instead, we are reaching out to external partners who share our goals and can co-fund TSC research projects with us. We intend that over time this approach will increase the pot of money that is invested into TSC research.
- **Raising more money.** As an independent charity, we receive no government funding and can only support and campaign on behalf of the TSC community through the generosity of our donors. We are working on new ways to raise funds, and will continue to regularly be in touch to ask individuals and organisations for donations to fund our life-changing work.

We know that these changes will be felt most by those who have been involved with the TSA for many years - this includes members of the board, with ten out of 12 Trustees directly affected by TSC. Today's AGM (09:15-09:45, Nelson/Hardy Suite) and the first session at Big Day 2019 is an opportunity to engage with the Board and share your thoughts with us.

The Board's passion and commitment to support the TSC community remains as strong as ever. We are looking forward to spending time together with the TSC community and renewing our bonds this weekend.

Welcome from the TSA team

Welcome to Big Day 2019, the TSA's biggest event of the year!

LOUISE FISH,
TSA CHIEF EXECUTIVE

I am looking forward to catching up with old friends and meeting new faces at this exciting and informative day aimed at everyone in our TSC community.

If it is your first time attending Big Day, then I would like to extend an especially warm welcome to you. Whether you and your family have recently received a diagnosis of TSC, or you want to find out more about the condition and how to live well with it, you will find a community of friends here who understand the impact that TSC can have on day-to-day life.

We are delighted to have so many TSC experts and external speakers taking part this year, bringing their fantastic expertise in different topics, from disability benefits to living with epilepsy.

The TSA is launching a free and confidential support line in January 2020. We have sessions at Big Day 2019 so that you can ask questions about the new service and give us your feedback, to help us make sure the support line serves the TSC community as effectively as possible.

We are aware that those living with TSC are increasingly making online links with others who share their experiences. As a result, we are delighted to be hosting a 'meet and greet' at Big Day 2019 in the Nelson/Hardy Suite over lunch for members of the TSC Mums and Dads Facebook page. This will give parents the chance to meet up with fellow parents whose families are affected by TSC, and put real-world faces to digital names!

Finally, our popular creche is back for 2019! We are looking forward to meeting all of the amazing children who are coming to this year's creche.

The TSA's 2019 Annual General Meeting

Everyone who has registered to receive information from the TSA should have received written formal notification that the TSA's 2019 Annual General Meeting (AGM) will be held at Nottingham Belfry, Mellor's Way, Off Woodhouse Way, Nottingham, NG8 6PY on Saturday 2 November 2019, 09:15-09:45.

With your AGM mailing, you should also have received:

- Our Treasurer's Report, Strategic Report and Summarised Statement of Financial Activities and Balance Sheet for 2018.
- Our Impact Report, outlining our achievements in 2018.

Please read through these documents ahead of the AGM.

This is your opportunity to raise any questions you have with the TSA Board. Your input will help us to focus our limited resources on the areas that will make the biggest difference for the TSC community.

If you have not received your copy of the 2019 AGM mailing, please speak to the TSA team on the registration desk and we will make sure that you get a copy of this year's mailing and that you are registered for future mailings.

Get to know Nottingham

We are delighted to be hosting the Big Day 2019 in Nottingham.

The TSA has a strong connection to Nottingham, with Anne and Tom Carter - who have supported the TSA as Trustees, members of staff and fundraisers - living in Nottingham. A lot of major events have taken place in the city over the past 40 years to shape the TSA into the organisation we know it as today.

Tom and Anne helped to launch the first ever TSC research appeal in conjunction with BBC Radio Nottingham, BBC TV, Nottingham Forest Football Team and various celebrities in an 'Appeal Day' on 6 December 1980. 10,000 dedicated people took to Market Square in Nottingham to bring their appeal envelopes and hand them over to sportspeople and celebrities, including football legend Brian Clough, actor Richard Todd and Everest climber Doug Scott. An incredible £50,000 was raised in a day, providing the perfect platform for future research into TSC and enabling the first TSC research grants to be made in 1982.

Today, Nottingham still plays a key part in TSC research, with the UK's only specialist lymphangioleiomyomatosis (LAM) clinic, being based here. We are delighted to have Simon Johnson, Professor of Respiratory Medicine at the University of Nottingham and Nottingham LAM clinic, at Big Day 2019. Professor Johnson will give us an overview of the fantastic work happening at the LAM clinic for people who live with TSC and LAM.

As well as achieving incredible things for people affected by TSC, Nottingham has a rich cultural and charitable history. William Booth, founder of the Salvation Army, was born in Nottingham in 1829, and the famous folklore of Robin Hood originated here.

If you are making a holiday of your visit to Big Day 2019, Nottingham has a wide range of interesting and free places to visit. For anyone who likes the great outdoors, Wollaton Hall and Deer Park is unmissable. If you prefer arts and culture, Nottingham Contemporary Art Gallery has a whole host of exhibitions for you to enjoy.

We hope you enjoy your time at Big Day 2019 and get a chance to explore what Nottingham has to offer!

Useful information

How to get there

The Nottingham Belfry hotel is very well situated, just one mile from the M1 and five miles from Nottingham City Centre and Nottingham train station. If you are driving, the hotel has 250 complimentary parking spaces.

Nearby accommodation

Hotels located nearby include DoubleTree by Hilton Hotel Nottingham - Gateway, Crowne Plaza Hotel Nottingham and Ibis Nottingham centre.

General event information

There will be photography and filming taking place throughout the event. If you would prefer to not have your photo taken or to be filmed, just let one of our team know and you will receive a different coloured lanyard.

Lunch will take place over two timeslots:

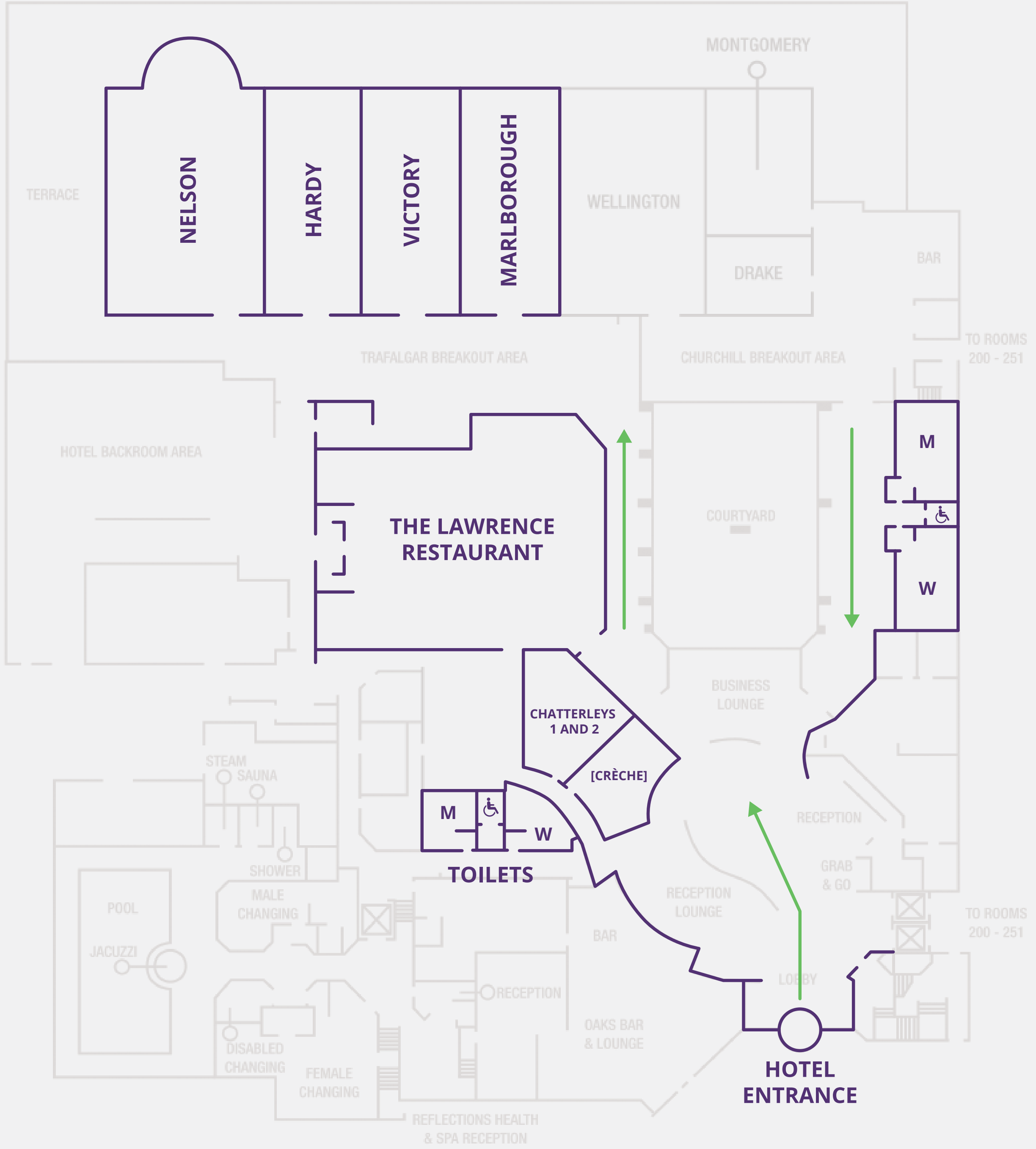
- Group 1 12:00 – 12:45
- Group 2 12:45 – 13:30

When you register at the event, you will find out which lunch group you are in.

There are accessible toilets located on the ground floor and first floor of the hotel.

The TSA are not responsible for any loss or damage to items that are brought on to the hotel premises.

Floor plan



Big Day 2019 agenda

2 NOVEMBER 2019
NOTTINGHAM BELFRY HOTEL

Nelson / Hardy Suite

Time	Title	Speaker
08:45 – 10:00	Registration	
09:15 – 09:45	TSA Annual General Meeting	**Martin Short** and **Sanjay Sethi** (Tuberous Sclerosis Association)
09:45 – 10:00	**Break**	
10:00 – 10:05	Welcome to Big Day 2019	**Louise Fish** (Tuberous Sclerosis Association)
10:05 – 10:30	Meeting our new five-year strategy - moving forward at the TSA ■ How the TSA is changing ■ Introducing the new support services for 2020 ■ What else is coming up in 2020	**Martin Short** and **Sanjay Sethi** (Tuberous Sclerosis Association)
10:30 – 11:00	Community speakers - living with TSC	■ **Marie James** (Community speaker) ■ **Nicola Morley** (Community speaker)
11:00 – 11:30	**Break**	
11:30 – 12:00	Mental Health with epilepsies	**Torie Robinson** (Founder, Epilepsy Sparks)
12:00 – 13:30	**Lunch** (Group 1 12:00 – 12:45) (Group 2 12:45 – 13:30) *In the Nelson/Hardy suite - meet and greet with the TSC Mums and Dads Facebook page*	
13:30 – 14:00	How recent research informs new UK guidelines for TSC	■ **Prof Julian Sampson** (Head of the Institute of Medical Genetics, Cardiff University) ■ **Dr Chris Kingswood** (Consultant Nephrologist, St George's University Hospital)
14:00 – 14:15	**Break**	
14:15 – 14:45	Promoting psychological wellbeing in TSC	■ **Dr Ingram Wright** (Head of Neuropsychology, University Hospitals Bristol NHS Trust) ■ **Prof Patrick Bolton** (Professor of Child and Adolescent Neuropsychiatry, King's College London)
14:45 – 15:15	**Break**	
15:15 – 15:45	The UK TSC clinic network - how to be referred and what to expect	■ **Dr Chris Kingswood** (Consultant Nephrologist, St George's University Hospital) ■ **Dr Frances Elmslie** (Consultant Clinical Geneticist, St George's University Hospital)
15:45 – 16:15	**Break**	
16:15 – 16:45	Everolimus for epilepsy - an update	■ **Prof Finbar O'Callaghan** (Professor of Paediatric Neuroscience, University College London) ■ **Dr Sam Amin** (Paediatric Neurologist, University Hospitals Bristol)
16:45 – 16:50	**Break**	
16:50 – 17:00	Closing remarks, International TSC Research Conference 2020 Community Day preview and thank you	**Louise Fish** (Tuberous Sclerosis Association)

Victory Room

Time	Title	Speaker
12:00 – 13:30	**Lunch** (Group 1 12:00 – 12:45) (Group 2 12:45 – 13:30) *In the Nelson/Hardy suite: Meet and greet with the TSC Mums and Dads Facebook page*	
13:30 – 14:00	New TSA support line - all about your new support services from 2020	Tuberous Sclerosis Association
14:00 – 14:15	**Break**	
14:15 – 14:45	LAM: symptoms, screening, assessment and treatment	**Prof Simon Johnson** (Professor of Respiratory Medicine, University of Nottingham)
14:45 – 15:15	**Break**	
15:15 – 15:45	New TSA support line – Q&A session 1: How your new support service will work	Tuberous Sclerosis Association
15:45 – 16:15	**Break**	
16:15 – 16:45	New TSA support line – Q&A session 2: How your new support service will work	Tuberous Sclerosis Association
16:45 – 16:50	**Break**	

Marlborough Room

Time	Title	Speaker
11:00 – 12:00	The needs of adult siblings	**Frances Danylec** (Sibs)
12:00 – 13:30	**Lunch** (Group 1 12:00 – 12:45) (Group 2 12:45 – 13:30) *In the Nelson/Hardy suite: Meet and greet with the TSC Mums and Dads Facebook page*	
13:30 – 14:00	TSC genetics and family planning	■ **Dr Jacqueline Eason** (Consultant in Clinical Genetics, Nottingham University Hospitals) ■ **Janine Bowes** (Genetic Counsellor, Nottingham University Hospitals)
14:00 – 14:15	**Break**	
14:15 – 14:45	Supporting marvellous children – Epilepsy advice and support for children	**Kirsten Johnson** (Roald Dahl's Marvellous Children's Charity)
14:45 – 15:15	**Break**	
15:15 – 15:45	Access to disability benefits and housing for adults	**Michael Paul** (Disability Rights UK)
15:45 – 16:15	**Break**	
16:15 – 16:45	Promoting positive behaviour in autism	**Kevin Pakenham** (Autism East Midlands)
16:45 – 16:50	**Break**	

Hear from some of our external speakers

This year we have a wide variety of external charities, speakers and workshop providers coming along to share their expertise! We are delighted to introduce some of them below:

TORIE ROBINSON: FOUNDER OF EPILEPSY SPARKS

I'd had a lengthy febrile seizure as a baby; this being the likely cause of my temporal sclerosis (brain damage) and epilepsy. Upon diagnosis aged 10 I was put on Anti-Epileptic Drugs (AEDs) and overnight went from being a bright, loud student to a quiet soul, at almost the bottom of the class.

I'd gone from my aspirations to become a pilot or a surgeon, to nothing. I was taught that I should be ashamed of my epilepsy because it was bad. I was made to feel like a mistake and that I was consuming resources that I wasn't worth. I felt like an expense to society. I never had anyone to talk to - not even family. People couldn't see my illnesses. Doctors didn't understand how depressed and alone I was. I looked fine, right?

My seizures, depression and emotional disorder worsened over time. I went from absences and focal seizures through to tonic-clonics. I even moved back from Australia to the UK to get help. I was having so many accidents. My life expectancy was low. Upon return I was very lucky to be suitable for brain surgery. I was excited because the potential advantages sure outweighed any marginal risks. They couldn't remove all my scar tissue, and although I still occasionally have seizures and am still on AEDs, I consider my surgery to have been a huge success.

After surgery I ended up being admitted to a psychiatric hospital because I was so clinically depressed. I nearly died. I was told by someone close to me that I'd cost them too much money in petrol and parking to visit me, so they asked me not to attempt suicide again.

Afterwards, I had extensive therapy (still in process) and made some big changes regarding the people that I had in my life. I started working with epilepsy and mental health charities, became an international public speaker and formed Epilepsy Sparks. I now have a purpose. It's often this that saves me. I've met so many inspirational people from around the world affected by epilepsies and mental health difficulties – either directly or indirectly (e.g. carers).

MICHAEL PAUL: HEAD OF ADVICE SERVICES AT DISABILITY RIGHTS UK

I've been Head of Advice Services at Disability Rights UK (DR UK), since the creation of the organisation on 1st January 2012. DR UK was formed via the unification of three charities – Disability Alliance (where I worked); RADAR; and National Centre for Independent Living. Coming together enabled all of the legacy charities to build on work we already did together and reach each others' audiences more effectively, as well as keeping costs down by moving into one single office space.

Our advice services, the area I look after, currently cover a multitude of subjects – we have helplines for personal budgets and direct payments; education for disabled students, and an expert level welfare benefits helpline aimed at advisers – the theory being that given limited resources, we reach more people by supporting advisers than if we directly addressed individual enquiries. Our website, containing over seventy factsheets, receives more than four million page views per annum from more than one million different web visitors. We also write, edit and publish the Disability Rights Handbook (DRH). Known as the 'benefits bible', the DRH is now in its 44th edition and sells more than 12,500 copies per annum.

I'm very much looking forward to The Big Day, and my talk will cover 'disability benefits and housing'. The ongoing climate of austerity means a lot of people aren't receiving benefits, or other linked non-financial support, to which they are entitled. There is a huge amount of benefit going unclaimed each year. My aim will be to make the benefits system more easily understood so people can make better informed decisions on whether they are entitled to them, as opposed to being frightened off by the rhetoric and bureaucracy around the system.

I look forward to seeing you soon. In the meantime if you would like to find out more about Disability Rights UK's work, please visit our website at **www.disabilityrightsuk.org**.

KEVIN PAKENHAM: AUTISM EAST MIDLANDS

Autism East Midlands has recently celebrated over five decades of providing services for autistic people, families and carers.

As the largest specific charity in the region, Autism East Midlands have been supporting autistic people since 1968.

Autism is a lifelong neurological condition which affects the way that a person communicates and how they experience the world around them.

Core features of autism are differences in communication, differences in processing and differences in social understanding.

Our promoting positive behaviour workshop will explore:

- Why autistic individuals display distressed behaviour
- Strategies to reduce distressed behaviour
- Communication differences
- Sensory processing differences
- Differences in understanding other people's intentions, theory of mind
- Differences in planning, executive functioning
- Differences in seeing the whole picture, central coherence
- How to build relationships, and overcome these differences, including strategies for change

FRANCES DANYLEC: SIBS CHARITY

Sibs is the only UK charity for children and adults who are growing up with or have grown up with a disabled brother or sister. We provide information, support and training on sibling issues for adult siblings, young siblings, parents and professionals.

At the Big Day, they will be focusing on how they can provide support for adult siblings of someone affected by TSC. Adult siblings, in particular those with a brother or sister with a lifelong learning disability and/or autism, provide support, advocacy and care for their brothers and sisters, at the same time as juggling support and care for their elderly parents, their own children, and their work. They rarely receive any acknowledgement of their role or expertise, information about service provision, or support for their own needs. As a result many adult siblings experience isolation, reduced wellbeing and negative effects on their work and finances. Many adult siblings just want to enjoy social time with their brother or sister, rather than time together being focused on care tasks.

Support for adult siblings:

- We provide phone and email support for adult siblings
- We run a network of peer support groups for adult siblings of people with a lifelong learning disability and/or autism
- We produce guides for adult siblings of people with a lifelong learning disability and/or autism on issues such as future planning and managing care
- We run workshops and events for adult siblings

Big Day 2019 speakers

Professor Julian Sampson
'How recent research informs new UK guidelines for TSC'

Dr Chris Kingswood
'How recent research informs new UK guidelines for TSC'

Dr Ingram Wright
'Promoting psychological wellbeing in TSC'

Prof Patrick Bolton
'Promoting psychological wellbeing in TSC'

Dr Frances Elmslie
'The UK TSC clinic network - how to be referred and what to expect'

Professor Finbar O'Callaghan
'Everolimus for epilepsy - an update'

Dr Sam Amin
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Dr Jacqueline Eason
'TSC genetics and family planning'

Janine Bowes
'TSC genetics and family planning'

Dr Simon Johnson
'LAM: symptoms, screening, assessment and treatment'

Frances Danylec
'The needs of adult siblings'

Michael Paul
'Access to disability benefits and housing for adults'

Kevin Pakeman
'Promoting positive behaviour in autism'

Torie Robinson
'Mental health with epilepsies'

Kirsten Johnson
'Supporting Marvellous Children – Epilepsy advice and support for children'

Moving forward at the TSA

2019 has been a year of changes here at the TSA.

NEW TRUSTEES AND MEMBERS OF STAFF

We are delighted to have new members of the TSA team on board. Each of them adds their experience and enthusiasm to help the TSA achieve our five-year Strategy to REACH more people and drive more REseArCH.

The new Trustees will be presented to the AGM (see page 3) for formal adoption. They are:

- Annemarie Cotton
- Dr Frances Elmslie
- Jane Rogers
- Sanjay Sethi

The new members of staff are:

DR POOJA TAKHAR,
HEAD OF RESEARCH

RACHAEL WYARTT,
HEAD OF INFORMATION AND SUPPORT SERVICES

CHARLOTTE STRAIN,
EVENTS AND COMMUNICATIONS ASSISTANT

NEW TSA SUPPORT LINE – LAUNCHING JANUARY 2020

The TSA is launching a free and confidential support line in January 2020. We have a session at the Big Day so that you can ask questions about the new service and give us your feedback, to help us make sure the support line serves the TSC community as effectively as possible.

Anyone wishing to access the TSA's support services will be able to do so through a free and confidential central support service, including a support line that will be open 9am – 5pm Monday to Friday each week. You will be able to talk to our trained advisers by calling, emailing, writing in, or sending a web chat message.

When you talk to one of our advisers it will be confidential. You will be free to talk about any TSC-related issue in a safe environment, such as a recent diagnosis, outreach for emotional support or help with filling out benefits forms.

The move to a support line will help the TSA to be more accessible, sustainable and ultimately support as many people living with TSC as possible. There are between 15,000 – 44,000 people in the UK affected by TSC. Yet, now, we reach only around 1,600 of these people.

The help of the TSC community in implementing the new Support Line is vital. If you have any questions, concerns or would like to be involved in focus groups to help us shape the service, please come along to one of our two central support line Q&A sessions which are taking place in the Victory Room between 15:15–15:45 and 16:15–16:45.

International TSC Research Conference 2020

The TSA is proud to be hosting the 2020 International TSC Research Conference from 12-14 November at the Royal College of Physicians in London. Conference attendees will include international TSC experts, academic researchers at an early stage of their careers and partners from government and industry.

This conference poses a unique opportunity for the TSA to facilitate access to world-leading experts in TSC for our community. On **Saturday 14 November 2020**, we will hold a **TSC Community Afternoon** where people living with TSC and their families can hear from international experts on TSC.

At the TSC Community Afternoon, speakers will summarise the key messages from their scientific sessions from the main conference, so the community can learn about the latest developments in TSC research, covering a range of subjects such as genetics, diagnostics, risk assessment and prevention, new and available therapies, and ongoing and upcoming clinical trials.

The Big Day will not take place in 2020, with the TSC Community Afternoon is happening instead.

Watch this space, as the Big Day will be back for 2021!

INTERNATIONAL TUBEROUS SCLEROSIS COMPLEX RESEARCH CONFERENCE 2020

A VISION FOR THE FUTURE

PROUDLY ORGANISED BY THE TUBEROUS SCLEROSIS ASSOCIATION

/THETSAUK @UKTSA 2020CONFERENCE@TUBEROUS-SCLEROSIS.ORG WWW.TUBEROUS-SCLEROSIS.ORG/2020

Catch a snowflake!

Support the TSA this Christmas by making a festive donation of £25 or more and you will receive a limited-edition TSA snowflake to display with pride on your Christmas tree!

While stocks list!

tsa tuberous sclerosis association

www.tuberous-sclerosis.org/Christmas | fundraising@tuberous-sclerosis.org | 0300 222 2737

Want to help us shape future TSA events? We would love to hear your feedback and ideas! Get in touch by emailing **comms@tuberous-sclerosis.org** or phoning **0300 222 5737**.

Contact the TSA

Head office

@UKTSA

Facebook.com/TSAUK

www.tuberous-sclerosis.org

0300 222 5737

admin@tuberous-sclerosis.org

Please note that the TSA's central postal address has changed to Tuberous Sclerosis Association, Unit 56, 1 Emma Street, London, E2 9FP.

Fundraising

fundraising@tuberous-sclerosis.org

Communications

communications@tuberous-sclerosis.org

Nine of the TSA's 12 staff continue to be home-based across the UK to keep our running costs down.

TSA
BIGDAY
2019

www.tuberous-sclerosis.org ☎ 0300 222 5737 admin@tuberous-sclerosis.org

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The Tuberous Sclerosis Association is a Company Limited by Guarantee registered in England and Wales No. 2900107, English Registered Charity Number 1039549, Scottish Registered Charity Number SC042780, Registered Office Tuberous Sclerosis Association, Unit 56, 1 Emma Street, London E2 9FP.