



# From Research to Real Life

Transforming TSC Together

## Research Champion Toolkit



# Thank you for choosing to become a Research Champion

**Thank you for joining our community of supporters who are helping to drive forward vital research into TSC.**

At the TSA we believe that research is at the heart of changing people's lives. Every study helps unlock the answers to improving treatments and care, as well as deepening our understanding of how TSC affects individuals throughout their lifetime.



Your fundraising helps ensure that the voices of people with TSC are driving our research projects.

This toolkit has been created to give you everything you need to succeed - from ideas and tips to research information, social media post ideas and even a poster on page 13 and 14 to help you publicise your fundraising. I hope it inspires you to feel proud of the part you're playing in improving the lives of people with TSC, now and in years to come.

On behalf of the TSA team and TSC community, thank you for championing research and for standing alongside us.

Good luck in your fundraising quest!

Two handwritten signatures in black ink. The first signature on the left is 'L. Langlands' and the second signature on the right is 'P. Takhar'.

**Luke Langlands and Pooja Takhar**  
**Joint Chief Executives**

**Providing help for today and a cure for tomorrow**



# From Research to Real Life:

## Our Three-Year Research Strategy

### 1. Understanding TSC - we're funding research that:

- Uncovers how and why TSC develops.
- Identifies new targets for prevention and treatment.
- Builds global collaborations to share discoveries.



### 2. Accelerating better treatments and care - to turn cutting-edge research into real-world results. We're supporting projects that:

- Develop and test new therapies.
- Improve diagnosis and monitoring.
- Enhance daily care and quality of life for people with TSC.
- Equip clinicians with the latest tools and evidence.



### 3. Empowering the TSC community - our goal is to ensure people with TSC shape the research that affects them. We're committed to:

- Hearing about lived experience in order to guide research priorities.
- Supporting families, carers, and individuals to have a voice.
- Making research findings open, accessible, and relevant.



### By 2028, we aim to:

- ✓ Fund more early-stage and translational research than ever before.
- ✓ Strengthen partnerships between researchers, clinicians, and families.
- ✓ Speed up the journey from discovery to life-changing treatment.

**Driving discovery, improving lives,  
empowering the community**

# What is a Research Champion?

**Being a Research Champion means being at the heart of progress for everyone affected by TSC.**

**Research Champions** are volunteers, families, and friends who use their energy, creativity, and voice to raise funds and awareness for the TSA's research programme.

## **As a Research Champion, you are:**



- A Fundraiser – turning ideas into action to support world-class research.
- An Advocate – helping others understand why research into TSC is vital.
- A Storyteller – sharing your personal connection or motivation to inspire others.
- A Connector – bringing together your community, friends, and networks to make a difference.

**What's Expected of You:** Being a Research Champion is flexible and rewarding. You can:

- Organise your own fundraising event or challenge.
- Join an existing TSA campaign or community initiative.
- Share TSA research stories online or in your local community.
- Encourage others to support or donate.

However you choose to get involved, your enthusiasm and advocacy help build a stronger, more connected research community.

**Every pound you raise brings us closer to breakthroughs that improve lives.**



**Turning passion into progress**





# From Research to Real Life:

## Behind every breakthrough is a family

**Research is not just about lab coats and data. The projects we fund can be transformational for people living with TSC.**

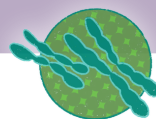
Marie and Perry's son Trystan was part of a ground-breaking discovery that changed everything about the way we look at TSC. It also improved his quality of life by uncovering treatments that previously hadn't been considered.

"Trystan was seven years old - it was a game-changing day. It felt like research was no longer a bottomless pit. Trystan's blood was analysed in a landmark study that led scientists to discover one of the genetic markets of TSC - the gene we now call TSC1. This quickly led to the discovery of TSC2 and has helped shape the huge improvements in treatments we have right now."

TSC research and the development of new ways to diagnose, treat and manage the condition wouldn't happen without funding into research and the amazing families like Marie's who take part.



"Getting involved in research has been empowering and therapeutic. Trystan is still alive because of the research work being undertaken and funded by the TSA. Anything we can do to strengthen research efforts is incredibly important."



**Research translating into real life**

# How to get started with your fundraising

**Getting started as a Research Champion is simple — and we'll be with you every step of the way.**

**Step 1: Choose Your Fundraising Activity** - Think about what feels right for you — something that fits your interests, time, and the people who might support you.



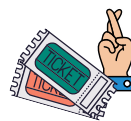
Quiz night



Coffee Morning



Run or Walk



Raffle

**Step 2: Set Your Goal** - Decide what success looks like for you and share it with everyone involved.



Fundraise

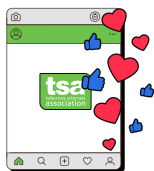


Raise Awareness



Meet the  
TSC Community

**Step 3: Register with the TSA Team** - Let us know what you're planning so we can support you.



Share online



Fundraising Resources



Completion Certificate

**Tip:** The best fundraising events reflect who you are. Choose something that excites you — your enthusiasm will inspire others to get involved.

**Every penny raised helps people in the TSC community**

# How to get started with your fundraising

**Step 4: Gather your supporters** - Fundraising is more fun when you do it together!



Invite friends and family

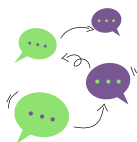


Ask for help



Fundraise at work or school

**Step 5: Spread the word** - Use the Social Media Toolkit and templates in this pack to tell everyone what you're doing and why.



Share your story

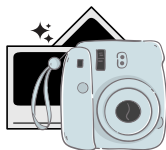


Post updates



Use event posters

**Step 6: Hold your event or challenge** - The big day is your time to shine!



Take photos and videos

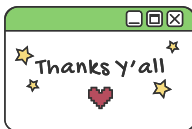


Enjoy it!



Share on the day

**Step 7: Celebrate and say Thank You**- Once your event is finished:



**Tip:** Don't forget to tag TSA use hashtags #TSCResearchchampion so we can celebrate your efforts

Together we're funding discoveries that change lives

# Telling your story

**Social media is a brilliant and powerful way to let everyone know what you're doing and why.**

By sharing your story online, you can reach friends, families and colleagues. Here are a few sample posts to inspire you. Including a photo can really help make sure your post is seen.

## Before your event

"I'm proud to be a Research Champion for the Tuberous Sclerosis Association. Over the next few weeks I'll be (insert activity) to raise funds for life-changing TSC research. The TSA is a charity close to my heart because (insert reason). Please support me if you can. Every donation helps support scientists who are working towards a better future for families and people living with TSC. "



## During your event

"It's happening today!! I'm (insert activity) to raise funds for the Tuberous Sclerosis Association's new research programme. Every pound is helping to fund the discoveries that will transform lives. Thanks to everyone who's supported me so far - together we're making a massive difference. Please come along/donate if you can."



## After your event

I did it!!! Thanks to your support, I've raised (£amount) for the Tuberous Sclerosis Association. These funds will help power the TSA's three-year research strategy, driving new treatments and better lives for people with TSC. I'm so proud to be part of this community of research champions. Thank you for supporting me and believing in research that changes lives.

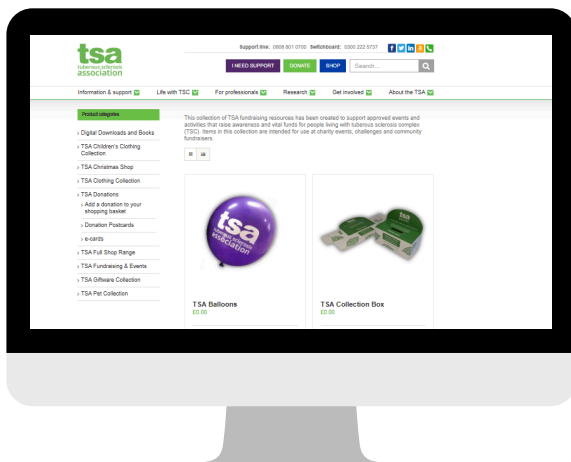


**Don't forget to tag us in your posts!**  
**#TSAResearchChampions**

# We are here to support you!

## Whatever you need to make your event a success, we can help

Whether you need posters, info leaflets, t-shirts, badges, balloons, wristbands, keyrings, bunting or any other extras to give your event the perfect finishing touches, get in touch with us and we'll send you everything you need.



**Visit our online shop at [tuberous-sclerosis.org/shop](http://tuberous-sclerosis.org/shop) to order your event merchandise.**

## Don't forget to get in touch after your event!

You'll receive a Research Champion Certificate and badge to celebrate your contribution and inspire others to follow your lead.



*Claim your Research Champion pin badge when you have completed your fundraising!*

**Don't forget the finishing touches for your perfect event!**







I'm raising funds for the  
**Tuberous Sclerosis Association**  
To provide help for today and a cure for tomorrow



Fundraiser Name: \_\_\_\_\_

Event: \_\_\_\_\_ Date: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Email: \_\_\_\_\_

Full name	Home address We need your address to claim Gift Aid on your donation.	Postcode	Wed like to contact you with information about TSA news and events. Please tick here if you wish to receive updates.	Donation amount	Donation date
			<input type="checkbox"/>		<input checked="" type="checkbox"/>
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☒ Tick the Gift Aid Box  
The TSA will receive 25p for every £1 that you donate.

Total raised £

**Thank you for your support!**

The donor information on this form will be used for processing your Gift Aid claim.  
Please refer to our privacy policy for more information: [www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org).

*giftaid it*  
If you are a UK tax payer please provide your full home address and postcode to make your donation go further.

By ticking the 'Gift Aid' box you are agreeing to the following statement -  
"I want Tuberous Sclerosis Association (TSA) to reclaim tax on my donation detailed above, given on the date shown. I confirm I am a UK taxpayer and understand that if I pay less Income Tax or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay any difference".

# Thank you for fundraising for the Tuberous Sclerosis Association

## Your details

Name

Address

Postcode  Telephone

Email  Date paid

Paid via ☐ Online ☐ Post ☐ Bank Transfer ☐

## Keep up to date with the TSA

We'd love to keep in touch with you about our services, support, events, charity news and fundraising. We will not be able to contact you without your permission. Please tick the boxes below so that we can continue to share information and ask for your help.

Post ☐ Phone ☐ Email ☐ Text (SMS) ☐



Complete and send a copy of this form to  
[fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org)

Event name

Event date

Total raised

## Pay in your donations



Online

Visit [www.tuberous-sclerosis.org/donate](http://www.tuberous-sclerosis.org/donate)

Post

Please make cheques payable to "TSA"

Fundraising Team, The Tuberous Sclerosis  
Association, Courtenay House  
Pynes Hill, Exeter EX2 5AZ



Bank Transfer

Account Name: Tuberous Sclerosis Association  
Sort Code: 40-52-40

Account number: 00007047

**tsa**  
tuberous sclerosis  
association



# From Research to Real Life:

I'm raising vital funds for research into  
Tuberous Sclerosis Complex

**Event:**

**When:**

**Where:**

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





# **From Research to Real Life:**

**I'm raising vital funds for research into  
Tuberous Sclerosis Complex**

**[www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)**





**From Research  
to Real Life**  
Transforming TSC Together

# THANK YOU

Together we raised

£ \_\_\_\_\_

We're incredibly grateful to everyone who has donated. It's only through your kindness and generosity that we're able to continue to be here to provide help for today and a cure for tomorrow. **Thank you!**

**[www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)**

# Information about safe and legal fundraising

## **Your fundraising should be fun, but there are some things you should know:**

Charity fundraising is regulated by law to ensure fundraising is legal and safe. You can view the full guidelines from the Institute of fundraising here: [institute-of-fundraising.org](https://www.institute-of-fundraising.org)

### **Your responsibilities**

You must ensure that all donations are paid to us. If any money you raise won't be paid to us, you must inform donors. If you have to cancel your fundraising, you'll need to contact your donors and ask if they're still happy for the money to come to us, if not the donation must be refunded.

### **Permissions**

If you're planning on holding an event in a public place then you'll need permission, either from the local authority, land owner or property owner.

### **Licenses and collections**

Check with your local authority as you may need a licence for selling alcohol, holding a raffle, lottery or auction, or to put up banners or signs in public places. If you're holding a street collection you'll need a license. Please don't carry out any house-to-house or business-to-business collections.

### **Fundraising with children**

If you're under 18, your parent or guardian is responsible for you. You'll need to show them this pack and make sure they're happy with what you've chosen to do. Please ask your parent or guardian to contact us to let us know that you're fundraising for us.

### **Photos, videos and data**

Make sure people at your event know you're taking photos or videos and ask their permission. Don't take or share any photos of children without their parents' permission. You could tell people beforehand or put a poster up at the event. Only collect the data you need, keep it safe, only keep as long as needed and don't share it.

### **Cash handling**

When counting money at events, have two people present if possible. If you're collecting cash in one of our cardboard collection boxes, please transfer it to a secure sealed container or cash box at the end of your event. Please bank any cash collected as soon as possible to the TSA charity bank account.

### **Keep everyone safe at your event**

Think about any risk assessments, first aid, and if you'll need Public Liability Insurance. If you're providing food you'll need to follow the simple guidelines for preparing, handling and cooking food set out by the Food Standards Agency.

**Get in touch if you have any questions:**  
**[fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org)**



# How to get the money you raise to the TSA

## Set up your own personalised online giving page

The easiest and quickest way is to set up a personalised online giving page. Setting up your own page is fast, easy and secure. Once your page is set up you can share the links with your family, friends and colleagues for instant online donations. Just Giving is the TSA's preferred giving platform and you can set up your page by following [justgiving.com/charity/tuberous](https://justgiving.com/charity/tuberous) You can also download a sponsorship form for any offline donations from our website [tuberous-sclerosis.org/fundraising-resources](https://tuberous-sclerosis.org/fundraising-resources)



## Pay directly into our charity bank account

You can pay your fundraising donations straight to our charity bank account. Please include your name as a reference and do let us know that's how you're sending the money, then we can make sure we get in touch to say thank you.



**Bank name: CAF Bank**

**Account name: Tuberous Sclerosis Association**

**Sort Code: 40-52-40**

**Account number: 00007047**

## Pay by debit or credit card

You can give our team a call on 0300 222 5737 to pay in your fundraising donations over the phone or head to our website to pay online [tuberous-sclerosis.org/payonline](https://tuberous-sclerosis.org/payonline)



## Sending your donations by post

Please make your cheque payable to The Tuberous Sclerosis Association and send it to our address below. Please remember to include a note with your cheque telling us your name, home or email address and your fundraising activity.

**The TSA, Courtenay House, Pynes Hill, Exeter, EX2 5AZ**



## Don't forget to tick the Gift Aid box

Please encourage anyone who supports your fundraising who are UK taxpayers and eligible for Gift Aid to 'tick the box' and include their home address and postcode. We can then claim an extra 25p for every £1 donated at no extra cost to the donor.

*giftaid it*

**Getting your donations to us quickly means we  
can put them to good use faster!**

# THANK YOU



If you'd like to find out about other ways to support us, please visit **[tuberous-sclerosis.org](https://tuberous-sclerosis.org)**



Registered with  
**FUNDRAISING  
REGULATOR**

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