

## Thank you for fundraising for SUDEP Action.

SUDEP Action exists to prevent unnecessary deaths from SUDEP (Sudden Unexpected Death in Epilepsy) and other epilepsy deaths.

So many people have been affected by an epilepsy death:

- Three people die from epilepsy each day in the UK
- Adults with epilepsy have a sudden death rate 24 times higher than the general population
- About 1200 people die from Epilepsy each year in the UK

But with your support, we can make a difference.

SUDEP Action uses the money you raise to offer support to people bereaved by an epilepsy death, provide grants for research into SUDEP and other epilepsy deaths, and campaign for more awareness among the public and in the health sector.

We really value our fundraisers, and if you email us ([fundraising@sudep.org](mailto:fundraising@sudep.org)) with details of any fundraising activity you are working on, we will assist and support you as best we can along the way. We have produced this guide to give you some ideas and tips to get you started, but the best way to get ideas is from talking to us. We are here to help, so please give us a call anytime on 01235 772850, or email us at [fundraising@sudep.org](mailto:fundraising@sudep.org) to discuss ideas.

On behalf of those we represent, thank you for fundraising for SUDEP Action.

*Rachel and Katie*

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# SUDEP Action

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## How will we use the money you raise?

No one should have to go through the agony of a loved one dying from epilepsy. With your support, we can help to reduce these tragic deaths through research, education and awareness.

Everyone who needs to know about SUDEP should be having that conversation with their health professional, sensitively, on or shortly after diagnosis.

Every case of SUDEP should be accurately investigated and reported. Every death should be researched and analysed and any lessons learnt shared with the medical community to prevent future deaths. This is what we are striving towards.

This is how we could use the money you raise:

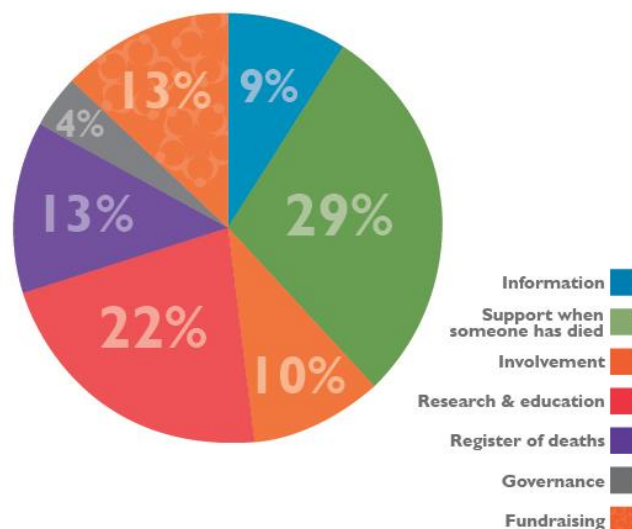
**£100** could pay for a research assistant to analyse one death in depth. Someone to unpick who is at risk of SUDEP and help doctors to act on that knowledge.

**£300** could pay for a bereaved mother to spend vital time talking to an experienced SUDEP Action support worker. Or even, access to someone who can support her through the complex process of an investigation and inquest. This can include practical help, such as getting medical experts to review the post-mortem findings.

**£10,000** could fund an additional research project into the causes of SUDEP.

The work we do is only possible thanks to people like you.

You can be confident that all of our funding is dedicated to work on SUDEP and the prevention of deaths. The following chart is a breakdown of what we spend our money on:



## Holding your own event

It is easier (and lots more fun) to fundraise with a group of people, family, friends or work colleagues. Working with others gives you the opportunity to share skills and knowledge and perhaps you can come up with new and exciting ways to raise money for SUDEP Action. Don't forget, if it moves—sponsor it!

It could be anything you and your friends will enjoy. From a football tournament to a dancathon; a pyjama party to a dinner party or a family fun day – whatever takes your fancy.

## Hints and Tips

**Budget:** It's essential to know your fixed costs (those you cannot recover) and the number of people you need to attract to your event to make a profit. If possible, try and use company resources such as telephone, photocopier or printing facilities, but remember to ask first! You will find in this pack a budgeting sheet, which will help you ensure you make more than you spend.

**Celebrities:** Attracting a personality may seem difficult but look around and see who is appearing at your local theatre at the time of your event, or ask a local footballer. SUDEP Action cannot help organise a celebrity for you but if you know anyone famous that lives in your area, do drop them a line. Ask your contacts in case they know a celebrity. You might be pleasantly surprised.

**Contractors:** Must have relevant experience and insurance and be able to demonstrate they have complied with health and safety regulations.

**Counting cash:** Cash raised should be counted by two independent people to protect fundraisers in the event of a query. You should bank the money (into the charity account) at the very earliest opportunity and within 28 days at the latest. Charity bank paying-in slips will be provided in advance of your event. Please be aware that money stored overnight is not covered by the charity's insurance.

**Entertainment & Booze:** If your event involves entertainment, for example two or more people performing or dancing, you will need a Public Entertainment Licence which is available from your local authority. Also if you are planning to sell alcohol at your event and the venue doesn't already hold a Liquor Licence, you will need to apply three months in advance to the Local Magistrates Court.

**Food:** It is important that anyone selling or handling food does so safely and hygienically. Ideally, at least one helper should have a Foundation Level Food Hygiene certificate. If you are not able to find someone who has this qualification, you may find the following website helpful [www.food.gov.uk](http://www.food.gov.uk).

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**Insurance:** You must ensure you have the necessary insurance; SUDEP Action cannot cover your event under its public liability insurance policy. You might want to also think about what risks there are of things going wrong, for example illness of key people, weather, accidents etc. Some of these things can be insured against. Others, you should have a “just-in-case” plan for each of the key risks you identify.

**Keep it legal:** Fundraising has to be carried out in accordance with the law. You must include the phrase ‘registered charity’ on fundraising materials.

**Photography:** Always take pictures of the event for publicity but please remember to get permission from parents of children.

**Publicity:** Can make or break an event. Although we cannot actually do your PR we can certainly help. We can provide a template Press Release for you to send to your local newspaper telling them about your event, and with your permission we may even be able to feature it via our social media accounts and website.

**Raffles and competitions:** Must be run in accordance with the law. If you have any doubt please refer to [www.gamblingcommission.gov.uk](http://www.gamblingcommission.gov.uk). If you want to run a raffle selling tickets on the day and your prizes are worth no more than £500, then you do not need a special licence.

**Say ‘thank you’:** This is the most important stage of all. Write to everyone who helped with your event. Write to companies, clubs and organisations, the venue and the people that helped before the event and on the day itself. Tell them how much you managed to raise and how that money will make a difference in preventing epilepsy deaths. Hopefully, they will want to help again.

**Venue:** Is there disabled access? Is there sufficient lighting and toilet facilities? Is there adequate parking and will you need car parking stewards? Is there a safety capacity at the venue? If so, do not exceed it. Ensure the venue is vacated at the agreed time, and returned in the order in which you found it and any residents nearby are not disturbed.

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## Once-in-a-lifetime experiences

For the more daring fundraisers there are plenty of opportunities to take part in incredible activities and events- while raising much needed funds for SUDEP Action at the same time! Please email us at [fundraising@sudep.org](mailto:fundraising@sudep.org) or call Nathan and Katie on 01235 772850 for more details on any of the below- and suggestions of further activities.

We have something for everyone!

### For the brave

Doing a sponsored skydive is a truly brave way to fundraise. You choose from three different types of jumps, with the amount of support and guidance from trained instructors that you need. You can jump from up to 10,000 feet into the air!



### For the cyclist

Some of our supporters have also done the London to Paris cycle ride in the past. This is a regular annual event, which gives fundraisers the opportunity to see some of the most beautiful parts of France and the UK, all while raising awareness for the charity.

### For the runner

Another great way to fundraise is to take part in the London 10K race. An event which is popular with SUDEP Action supporters every year, there are always a large group of us who are easy to spot in our bright orange t-shirts! Places have filled up for 2014, but call or email in to get on the waiting list for 2015.



### For the explorer

There are such a variety of treks across the world you can do for SUDEP Action. These include treks in China, Iceland, Peru, Kilimanjaro, the Sahara, Petra, and stunning cycle rides across Vietnam. The treks are tough, but the experience is unforgettable. If you think you might be up for the challenge, let us know and we will back you all the way.

# SUDEP Action

Registered Charity No. 1050459

## Sponsorship Form

In memory of ..... Event:.....

Event Date .....

Name.....

Address.....

Postcode.....

Email\* .....

\* I agree to SUDEP Action contacting me by email.

Full Name	Home Address	Amount in £	<input checked="" type="checkbox"/> If UK tax payer*
John Smith	1 Street, Town, County OX12 9AQ	10	√

\*I confirm that I am a UK Income or Capital Gains taxpayer. I have read this statement and want the charity named above to reclaim tax on the donation detailed below, given on the date shown. I understand that I must pay an amount of Income Tax and/or Capital Gains Tax in the tax year at least equal to the amount of tax that all the charities and CASCs I donate to, will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I have given.

