

scan

Autumn 2023

The magazine of the TSA



**Step-by-step:
Transition from
child to adult services**

Registered charity 1039549 (England & Wales) Registered charity SC042780 (Scotland)

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A word from your Chair

Looking ahead to future years, learning from recent challenges and victories

The focus of our five-year strategy for 2019 - 2023 was to 'Reach more people and drive more research'. With the strategy now ending alongside my position as Chair, we can consider the major challenges and victories of this time and what we achieved.

Our latest and recently submitted annual report shows that in 2022 we contacted 5,253 people in the TSC community – 55% higher than the number we contacted in 2018 (3,394 people). Our focus on progressing TSC research during this strategy period has also had clear results – diagnosis, treatment and management of TSC is much improved (although more still needs to be done). New medicines, like everolimus and cannabidiol for TSC-related epilepsy, are now available to everyone in the UK. We're also better at identifying and managing TSC-Associated Neuropsychological Disorders (TAND), as well as wider TSC issues.

The TSA itself is now in a stronger position than five years ago. Difficult but important changes to our team structure

and ways of working mean that the small TSA team is now better at offering more equitable services across support and information (like the TSA Support Line), research and campaigning. Improving TSA communications (follow us on all channels, including 'Liking' and resharing content) has given us wider exposure, strengthening our corporate support such as with medical organisations – although the TSC community remains the backbone of our fundraising support.

We take pride in the achievements of our current five-year strategy, but our work doesn't stop until we've got a cure for TSC. We progress only thanks to the TSC community, including those who fundraise and donate to us. I hope that we can continue to count on you as a pillar of support.

Best wishes,
Sanjay Sethi

TSA Chair



SANJAY SETHI, CHAIR

Welcome Chris and Ella!

We say a big 'Hello' to two of the TSA's newest members of our team, and give them the chance to tell you a bit about themselves



I'm Chris and I joined the TSA as the new Fundraising Officer. I help make sure that the TSA's income is healthy, so we continue to be here for everyone affected by TSC.

I've worked for and been supported by many wonderful charities, in my personal and professional life. Charities are really important to me, as I've seen the massive impact that organisations like the TSA has.

I've already met lots of wonderful people in the TSC community, such as at this year's Outlook event. As I continue in my role, I look forward to getting to know as many of you as possible.

In my opening few months at the TSA, it's been clear to me just how kind and determined the TSA's incredible supporters are. It makes me proud to be able to do my bit to help people in their fundraising journeys. There's never been a more important time to fundraise or give to the TSA! If I can ever be of any help, get in touch: fundraising@tuberous-sclerosis.org / 0300 222 5737.



I'm Ella and I'm thrilled to be the TSA's the Research and Partnerships Officer!

Before joining the TSA, I worked as a researcher exploring how we can help bits

of our body recover after they've been damaged by injury or certain treatments.

A big part of my role is to support TSC researchers with their projects, while making sure they're addressing the questions that are most important to the TSC community. I'm also the main point of contact for the TSC Research Volunteer Network – a group of people affected by TSC (including parents, carers and loved one) who are helping us to shape the future of TSC research.

I work part-time with the TSA and spend the rest of the week with my two-year-old daughter. I enjoy playing guitar and listening to audiobooks. I used to be a scuba diver and have previously spent time working abroad in Thailand and Greece, but I hung up my fins after moving to Scotland.

I feel so privileged to be part of the TSC community and driving research forward. If you'd like to have a chat about how you be get involved with TSC research, please message me: research@tuberous-sclerosis.org.



TSA celebrated for the quality of our information



We recently earned accreditation with the Patient Information Forum

The Patient Information Forum (PIF) is a non-profit organisation that reviews print and online information focused on health and care. PIF gives organisations a 'PIF Tick' if they can prove that the information that they provide is of high quality. We were delighted to recently receive our very own PIF Tick!

The PIF Tick was created to help people who have health challenges be sure that the things that they're reading are trustworthy. This is especially important these days, with the internet being full of information but with not a lot of guidance on which sources are dependable and trustworthy.

Getting a PIF Tick isn't an easy task. The TSA had to show that we consistently use information that comes from reputable places and people. We also had to prove that we regularly review and change our information so that it doesn't go out of date. PIF also looked at how user-friendly our content is, such as if our website is easy to navigate and that nothing is too confusing.

"Gaining the PIF Tick demonstrates our commitment to providing our community with reliable health information. This quality mark offers a quick and easy way for people to trust our information," said Luke Langlands, TSA Joint Chief Executive.

Dan Wills, PIF Tick Manager, expressed his pleasure about our accreditation: "We're thrilled to welcome the TSA to our ever-growing community of accredited PIF Tick members. Accurate, accessible, evidence-based information is key to increasing people's empowerment and improving health outcomes."

Now that we have a PIF Tick, you can be even more confident that the information is reliable and meets the highest standards of quality.

Play the weekly
TSA Lottery for
your chance to
win **£25,000!**

From just **£1 a week** you can have the
chance of winning it big, all while helping
to improve the lives of people with TSC

tuberous-sclerosis.org/tsa-lottery

Full terms, conditions and information on self-exclusion available on the TSA website. Responsible gambling means not spending more money or time than we can reasonably afford on gambling activities, keeping in mind all our other responsibilities in life.

GambleAware



tsc
Lottery

The Big Give 2023 returns!

At the start of December we'll be taking part once more in The Big Give Christmas Challenge!

The Big Give is the UK's most popular matched-funding campaign, giving charities the chance to focus on a project or campaign that needs vital support. We were delighted with your response in previous Big Gives and hope that we can rely on you again!

For this year's Big Give Christmas Challenge, we're aiming to raise £10,000 for the TSA Support Fund, which helps people with TSC who are in financial crisis. The TSA Support Fund is currently at breaking point, with double the number of applications this year compared to 2022.

The best thing about The Big Give Christmas Challenge 2023 is that every donation you make is doubled! That means that a £25 donation from you is actually worth £50 to us.

The Big Give Christmas Challenge 2023 takes place **28 November – 5 December**.

We'll be sharing lots more information on how you can get involved as we get closer to the date.

TSA-funded researcher has work in scientific journal

Muireann Ní Bhaoighill's important work helps us understand how we might be able to slow down TSC tumours

In people with TSC, the body tells different areas grow too big, too quickly. This leads to TSC tumours. Muireann researched if there's ways that we can tell these tumours to stop growing.

In her research, Muireann studied a part of the body called the 'tumour microenvironment' (TME) – this is the area that surrounds a TSC growth. One way that the cells within the TME tell the tumour to grow is something called 'extracellular vesicles' (EVs). EVs are like little parcels of information – one cell will package up their message and send it to another one to open. In people with TSC, these parcels are messages for TSC tumours to grow. By understanding what's inside these EVs, researchers can understand whether we can re-write these parcels so that they say 'stop growing' instead of 'keep growing'.

As part of Dr Elaine Dunlop's team, Muireann discovered that the EVs (message parcels) in people with TSC contain very different messages compared to people without TSC. They also found that treatment with sirolimus changed the EV messages, so they became instructions for TSC tumours to slow down their growth. This is potentially a very exciting finding that was not known until now.

The team also learned that they could spot differences in the EV message parcels by analysing the blood of people with TSC compared to those without. This could mean that one day we can monitor TSC tumours with a simple blood test. This would replace the long journeys to specialist clinics for scans and tests that happens today.

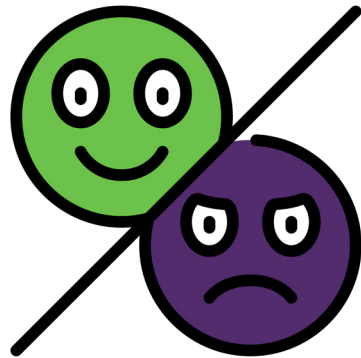
Dr Elaine Dunlop commented: "This study has allowed us to understand more about how TSC cells communicate, and how this might support tumour growth. This could help scientists identify new treatments in the future. It's also exciting to show that EVs in the blood have potential TSC-specific markers as this could lead to new, simpler ways to monitor people with TSC in future."

Trending topics: Managing behaviours that can be challenging

Tantrums, harm and abuse are just some of the actions that come under behaviours that can be challenging, a common obstacle in the lives of people with TSC

What are 'behaviours that can be challenging'?

A behaviour is considered challenging if it puts someone at risk of physical or emotional harm. It might include hurting others, self-harm, or destructive actions (like breaking or throwing items). People with learning difficulties or disabilities are more likely to show behaviours that can be challenging, but everyone is capable of them. In TSC, behaviours that can be challenging come under TSC-Associated Neuropsychiatric Disorders (TAND).



Why do behaviours that can be challenging happen?

It might be because of a stressful situation (like a room being too loud) or to get a need met (like being hungry or thirsty). It might also be a release valve for wider frustrations or other strong emotions. This is especially true for people who are nonspeaking. Imagine being unable to use your voice to tell someone that you want something to happen, or that you need something. In this context, behaviours that can be challenging become much more understandable.

How can I predict behaviours that can be challenging?

Keep a record, as and when they happen. This could include things like where you were when it started, what was happening beforehand, what happened afterwards, and what the actual behaviour was.

A useful tool is the Antecedent (meaning 'before'), Behaviour and Consequences (ABC) chart:

Date, time and place	Description of setting, location and activity	What was happening before the behaviour?	Description of behaviour	What was the result of the behaviour?
Monday 5 June, 12:00, home	Tom in his bedroom. Nearly lunchtime	Tom came down to the kitchen, Dad in the garden	Tom picked up a bowl and threw it at Dad	Dad made lunch for Tom

How can I reduce behaviours that can be challenging?

Most people have an 'early warning system' for upcoming challenging behaviour. This warning might be hard to spot until you start an ABC chart. It might be things like repetitive behaviours, a certain noise, or tensing muscles. If you're able to spot the 'early warning system', you can use this as a way to then manage a behaviour that might be challenging before it happens.

How can I support someone during the behaviour?

Try to act as calm as possible, even if you don't feel like this inside. Gently smile and keep your voice low and clear, to encourage mirroring of your behaviour. Don't ask too many questions, and be open to giving the person space if appropriate. If the situation could become dangerous, don't think twice about contacting 111 or 999 emergency services. Be kind to yourself and remember that it's very difficult to prevent or manage these sorts of behaviours

How can I support the person after the behaviour?

The experience can be draining for everyone involved. A change of environment or doing something different, such as going for a walk or doing an activity, can be helpful to reset everyone. Once everyone is calm again, consider reflecting on the incident for the future.

We recently hosted a virtual event with the Bath TSC clinic, fully focused on behaviours that can be challenging. You can rewatch this in full by visiting the TSA Video Hub on our website, or our Facebook page

You can also contact the TSA Support Line completely for free, for further information or even just a listening ear (0808 801 0700 / support@tuberous-sclerosis.org / webchat)



DR FELIX CHAN

Researcher in focus: Dr Felix Chan

In this new ongoing feature, we meet the people behind the incredible TSC research taking place all around the world

Dr Felix Chan (Aston University) is a TSC researcher focused on TSC-related epilepsy. We spoke to Dr Chan to discuss his current research, plans for the year ahead and his signature chocolate brownie!

What was your background before becoming a TSC researcher?

"Before becoming a TSC researcher I worked on mitochondrial disease and it's connection to epilepsy. Mitochondria are parts of our cells that make energy for our body and in certain diseases they don't work as we'd expect them to.

I fully believe that by understanding the metabolic aspect of epilepsy (metabolism is the process your body uses to turn the food you eat into the energy it needs to function) that we can create new, targeted approaches to treat severely drug resistant epilepsy. This is the approach that I'm hoping to bring to my TSC research."

What was your motivation for getting involved in TSC research?

"My interest in TSC research began while studying drug-resistant epilepsy at Brown University in the USA. My work included looking at samples from children with TSC. This made me very interested in the condition."

Can you tell us about your current TSC research projects?

"I've established my own lab at Aston University in Birmingham, where we're interested in understanding how cells produce energy and its role in TSC-related epilepsy. Currently, we're focusing on an energy source in the body called 'lysine'. Lysine is something we can only get from our food. So far, we've found that in TSC some people's brains will break down more lysine than people without TSC, which can contribute to seizures. A lot of our research right now is focused on whether we can target this pathway to develop new treatments to treat epilepsy in TSC."

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

"I hope we make real advancements in understanding epilepsy in TSC, especially as a lot of it remains unsolved. Whenever I speak to people with TSC, they tell me that epilepsy is one of their biggest challenges. I'm hoping that with my ongoing TSC epilepsy research here in the UK, alongside many other great researchers, will mean that it will become better understood."



I hope we make real advancements in understanding epilepsy in TSC, especially as a lot of it remains unsolved.

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

"Often when I speak to people with TSC they tell me about the challenges they face with epilepsy. Hearing these experiences is such a privilege and it always solidifies my passion to pursue epilepsy research. I'm determined to make a change for the TSC community and would like to address the challenges most important to you."

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

"I love trying new food and cooking new recipes. I'm also a good baker and make a wonderful chocolate brownie. I'm also a music fan and a big fan of Taylor Swift."

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

"I did my first degree in Medical Sciences in Indonesia and had the option of going to medical school. I think if I hadn't got into research, I would've continued my medical education and become a doctor. I would've probably still got into TSC research eventually as I was hoping to help sick children."

New partnership to better understand conditions like TSC

We're proudly taking a central role in a new project focused on rare diseases

TSC is one of 14 rare conditions that happen because of problems with something called the 'mTOR pathway'. The TSA and other organisations have formed the 'mTOR Pathway Diseases Node' to understand this more.

The partnership, led by Kings College London, hopes to find ways to treat multiple rare conditions by learning more about the mTOR pathway and why things go wrong with it. The project has even been awarded £1.1m by the National Institute of Health and Care Research (NIHR) and the Medical Research Council (MRC).

In the body, the mTOR pathway is responsible for how quickly cells grow. Cells are the building blocks of our body, forming things like our heart, lungs and other organs. Our cells are given instructions on what to do and one of these sets of instructions, the 'mTOR pathway', is responsible for how quickly they grow. In people with TSC, the gene that acts as a 'brake' on the mTOR pathway doesn't work as it should, meaning that cells grow too large – this is what leads to TSC growths and tumours. Commonly used medicines to treat and manage TSC, like everolimus and sirolimus, add this 'brake' to the mTOR pathway.

"mTOR pathway diseases share a common cause and so people with these diseases can potentially be treated using the same medicines" commented Professor Joseph Bateman, mTOR Pathway Diseases

The logo for Kings College London, featuring the text "KING'S College LONDON" in white serif font on a red background. The word "KING'S" is in all caps, "College" is in a script font, and "LONDON" is in all caps. There are two horizontal white lines below "LONDON".

KING'S
College
LONDON

The partnership, led by Kings College London, hopes to find ways to treat multiple rare conditions by learning more about the mTOR pathway and why things go wrong with it



DR CHARLOTTE TYE



Involving individuals and their families who have lived experiences of mTOR-related conditions is key to this research.

Dr Charlotte Tye

Node Lead. "This project will unite mTOR pathway diseases into a single group for this research. This will include bringing together clinicians, researchers, charities, industry and not-for-profit organisations to improve the diagnosis, treatment and clinical outcomes for people with mTOR pathway diseases."

The TSA is ensuring that TSC is at the centre of research by the mTOR Pathway Diseases Node. This will help to ensure that the research's perspectives and priorities recognise the voices of people who live with the impact of TSC.

Formation of the mTOR Pathway Diseases Node comes after lots of

hard work and dedication from a wide range of people and organisations. The project is an exciting opportunity to push TSC research and rare disease research forward, which is why the TSA is delighted to be a major group within the node. We'll ensure that TSC and the TSC community have an important voice as the project is established and continues to develop.

If you'd like to be involved in the mTOR Pathway Diseases Node or other similar projects, speak to our research team about signing up to the TSC Research Volunteer Network (research@tuberous-sclerosis.org).

Fundraising champion: Megan Salvidge



After little Darcie was diagnosed with TSC at just seven months old, Super Mum Megan and her family are doing everything they can for the TSC community

Megan and her partner Liam contacted the TSA's fundraising team to see what they could do to improve lives of people affected by TSC. They wanted to channel their energy into something positive after Darcie's TSC diagnosis. Ever since then, the young couple and their family have been an inspiration!

Megan set herself a goal to complete a sponsored walk. With incredible support from Liam and their family and friends, Megan's JustGiving page exploded in interest after people heard her story. Megan, Liam and 18 family and friends completed the walk, raising an amazing **£11,632!**

In Megan's words: "We were lucky that the weather held out for us! We ended up completing the 11.1 miles and finished at the pub! We hope the amount we've raised will help families like our own, and that we've raised awareness in our local area!"

On her daughter's diagnosis, Megan said: "We still have a long road ahead of us, and plan to take each day and appointment as it comes. We're so lucky we were taken seriously by all medical professionals that we came into contact with, despite it being such a rare condition that isn't often diagnosed quick enough. Darcie was diagnosed within 48 hours of us turning up at the hospital, and her first brain scan within 24 hours. Despite living a nightmare, I hope more awareness can come from this and I love to raise money for a charity so close to our hearts."

If you've been inspired by Megan, you check our website for lots of tips on organising your own fundraising event, or contact our fundraising team (fundraising@tuberous-sclerosis.org).

The return of Outlook and Big Day!



Our face-to-face events have returned! Plus, we've got the dates for 2024 confirmed

Outlook is our face-to-face event for adults who identify as being mildly affected by TSC. Big Day is our annual conference, where everyone in the TSC community can come together.

We were delighted to bring Outlook 2023 to Leicester and Big Day 2023 to Manchester. Both were a big success! At Outlook and Big Day, the TSC community can share experiences, gain valuable knowledge, and feel part of a supportive community. You can make new and meet old friends, attend workshops and be in a place where TSC is well understood. At both events this year we welcomed a wonderful mix of people in the TSC community from around the UK and beyond – including people with TSC, their loved ones, and also TSC professionals like doctors and nurses.

Outlook 2024
will take place
Saturday 20
April 2024 at
the **Cardiff**
Masonic Hall
Big Day 2024
is set for
Saturday 25
May 2024 in
Reading!

TSC story: Lauren McWhinnie

After sharing her TSC story for a previous issue of Scan, Lauren has kindly updated us on what she's been up to

"Living with TSC has brought many ups and downs. It can feel like a rollercoaster, with trying to juggle emotions and different scenarios."

TSC and mental health

"Many people know very little or even nothing about TSC, which is a major issue in mental health – especially for the people who have TSC themselves. It can feel isolating and lonely at times when there's people who don't understand the condition. Some days I ask myself why I see the world so differently compared to all my friends and family. However, I believe in the power of uniqueness and the importance of acceptance amongst one another. If you've the confidence to stand alone on two feet, and can pick yourself up from a fall, then you've the power for anything you choose in life – that's what makes you a unique."

The powerful meaning of sport in disabilities

"I recently joined my local Ability Football Club, which are football clubs organised for people with disabilities. It has helped me massively with my mental wellbeing. It's a place I can escape to and not be afraid to be myself. When I first joined, I didn't know any of the rules to football, even how you score a goal. However, now I've made lots of friends. I've loved my time being part of the club and everyone is like family to me there."



I play in midfield, and have captained my team many times. I've also won a medal at a spring tournament this year and won 'Best new player' for the 2022-2023 season.

The coaches and teammates at my club have supported me and taught me there's a sport and position for everyone to play, no matter what your disability or abilities are. You can be really successful if you believe in yourself and the sport."

Confidence through music theatre

"Back when I was in college I studied performing arts, but I was bullied for being different. However, I'm now able to be part of lots of musical theatre opportunities. Thanks to this, I've got back my confidence to perform again.

Over the last year, I've been involved with a local theatre group and the musical 'School of Rock.' I loved every minute of being part of the show.

I was recently successful in gaining a part for a show next year with a local Special Educational Needs and Disability (SEND) theatre group. I did a solo audition where I sang and acted, sharing my story of what it's like living with TSC. I'm very excited to be sharing the experience with all my friends back home who have special needs like me.

I hope that by reading my update you can feel inspired to try new things and see that someone with TSC can still live a full and meaningful life."

“

I believe in the power of uniqueness and the importance of acceptance amongst one another. If you have the confidence to stand alone on two feet, and can pick yourself up from a fall, then you have the power for anything you choose in life – that's what makes you a unique individual."



Fundraising thank yous

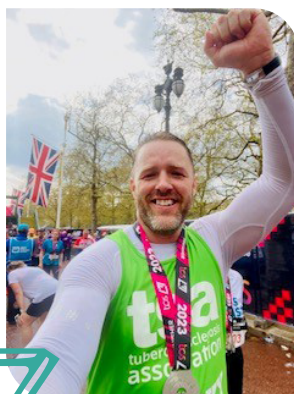
We give thanks to some of the incredible fundraising taking place that means we can continue to be here for the TSC community

After months of preparation and all-weather training the fantastic TeamTSA at the **London Marathon 2023** completed the world's most iconic marathon's and raised a staggering **£22,670!** This is a record-breaking amount for TSA runners at a single running event!



London Marathon 2023

Here's what some of our amazing runners had to say after hitting the finish line:



"What an incredible day. The blood, sweat and tears (literally!) were all worth it for that feeling of crossing the finishing line. I don't think I can ever sum up to anyone just how that felt" – **Hayley, first-time London Marathon runner**



"I ache like I've been hit by a train and still very emotional but so worth it for this amazing charity!" – **Claire**

A massive congratulations and huge thank you to all of our runners: **Claire Felstein, Chris King, Daniel Marks, Duncan Warner, Emily White, Hayley Grainger, James Black, James Harper, Lewis Bastin** and **Sam Cooke**! You're all amazing!

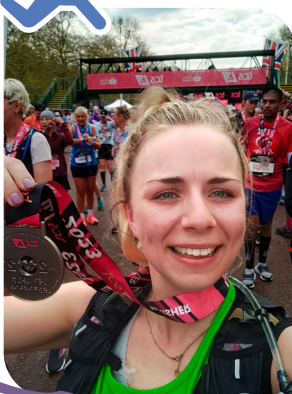
Inspired by TeamTSA to take on a running event? Head to [RunforCharity.com](https://www.runforcharity.com), select the Tuberous Sclerosis Association and choose an epic challenge that best suits you – there's something for everyone, from fun runs to ultras!



“It was really tough but I loved every minute! And have entered again for next year!” - **Emily**



“I loved the whole experience and the support from the public is incredible. An amazing experience I'll never forget!” - **James, longstanding TSA supporter**



“I finished in 03:58:25 and was greeted by the little girl who it was all in aid of. It was a brilliant day and I have memories that will last a lifetime!” - **Sam, uncle to Avery who has TSC**

FUNDRAISING



Superstar **Dexter** raised a phenomenal **£1,289** by recently completing a duathlon to improve the lives of people with TSC, like his little sister!



Darian Thomas raised a fantastic **£200** through collections he organised from the recent production of the Cat on the Hot Tin Roof at the Dolman Theatre in Newport. The theatre kindly matched the donations, putting the total up to **£400**!

Many of you generously responded to our TSA Support Fund Appeal. Your support helps us provide a much-needed lifeline to those with TSC when the

devastating financial costs of the condition become too much. Thank you!



Sam Cooke was one of our London Marathon 2023 runners, he raised a further **£1,073** by organising a charity football match with his Border Force colleagues. The event was a huge success, particularly for Sam as his team walked away with the trophy after a 6-2 win!



Longstanding TSA supporter **Linda Smith's** efforts have continued. Her incredible supporters at The Swan pub in Needham, have helped raise a staggering **£1,850** so far this year, by hosting

things like bingo nights and raffles. Well done!



Emma Staniforth organised a charity golf day and raised a phenomenal **£2,370**! The day included players paying a set donation fee to participate, plus a disco, raffle and tombola. Emma has a very personal reason for supporting the TSA, with her little boy being diagnosed with TSC at just seven months old. A further **£500** was donated by Emma's employer HSBC as a part of their employee charity match-funding pot – fantastic!



Thank you to everyone who set up and supported a **Facebook fundraiser** recently, with occasions such as birthdays, anniversaries and other special events. So far this year you've helped raise a brilliant **£5,890!**

Our sincere condolences and thank you to the family and friends who chose to give in memory of loved ones who recently passed away: **Alex Mitchell, Gladys Attwater, Michael Bill, Michael John Futcher, and Peter Collier.**

Legacy and in memory giving is an incredibly powerful and heartfelt way to give to the TSA, helping us to continue to be here for the TSC now and forever. If you've recently lost a loved one, you can use MuchLoved.com to setup an online tribute for free. You can also setup donations and many other tribute options.

Everyone at the TSA was also very saddened to hear of the recent loss of **Jay Mason**, a longstanding supporter of the TSA and TSC community in Scotland.

Trusts and foundations

Thank you to the following trusts and foundations for their recent support:

- The Hobson Charity
- The Meikle Foundation
- Baily Thomas Charitable Fund
- The Beechwood Trust
- Jeans for Genes
- The Charities Trust

Corporate support

Thank you to our recent amazing corporate supporters, including:

- Aubrey Allen
- Davis Creative Ltd
- The Lansdowne Club

Corporate fundraising is a brilliant way to get your workplace involved in improving the lives of people with TSC. Whether it's a one-time donation, choosing us as your 'Charity of the Year', payroll giving or something completely different!

Feeling inspired? Be part of TeamTSA and make a huge difference to the lives of people affected by TSC.
Visit tuberous-sclerosis.org for lots of fundraising ideas!

The big step: Transitioning from child to adult services

It's important to prepare for the move from child to adult care services, as it can pose many obstacles



Child services involves familiar and highly-structured care. The transition from this to adult services, which are more self-directed and independent, can be daunting. However, it can also be framed as a time of positive change.

Through better understanding and clarity on the transition process, young people with TSC and their families can feel empowered and armed with the knowledge to navigate the change with confidence and ease.

The five pillars of a strong transition

A successful transition to adult care depends on a coordinated efforts across five key pillars, with the young person at the core. These are:

Healthcare. Adult healthcare likely means support by different TSC specialists and at a different TSC clinic to the care received as a child.

Speak to the young person's existing children's TSC clinic well in advance of the transition, so a plan can be made. This will mean that no health challenges of TSC are missed following the move. You might also want to speak to the young person's GP to share any concerns.

Social care. If the young person has a disability, social care has a major focus in the initial steps towards adulthood. This ensures that nothing is missed, and will include a Transition Assessment (more on this later). Over time, social care services should be flexible and adapt to continue meeting the young person's needs.

It's important that there's never a break in social care services. Child services should not stop funding a young person's social care support until adult services have taken over.

Education. If a young person with TSC doesn't require major social care or health support, education – especially school – takes the lead in transition planning. It's important that the young person has the opportunity to fulfil their education potential.

When a child with complex needs is approaching school leaver age and wants to continue in education, it's understandable to be concerned about finding an appropriate placement or college. If the child doesn't have an Education, Health and Care Plan (EHCP) and there's concerns that a placement can't meet their needs because they require specialist support, consider requesting an Education Health and Care (EHC) needs assessment.

One option is to seek a specialist colleges that offers courses for students with learning disabilities. The membership organisation for centres like this is called Naspec. They should be able to provide more information.

Work and leisure. The importance of employment and leisure can't be underestimated. Although everyone's capabilities are different, work and hobbies can massively contribute to a person's sense of independence and self-esteem. This should not be ignored in the transition to adult care.

Understanding the different phases of transition

Moving to adult services is a gradual progression across health, social and education providers. This makes the change easier to plan and anticipate. The first phase usually starts slowly, from around 14 years old, but the specific age will depend on where you live in the UK. This process usually has three main phases:

Preparing for adulthood. This can span several years and is the foundation of the transition process. This stage might involve a 'Transition Assessment'. This can help the young person create a 'road map' for what the transition will involve, focused on helping the young person achieve the best outcomes.

A good transition assessment should look at a young person's strengths and (when able) involve the young person as much as possible, so that they are central to the planning of their own life. Young people or their caregivers can request a transition assessment from their local authority. The local authority has a duty to do this assessment under the Care Act 2014.

This stage is often done in school, especially if the young person has an EHCP or Statement of Special Educational Needs (SEN).

To achieve the best preparations possible, ensure that the professionals supporting the young person across health, social and education care are coordinated and prepared to communicate together

Although transition to adult care can be a stressful time, for many it can also be approached as an occasion for positive change.



First steps into adult services. This phase is when the preparations from the previous step start to be put into action. The young person will probably still be seen by child services during this phase, but it's an opportunity to put one foot into the world of adult care.

This 'moving in' stage gives the young person a chance to feel more comfortable with the transition and interact with adult services – this could include a day visit to their new special needs residential college, or being introduced to the TSC specialists at their adult TSC clinic.

Use this stage as a chance to make sure that you've thought of everything that'll be needed, such as transportation and appointment tracking..

Settling into adult services. This phase involves the young person settling into their new adult services. It ensures that the young individual is well supported across health, social and education care, and has everything that they need.

The TSA strongly believes that it's only through joined-up working that the best support and management of TSC can be given. Health, social and education care professionals should continue to communicate even beyond this stage.

At this stage, closely monitor the young person's progress, development and overall care. As in previous steps, a major focus should be on ensuring that no services or needs go unnoticed.

Looking Ahead

Transitioning from child to adult services is a significant milestone for young people with TSC. It's a time of change, growth, and increasing independence. With a carefully crafted transition plan, a multi-agency team that communicates well, and the unwavering support of family and friends, young individuals can thrive in their new adult care environment.

Remember that every individual's transition experience is unique. There's no one-size-fits-all approach. Flexibility, patience, and open communication among all involved parties are key.

A parent's experience of transition to adult care

Annemarie Cotton, TSA Trustee, took the time to tell us about her family's experiences of when daughter Esme made the move from child to adult healthcare

"Support for Esme in children's healthcare wasn't all perfect, but we did have some excellent care and built up good relationships with key professionals. This was something we were lucky to have, and we didn't want it all to end. When we left the child clinics for the last time I might have looked cool, calm and collected but in truth I felt like a reluctant child on the first day of school being peeled away from their parent. I knew we'd have to start again with new professionals, to tell Esme's story again, to navigate new hospitals. I was worried that we wouldn't be able to be as involved in Esme's care as she was over 18 and legally an adult. I was concerned the staff in an adult hospital just wouldn't understand how to talk to her and how to help her feel comfortable.

It's now almost two years since Esme's move to adult healthcare care. She's now nearly 20 and although the path hasn't completely smooth there have been some real successes and picked up some top tips along the way. The main thing has been in developing relationships with healthcare professionals and in proper planning for procedures and hospital visits.

Our first adult TSC clinic appointment felt quite different from the children's appointments. The waiting room is for adults, so no toys, no DVDs playing and no fish tank - all of which were welcome distractions in the children's clinics. We took Esme's Hospital Passport with us - this is a document that discusses a person's medical history, preferred ways of communication and likes/dislikes (it's especially useful for people with learning disabilities). I encouraged Esme to show it to everyone who spoke to her. We had the opportunity to meet the Adult Learning Disability (ALD) nurse and this proved key to our transition. She shared an easy read pack about her team and how they could help. I felt like we'd started to make the key relationships that we'd need going forward.

Not long after this, Esme had an MRI scan under general anaesthetic. We knew what worked for her at the children's hospital and wasn't sure how it would all come together on an adult ward. I contacted the ALD nurse and she asked me for details about what would help Esme to get the scan. The nurse then shared this with the anaesthetist and all the ward staff. I know the key thing that made it all work was the effort the ALD nurse put in behind the scenes.

The next time Esme needed an MRI scan, the TSC nurse asked if we wanted to try it out without an anaesthetic, which we did. The nurse arranged for us to have an appointment at the very end of the day, so it was quiet. The staff took everything really slowly and let Esme lead how the appointment went. Again, this was down to the key role of the TSC nurse in setting it all up before we got there.

Earlier this year, Esme had an inpatient video electroencephalogram (EEG – a painless procedure where sensors are attached to the head to read brain activity). For the EEG to happen, Esme had to be in hospital for four days. I was worried how things would work out, but I asked the epilepsy nurse there for advice and she acted as a coordinator for it all. The nurse liaised with many people in Esme's team to create a visual timetable for Esme and her stay. This made most of the actual stay a success, which was down to the work that went on behind the scenes before we got there.

It hasn't all been seamless, and there's been a lot of work involved to get us to where we are today. But, it's been worth it. These are some of the key insights I've gathered from Esme's transition to adult healthcare:



- **Parents and carers are still vital.** The professionals do want us involved and recognise we know our young people better than anyone else
- **Making relationships is key.** Identify the right people who can help, and make sure that they get to know your family and you get to know them. Epilepsy nurses, TSC nurses, ALD nurses – find yours and get to know them
- **Don't be afraid to ask for help.** Or for 'reasonable adjustments' to be made for your young person. Just because something hasn't been done before doesn't mean it can't be done now
- **Get a Hospital Passport.** Or create a one page profile and ask professionals to read it before they meet or care for your young person
- **Be ready for setbacks.** Any kind of change can be tricky and it's ok to get frustrated. Just keep going, you are the best advocate for your child no matter how old they are"



A tribute to Alice Dew

Alice Dew, who was known to many in the TSC community, recently passed away. Alice's cousin, Hugh Williamson, pays tribute

My cousin Alice Dew was a long-standing, active member of the TSA. Alice devoted much of her life to bringing up her two children, who both had TSC, and promoting social awareness of the condition.

Alice was born and lived most of her life in Southport, Merseyside. She first became active in the TSA in the early 1990s after her beloved brother Andrew was diagnosed with TSC. Andrew was almost 30 years old at the time of diagnosis and it was a shock. Alice and her mother Lucy Woolfenden were also diagnosed with mild forms of TSC. Alice's son Mark, 18 months old at the time, was also diagnosed with the illness.

This news of TSC came as a huge challenge to Alice and her family. However, Alice embraced this new situation and it became a cause to which she devoted the rest of her life. Her second son, Adam, was also diagnosed with TSC.

Alice campaigned for more recognition and support for people with TSC and for their families. She was an active member of the TSA for many years. She regularly attended and helped organise national TSA gatherings, served on committees and met locally with other parents of children with the condition.

Alice left school at 16 and started working as a shop assistant in Boots, where she met her former husband. They had three children, including their first, Sarah Louise, who was stillborn. Alice's husband left her in 1994, shortly after Andrew's TSC diagnosis. She became a lone parent to Mark and Adam, to whom she was completely dedicated.

In 1996 the Independent newspaper published a feature on TSC that focused on Alice and her family. She told the newspaper of the challenges she faced but that she remained positive:

"Some people sail through life while others, like me, seem to have more than their fair share of problems. For seven years I've put my sons first, second and third. I wouldn't swap my children's personalities for the world. I wouldn't want to be without them".

When Alice's sons became young adults, Alice was clear that they needed the opportunity to develop their own independence through supported living.

Alice went on to train as a counsellor. She had a very active social life in Southport and is very sadly missed by her family and many friends. She is survived by Mark (aged 34) and Adam (aged 31).

We're here for everyone affected by TSC only thanks to the people and groups who kindly take the amazing step to provide us with donations.

**Help us to continue to be here for you and others:
tuberous-sclerosis.org/donate**

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