

# FUNDRAISING GUIDE



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tuberos scleross  
association

# WELCOME

On behalf of the UK's Tuberos Sclerosis Complex (TSC) community, thank you for choosing to find out more about fundraising for the Tuberos Sclerosis Association (TSA).

Fundraising is a brilliant way to get involved, stay active and have fun while raising vital funds for our work. We're here to help, and this guide aims to give you plenty of inspiration to get you started.

**Thank you so much** for your amazing hard work, enthusiasm and commitment to help people living with TSC and their families. We simply couldn't do everything that we do.



**LOUISE FISH,**  
CHIEF EXECUTIVE

## Who are the Tuberos Sclerosis Association (TSA)?

**The TSA is the only UK charity dedicated to supporting and representing people living with TSC.**

The TSA is here for everyone in the TSC community, including individuals living with the condition, families and entire communities. We help through:



### Support for the community

We support individuals and families affected by TSC, through our dedicated support team, up-to-date information and annual flagship events



### Campaigns

We work to influence NHS policy to ensure that people affected by TSC get the treatment and care that they deserve



### Research

We fund world-class research into the causes, management and treatment of TSC



### Support for professionals

We expand the knowledge and expertise of health, social care and education professionals who help people affected by TSC

To help you decide on your plans, we've developed this guide to give you lots of ideas and tips to kick-start your fundraising.

**Thank you again and good luck!**

# How your money makes a difference

No-one can be prepared for the overwhelming diagnosis of TSC. By supporting the TSA, you're ensuring no-one needs to go through it alone.



Your support is vital in helping the TSA in our work to improve the lives of the hundreds of families in the UK living with the impact of TSC

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*Receiving a diagnosis of a rare condition for a loved one, that not a lot of people know much about, is a scary and lonely existence. When I speak to doctors, many of them have never even heard of Tuberous Sclerosis Complex. You just want to talk to people who know what you're going through, or who can help with questions – The Tuberous Sclerosis Association has been amazing for this.*

*The TSA Support Line is there if you're ever feeling down, or have TSC-related questions. The TSA's website is also phenomenal, with facts and figures that are hugely helpful, as well as stories of other people.*

**TSC Community Member**

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## YOUR IMPACT

**£25**

Could provide a month's worth of welcome packs for people who have received a new diagnosis of TSC, introducing them to the TSA and our support services, ensuring that they are not alone on their TSC journey

**£100**

Could help us develop important materials, like those in our support services, events and campaigns

**£250**

Could provide laboratory equipment for a week's research into the causes, management or treatment of TSC

**£1,000**

Could provide online training materials and advice for social care professionals across the country to help them learn about the unique needs of individuals with TSC

**The TSA receives no government funding and can provide the TSC community with help for today and hope for tomorrow only with your support**

# Fundraising ideas

There are so many fun and exciting ways to raise money for the TSA. We're sure that with a little bit of inspiration, you'll find one to suit you!

There's no better feelings than knowing that you've done your bit to help the TSA's support services and research. Whether its a collection at a football match or you organise your own fun run, it's easy to get involved.

## Ideas that other TSA supporters have took on:

- Head shave
- Mountain climb
- Run 5k every day
- Bungee jump
- Give up chocolate
- Sponsored silence
- Bake sale
- Concert or gig
- Triathlon
- Dress down day
- Pantomime
- Quiz or race night



- Ceilidh
- Barbecue
- Space hopper race
- Garden party
- Easter egg hunt
- Bake-a-thon
- Wine tasting evening
- Bingo night
- Ironman
- Karaoke night
- Coast to coast bike ride
- Golf tournament



Longtime fundraiser **Linda** has collected donations from the generosity of the clientele of her local pub The White Swan in Needham Market, Suffolk, for years, in support of her son Ben who lives with TSC.



*We decided to run 2.6 miles (with our parents) for the 2.6 challenge. We wanted to support the TSA as Alex has TSC, and we raised £3,609 which will fund work by doctors looking at new medicines.*

**Evie aged 8 and Alex aged 11**



**Why not try an idea from the list or choose to start with a simple fundraising idea, which can involve all of your family and friends, like these:**

### Quiz night

Grab your thinking caps and organise a quiz. Invite your friends and play quiz master in your living room, or have a chat with the landlord of your local pub to see if you could hold it there. Charge an entry fee and sell refreshments to raise funds.



### Team challenge

Gather a team of friends and family and enter a run or challenge as a group - training is always more enjoyable when you've got company. As a group you can inspire one another and set a team fundraising target.



### Tea & SCones for TSC

It's really easy to get involved – it's all about drinking tea, eating scones (or any treats you fancy!) and sharing information about TSC and the TSA with your family, friends, neighbours, colleagues, team mates, school friends, club or society pals. At the same time, you will be helping us raise much needed funds so the TSA can continue our vital work.



### TSA Gaming Champion

Calling all gamers! Would you like to combine your passion for gaming with the chance to improve the lives of people affected by TSC? Then become a TSA Gaming Champion. Maybe you'll choose a marathon session of a chosen game, organise a gaming tournament, or even a speedrun? Whatever you do, you'll be changing people's lives!



**Questions? Contact us: 0300 222 5737 / [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org)**

# Planning an event

## The event

Decide what you want to do and think about who you know and what they would be interested in, such as a black tie gala dinner, a five-a-side footie match, a virtual quiz or a cake bake.

## The location

Where are you planning on holding your fantastic fundraising event? Perhaps you could host your event at home, at work, or at a local hotel or community centre?

## The date

Have a think about which date will be best for attendance. Make sure you consider other events and special dates such as national holidays or sporting fixtures which may clash with your event. Give yourself enough time to plan and prepare.

## The fundraising

How are you going to raise as much money as possible? Will you hold a raffle or auction on the day? Will you be selling cakes, drinks and gifts? Will you charge for attendance? Be ambitious but set achievable targets.

## Spread the word

Make sure everyone knows about your event. Download TSA poster templates, sponsorship forms and leaflets about the TSA at [tuberous-sclerosis.org/fundraisingresources](https://www.tsa.org.uk/fundraisingresources) or contact us.

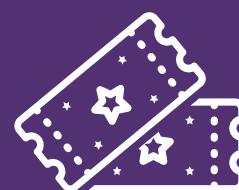
**Once you have a plan for your fundraising you need to inform the TSA, by emailing [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org) or by calling 0300 222 5737**

## The online part

If you use social media then use it to tell people about your event. Don't forget to set up your online sponsorship page and share this too!

## Publicity

Contact your local newspaper, radio and TV station to tell them what you're doing and why. Share your activity at work and mention it to HR - your employer may have a matched funding scheme. For more publicity tips see [page 8](#) of this pack.





## Support

Get in touch with local businesses to ask if they'll donate any prizes for your raffle, or if you can get your venue or catering for a discounted price (or free), as it's an event in aid of a charity. Get friends and family involved and divide the tasks between everyone - you'll be surprised at how many people are willing to help when it's for a good cause.

## On the day

We can provide a range of TSA materials for you to use at your event. If you're looking for t-shirts, collecting boxes, banners or leaflets, just email us: [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org).

## Tell us how it went and send in the cash

Once your event has finished, collect in the money you have raised and send us the proceeds along with any leftover materials.

**We love hearing all about what you've been up to. Please send any updates or pictures to [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org).**

# The Money

**So, you've held your event - we hope you enjoyed it! The hard part is now done, and you just need to pay in your hard-earned money.**

### Send a cheque to our office:

Made payable to: Tuberous Sclerosis Association  
The TSA, c/o Nightingale House,  
46-48 East Street, Epsom,  
Surrey, KT17 1HQ

### Pay directly into our bank account:

CAF Bank

**Account Name:** Tuberous Sclerosis Association

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

**Account number:** 00007047

### Pay by credit or debit card:

#### Either online:

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

#### or over the phone:

0300 222 5737

*giftaid it*

Please encourage your eligible sponsors to make Gift Aid declarations (using their home address). We can then claim an extra 25p for every £1 donated

**We ask that you pay the money you have raised to us within six weeks of your event. If this is not possible, please let us know**

# Sponsorship

**Sponsorship is a great way to raise funds and get family, friends and colleagues involved in what you're doing. You can do this online or offline, or a combination of both.**

Just make sure you let everyone know what you're doing and why. Sharing your personal story can really encourage people to get behind you. You'll be amazed at how supportive and generous people can be.

## The online part

Whatever type of fundraising you're doing, setting up your own personalised sponsorship page online is a quick, easy and secure way for people to support you. Within a few minutes you can create a personal online fundraising page. Email the links and share on social media with all of your friends, family and colleagues for immediate donations.

There are a wide range of online giving platforms, but JustGiving is the TSA's preferred online giving site, sending your donations straight to the TSA. JustGiving takes a fee from each donation and in return they help people raise money, and also take on the costly and time-consuming administration. This means, the TSA can spend more time, energy and money on supporting everyone affected by TSC.

## The offline part

If you've got friends and family who aren't online, or you're going to an event where you know you can ask people to sponsor you, you can also raise money offline.

Download a sponsorship form from [tuberous-sclerosis.org/sponsorform](http://tuberous-sclerosis.org/sponsorform). Alternatively, call or email us and we'll post the forms to you. If you raise money offline, please refer to **page 12** to find out how to return the money to us.

# Promotion

**Gaining publicity for your event or challenge will help you raise funds, while raising awareness of TSC and the fantastic fundraising that you're doing.**

## Press

Your local paper will be interested in your fundraising and why you're doing it (your personal story), especially if you're doing something unusual or quirky. Your story has a greater chance of success if it's sent with a picture, so ask friends and family to take high quality pictures on the day before, during and after your event.

# JustGiving™

[justgiving.co.uk/tuberous](http://justgiving.co.uk/tuberous)

*giftaid it*

**Don't forget to encourage your sponsors to Gift Aid their donation if they're a UK taxpayer**

**- we can claim an extra 25p for every £1 donated**





## Social media

At the TSA we use Facebook, LinkedIn, YouTube and Twitter to post about our latest news, fundraising and research breakthroughs. Join us online and tell us about your events and share your pictures.



/thetsauk



Tuberous Sclerosis Association



@UK\_TSA



Tuberous Sclerosis Association

**Social media is one of the easiest and most powerful ways to help raise awareness of the amazing work that you're doing!**

The more that word is spread about your fundraising, the more awareness you can gain – ultimately, improving the chances of smashing your fundraising target!

### Where to post messages

- Update your JustGiving page and then post on your personal social media pages, but also remember the TSA's pages and other TSC-related groups
- Be persistent with multiple messages, ramping up with more towards the day itself

### Pre, during and post-fundraising messages

- Messages before the event can focus on preparation and planning – such as training or putting the final touches on an event
- Posts during an event can be very powerful – showing you in action! This could include things like posts during the middle of a run, or when an event is in full swing. Make sure you're linking your fundraising page to every post
- After the event, keep the momentum going! Be sure to post your thank you to everyone who has been involved and continue to encourage donations.



### It can be helpful to include

- Your story (including the background of why you are fundraising) Specific details about your fundraising (for example, the date, time and what you are doing)
- The work that the TSA does in improving the lives of people affected by TSC
- Any fundraising target amount that you've chosen
- Using videos and images - they can make a huge difference to the amount of interaction and interest you get in your event



**Remember to share any interesting stories with the TSA, so that we can share these with our community when promoting your work!**

**For more tips on using social media to promote your fundraising visit: [tuberous-sclerosis.org/fundraisingresources](https://tuberous-sclerosis.org/fundraisingresources)**

# Safe and legal fundraising

**It's important to make sure that your fundraising is safe and legal as well as fun and successful! We don't want to make it daunting, but here are a few things you should know.**

## Is it legal?

Charity fundraising is regulated by law. The guidelines below will help to ensure your fundraising is both legal and safe. In addition, full guidelines are available from the Institute of Fundraising ([institute-of-fundraising.org.uk](http://institute-of-fundraising.org.uk)).

### Your responsibilities

In law, you'll be a trustee of funds raised and must ensure that all donations and sponsorship money from your event is paid to the TSA. You must inform potential donors if any of the funds you raise will not be paid to the charity.

Please understand that if you do something that threatens or damages the name or reputation of the TSA we will ask you to stop fundraising.

### Licences

You may require a license for the following:

- Alcohol or entertainment, including recorded music
- Holding a raffle, lottery or auction
- Doing a public money collection
- Putting up banners or signs in public areas

### Collections

You must have a licence or permit from your local authority if you want to hold a street collection or any other collection in a public place. Similarly, if you're fundraising on private property, make sure to ask the owner's permission first.

House-to-house and business-to-business collections (including pubs) also require a licence. However, due to increasing levels of public concern and distrust about these activities, the TSA asks that supporters do not carry out these types of collections on our behalf.

### Publicity material

When you're writing about your event you need to say it is being held '**in aid of Tuberous Sclerosis Association**'.

Please also include our charity number, using these words:

**Registered charity number 1039549  
(England and Wales)  
and registered in Scotland (SC039857).**

Use of the TSA logo is at the discretion of the charity, if you would like to use our logo please contact us.

### Raffles and lotteries

The legislation surrounding lotteries and raffles can sometimes be confusing. Make sure you check the latest information and advice at [gamblingcommission.gov.uk](http://gamblingcommission.gov.uk).

If your raffle lasts longer than 24 hours you will need a lottery licence and printed tickets, which must have certain details on them.

### Under 18s

If you are under 18, your parent/guardian is responsible for you – please show them this pack and make sure they're happy with what you've chosen to do.

### Cancellation of fundraising activity

In the event that a fundraising event is cancelled, it's essential that the fundraiser contacts donors and ask if they're still happy for monies to go the TSA, if not, the donation must be refunded.

**If you have any questions or concerns please don't hesitate to contact the fundraising team on: [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org) / 0300 222 5737**

## Is it safe ?

The TSA really appreciates everything you do to raise money for people with TSC, but we want you to do this safely. Always plan an event carefully and well in advance.

### Risk assessment

We advise you to identify any potential accidents or hazards before you decide to hold the event by completing a risk assessment. The Health and Safety Executive provide some excellent free resources on health and safety at [hse.gov.uk/risk](https://www.hse.gov.uk/risk).

### First Aid

You can get advice from a professional first aid provider such as St John Ambulance or the Red Cross about what first aid you should have at your event.

### Public Liability insurance

The TSA is unable to accept any liability or responsibility for anything that might happen to people or property because of your fundraising activity. If you're planning an event that involves the general public you'll need to get public liability insurance. The TSA suggests you contact your own insurance broker to check that you are covered to undertake your fundraising.

If you're holding an event at a place which has public liability insurance (like a school or workplace) you should check the cover with them in case you need to secure extra cover.

### Food

If you're providing food, you need to follow the simple guidelines for preparing, handling and cooking food set out by the Food Standards Agency. Visit [food.gov.uk](https://www.food.gov.uk) for more details.

If you've asked a caterer to come to the event you must ensure they provide you with a copy of their food hygiene certificate and public liability insurance.

### Environmental consideration

When organising an event please consider the environmental impact of your events or activities and take steps to make sure these are minimised as much as possible.

For example, If using TSA balloons at your event please ensure these are deflated and

placed in the bin following the event. The TSA does not encourage the use of balloons or sky lanterns for releases, please contact us to find environmentally friendly alternatives.

### Are children involved in your event?

As a charity supporting families we take the safety of children very seriously.

If children are going to take part in your fundraising event, there are some things that we would like to bring to your attention for their safety and your protection.

- Do not hold an event which specifically encourages children to attend without their parents
- If children can attend your event, you need to make sure the environment is safe for them. Think about any potential risks such as cars, equipment, doors, toilets and facilities for lost children
- If you plan to hold a crèche/supervised play area for children, you need to seek advice from your Local Authority
- If you've asked other adults or organisations to provide a service at your event for children, (for example, a Punch and Judy show or a bouncy castle) check their insurance safety certificates and ask for references and their DBS check
- Do not take or share photographs of children without their parents' permission

### Cash handling

Advice for handling and counting money at fundraising events:

- Where possible have two people present when money is being counted
- Collect cash using a secure container for example a sealed container or a secure cash box for change
- Bank the money collected as soon as possible

We would love to hear your fundraising plans!  
Contact our fundraising team on 0300 222 5737  
or email [fundraising@tuberous-sclerosis.org](mailto:fundraising@tuberous-sclerosis.org)



This publication was developed by the Tuberos Sclerosis Association (TSA). We have made every effort to ensure that the enclosed information is correct at the time of its design, development and print. However, policy and/or practice may change, and the TSA does not accept liability for any errors or omissions in this publication.

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