Please help us to raise vital funds

Your guide to organising/taking part in a successful fundraising event or challenge for The SMA Trust

www.smatrust.org
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Thank you for choosing to fundraise for The SMA Trust and support our current campaign:

Our aim is to:

- Work with partners in the UK, Europe and the US to advance clinical trials for new treatments for SMA
- Ensure that funding is also available for scientists to investigate exciting new avenues as they emerge
- Continue our support of UK centres of excellence for SMA, in particular the new UK SMA Research Consortium

£1.3m is our target to fund the new UK Research Consortium for the next 3 years
About The SMA Trust

We are the only UK charity solely dedicated to funding medical research into SMA and fund 75% of UK charity funded research. The charity was founded in 2003 and since then has funded around £3 million of research projects in the UK, Europe and the US.

Our aim is to be active and progressive in the search for a cure and treatments for SMA.

Research activities include:

- Increasing understanding of Spinal Muscular Atrophy and its devastating effect
- Developing new drugs and therapies
- Laying the groundwork for European clinical trials
- Encouraging the best scientists to work on SMA and related neuro-muscular conditions
- International collaboration

About Spinal Muscular Atrophy

Spinal Muscular Atrophy is a genetic neuromuscular disease, which means it is inherited and affects the nerves responsible for muscle function, especially those around the trunk or spine.

There are 3 types of SMA that affect children. Type 1 is the most common and the most severe, with 95% of children dying before their 2nd birthday. Types 2 and 3 are less severe, but still result in progressive muscular weakness and varying degrees of disability. Type 2 children never walk and rely on electrically powered wheelchairs to achieve independent mobility.

Key Facts

- SMA is genetic, incurable and currently untreatable
- SMA is the leading genetic killer of infants and toddlers
- 95% of babies diagnosed with SMA Type 1 don’t live to see their 2nd birthday
- 1 in every 6,500 births is affected by SMA (about 112 new cases each year)
- 1 in every 40 people is an SMA carrier (around 1.5 million people in the UK)
- The SMA Trust is the only UK charity solely focussed on finding a cure
There are so many different ways you can fundraise for The SMA Trust:

- **Push yourself to the max and take part in one of our challenges**
  Look at our events calendar and see all the wonderful, wacky things you can do. Whether you like walking, running, cycling, trekking or sky-diving (to name but a few), there’s something for you. Just follow the link on the website to register, and check out the advice later on in the pack about setting up your online fundraising page, getting sponsorship, Gift Aid, etc.

- **Organise a 1000 mile challenge**
  It might sound daunting, but it isn’t! Get together with friends, family and colleagues and clock up a cumulative 1000 miles as a team. All you have to do is travel 1000 miles – there’s no time limit and no limit on how many people you get to help you; you certainly don’t have to do it on your own! You could bike, row your boat, walk the dog, take part in a run, do an exercise class, ride your horse or even knit! Everyone can take part and every contribution will help you reach your 1000 mile target.

- **Organise your own event**
  Why not come up with your own great event idea? You could tie it in with the time of year, like Lent or Christmas; or you could choose something that your friends and colleagues particularly enjoy, like a pub quiz or a cookery event. Have a look at our A-Z of fundraising for more ideas.

We’ve tried to provide as much helpful information as possible to get you started but, first and foremost, let us know what sort of thing you’re planning so we can help you from the word go.

Just email info@smatrust.org or phone 01789 801155. We’d love to hear your plans!
get online

setting up an online fundraising page

It’s the quickest, safest, most cost-effective way to fundraise from contacts all over the world and also makes it easy to claim Gift Aid on donations, maximising the funds raised for The SMA Trust.

Many of our supporters choose Just Giving for their online fundraising. Just go to www.justgiving.com, choose the ‘Make your Page’ button and follow the easy steps.

Don’t forget to choose The SMA Trust as your chosen charity. Write a small story and add photos. Check the website for more information on The SMA Trust www.smatrust.org.

Then you can share your personalised webpage with friends and family to encourage them to sponsor you. They will be able to see your target and how much you’ve raised. They can then make a direct donation using a debit or credit card.

Many people use their pages for traditional sponsored events but they can also be used to celebrate a special occasion such as a birthday or wedding, where you ask for donations instead of gifts.

It really should be a very straightforward process, but if you have any problems, email info@smatrust.org or phone 01789 801155.

1 in 6,500

births is affected by Spinal Muscular Atrophy (SMA), that’s around 112 new cases each year

1 in 6,500 births is affected by Spinal Muscular Atrophy (SMA), that’s around 112 new cases each year.
Publicising your event

Apart from inviting people to attend, you may wish to publicise your event more widely, for example in the local media. They are always on the look-out for new stories and usually like receiving the information as a press release because it contains all the information they need. The events that get coverage have usually got a real ‘human interest’ story behind them, so think about how you can focus on this aspect of your story.

Here are some other things to think about:

• What would interest/intrigue the media most about your event? Try and narrow the main focus down to a single focus in your opening paragraph, with other details included as support information.

• Include the WHO, WHAT, WHEN, WHERE and WHY of your activity as clearly as possible.

• Is there anything happening that will make a particularly good photograph?

• Why have you chosen to fundraise for The SMA Trust (a personal connection to someone who has been affected by SMA is always good to emphasise)?

• Add your Just Giving details if appropriate so people can sponsor you or donate.

• If possible, include 1 or 2 quotes from people who are involved or affected. We’re always happy to supply a quote too.

• Include a contact name and details in case they need to follow up for further information.

• If you are supplying your own photograph, remember that you will need to obtain permission from the people involved if they are likely to be recognisable (this is particularly important if children are involved).

You can use our template as a guide for your press release and then email it to your local media. It is always a good idea to find out the name of the right person to send it to whenever possible, rather than a general email address.

It is often best to contact the media directly about your event. However, if you would like more advice contact us at info@smatrust.org or call 01789 801155.

Social media

Don’t forget to use Facebook and other social media to publicise your event too. You can keep people up to date with your progress and include a link to your fundraising page.
There are a number of rules that you need to follow when fundraising or collecting for a charity. We have put together the following guidelines to help you follow the rules.

• All printed materials need to include ‘The SMA Trust’, with the correct logo and our registered charity number 1097765.

• Collecting money from the public
  (i) Anyone collecting money for the charity in a public place needs a Street Collection Licence from the local authority. If you are planning a collection and have the correct permission, please only use official SMA Trust collection tins, which are available from the Fundraising Team.
  (ii) Collections on private premises in public areas (e.g., shopping centres) require the permission of the owner.
  (iii) Door to door collections are illegal without a licence and are not recommended.

• Lotteries and Raffles. If you wish to hold a raffle at your event, you do not need a licence as long as the tickets are sold and drawn at the event and there are no cash prizes. If you wish to sell tickets to the general public over a period of time, you may require a licence and will certainly be required to register your raffle with your local authority. It is important to check with The Gambling Commission or your local authority before proceeding with this kind of public raffle.

• If you are organising a public event that involves music and/or the sale of food and alcohol you may require additional licences. Hired venues usually have their own licences but it is always worth checking this with them, together with their Public Liability Insurance. The SMA Trust’s insurance policy does not cover events that we are not organising ourselves.

• Other information on keeping your fundraising legal can be found on: http://www.hmrc.gov.uk/charities and also from the Institute of Fundraising Code of Practice: http://www.institute-of-fundraising.org.uk/guidance/code-of-fundraising-practice

...and safe

For certain events, you may need to think about issues such as marshalling, first aid provision, informing emergency services, supervision of children, electrical equipment, etc. Helpful guidance can be found in the Events Section of the Institute of Fundraising Code of Practice: http://www.institute-of-fundraising.org.uk/guidance/code-of-fundraising-practice/events

Remember, for larger events it is always a good idea to complete a Risk Assessment!
**What is Gift Aid?**

Gift Aid allows charities to claim back the tax that has already been paid by donors as income or capital gains tax. This means The SMA Trust gets an extra 25p for every £ donated by a UK tax payer.

**How does it work?**

Anyone can make a Gift Aid donation as long as they are a UK taxpayer and pay sufficient tax. The SMA Trust then claims the tax back from HMRC. There is no cost to the donor and Gift Aid can be applied to any amount. For joint donations, we can only claim Gift Aid if we have details of what each person has contributed and they have completed their own Gift Aid declaration.

**What you need to do**

Ensure your sponsors/donors sign and date the Gift Aid box on the sponsor form and fill in their home address (work addresses are not acceptable). To ensure that our Gift Claim is considered valid, it is important that sponsors fill in their own details (rather than you doing it for them) and that you only use SMA Trust sponsorship forms. You should then send the form(s) to us with your donation.

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**An extra 25p for every £1 donated is received by The SMA Trust by asking donors to sign up to Gift Aid**

**Can Gift Aid be claimed on all donations?**

In addition to stipulations about donor’s UK tax status, there are a few other exceptions. Donations cannot be ‘Gift Aided’ if:

- The donor is receiving a ‘substantial benefit’ from taking part in the event, e.g. an overseas flight, a meal, entertainment, etc. If you are receiving a ‘benefit’ from an Adventure fundraising event this may have implications on the person/s sponsoring you to claim Gift Aid. Please see guidance on the HMRC web site: [http://www.hmrc.gov.uk/charities/gift_aid/rules/adventure.htm#4](http://www.hmrc.gov.uk/charities/gift_aid/rules/adventure.htm#4)

- The SMA Trust cannot claim tax back on company donations.
Gift Aid Declaration
For past, present & future donations

Please treat the enclosed donation of £

As a Gift Aid donation and all qualifying gifts of money made
Today ☐ in the past 4 years ☐ in the future ☐

Please tick all boxes you wish to apply
I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charity that 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 give on or after 6 April 2008.

Donor’s details

Title: First name or initial(s):
Surname:
Full home address:

Postcode:
Email:
Telephone: Mobile:
Date:
Signature:

Please notify the charity if you:
Want to cancel this declaration
Change your name or home address
No longer pay sufficient tax on your income and/or capital gains
If you pay Income Tax at the higher or additional rate and want to receive the additional tax

The SMA Trust, 1c Atherstone Barns, Atherstone on Stour, Stratford-upon-Avon, Warwickshire CV37 8NE
Registered Charity Number: 1097765
Gift Aid What is it?
Using Gift Aid means that for every pound given, the charity will receive 25p from the Inland Revenue, helping your gift go further at no cost to the donor. Please tick if you want all donations you have made since 6th April 2008 and all donations you make in the future to be eligible for Gift Aid. You understand that you must pay an amount of UK income tax and/or capital gains tax at least equal to the tax that the charity recovers on your donation.

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**Sponsorship Form**

| Name of Participant: |
| Event: | Event Date: |

Please sponsor me. I am raising funds for the SMA Trust which funds research into a cure and treatments for Spinal Muscular Atrophy.

*Gift Aid: Please detail your full name, address and postcode and tick the box to state you have read the declaration above and would like the tax claimed back on your donation. Sponsors must complete their own details – forms in the same handwriting are not valid for Gift Aid purposes.*

<table>
<thead>
<tr>
<th>Full Name</th>
<th>Home Address*</th>
<th>Postcode*</th>
<th>Gift Aid*</th>
<th>Amount Paid £</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
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<td>Please tick</td>
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</tbody>
</table>

Total Donations Received £

Please make cheques payable to:
The SMA Trust and send to 1c Atherstone Barns, Atherstone on Stour, Stratford-upon-Avon, Warwickshire CV37 8NE
Registered Charity Number: 1097765
Other ways we can help you

We can provide promotional materials and SMA Trust branded merchandise, and can also supply collection tins and banners. Please use the order form to let us know what you need. You can also use the form to let us know if you would like someone to come and talk about The SMA Trust at your event. We are a small team and this isn’t always possible, but we like to try and make the most of opportunities to thank people in person and tell them about more about our work.

Name:
Address:
Postcode:
Telephone: Mobile:
Email:

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<tr>
<th>Item</th>
<th>Size</th>
<th>Size Required</th>
<th>Number</th>
<th>Cost</th>
<th>Total Amount</th>
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</thead>
<tbody>
<tr>
<td>Leaflets</td>
<td></td>
<td></td>
<td></td>
<td>FOC</td>
<td></td>
</tr>
<tr>
<td>Posters*</td>
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<td></td>
<td></td>
<td>FOC</td>
<td></td>
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<tr>
<td>Newsletters</td>
<td></td>
<td></td>
<td></td>
<td>FOC</td>
<td></td>
</tr>
<tr>
<td>Collection Tins</td>
<td></td>
<td></td>
<td></td>
<td>Available to borrow</td>
<td></td>
</tr>
<tr>
<td>Collection Buckets</td>
<td></td>
<td></td>
<td></td>
<td>Available to borrow</td>
<td></td>
</tr>
<tr>
<td>Balloons</td>
<td></td>
<td></td>
<td></td>
<td>FOC</td>
<td></td>
</tr>
<tr>
<td>PVC Banners</td>
<td></td>
<td></td>
<td></td>
<td>Available to borrow</td>
<td></td>
</tr>
<tr>
<td>Thunder Sticks</td>
<td>S-XL</td>
<td>Pack of 2</td>
<td></td>
<td>FOC</td>
<td></td>
</tr>
<tr>
<td>Cotton T-Shirts</td>
<td>S-XL</td>
<td></td>
<td></td>
<td>£15.00</td>
<td></td>
</tr>
<tr>
<td>Child’s Cotton T-Shirts</td>
<td>One size</td>
<td></td>
<td>£10.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mens Performance T-Shirt</td>
<td>S-L</td>
<td></td>
<td>£15.00</td>
<td></td>
<td></td>
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<tr>
<td>Ladies Performance T-Shirt</td>
<td>S-L</td>
<td></td>
<td>£15.00</td>
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<tr>
<td>Running Vests</td>
<td>S-XL</td>
<td></td>
<td></td>
<td>£15.00</td>
<td></td>
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<tr>
<td>Cycle Tops</td>
<td>S-XL</td>
<td></td>
<td></td>
<td>£25.00</td>
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<tr>
<td>Wristbands</td>
<td>Adult/Child</td>
<td></td>
<td>£2.00</td>
<td></td>
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<tr>
<td>Key Rings</td>
<td></td>
<td></td>
<td></td>
<td>£2.00</td>
<td></td>
</tr>
<tr>
<td>Cotton Bracelets</td>
<td>One size</td>
<td></td>
<td></td>
<td>£2.00</td>
<td></td>
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<tr>
<td>Enamel Lapel Pin</td>
<td></td>
<td></td>
<td></td>
<td>£1.50</td>
<td></td>
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</tbody>
</table>

TOTAL £

Please make cheques payable to: The SMA Trust and send to 1c Atherstone Barns, Atherstone on Stour, Stratford-upon-Avon, Warwickshire CV37 8NE

* Various designs including blank versions to add details of your own event. Please allow 14 days for delivery. For delivery outside the UK please call first.
Paying-in

Paying-in details

There are several ways you can send us your donation(s). If you are in any doubt, just contact us at info@smatrust.org or call 01789 801155.

Pay online on our website
You can pay directly on our website. Simply go to www.smatrust.org/donate and follow the instructions. The money will be transferred into our account.

Cheque
Please make cheques payable to The SMA Trust and send to:

The SMA Trust
1c Atherstone Barns
Atherstone on Stour
Stratford-upon-Avon
Warwickshire
CV37 8NE

Please include a note with your name and details of how the money was raised.

Bank payment/transfer
You can pay directly into our bank account, either by going into a Lloyds branch or else transferring the money online. Our account details are as follows:

Bank: Lloyds
Sort code: 30 98 26
Account No: 02628431

Please include your name and/or Team as a reference and let us know that you’ve made the payment.

Don’t forget to send us a Gift Aid form if appropriate, either with your cheque or separately if you are transferring the funds online.

Online fundraising page
If you have already set up an online fundraising page such as Just Giving, you can pay the money directly onto that, which will be added to your total and will then come to us automatically, albeit with the usual commission deducted.

25% of babies born to 2 carriers will be affected by Spinal Muscular Atrophy (SMA)
We depend entirely on people like you fundraising on our behalf to be able to continue to fund ground-breaking research into finding a cure for Spinal Muscular Atrophy. Every £ you raise makes a huge difference and we simply could not exist without you.

An average research project costs £70,000 a year, which might sound an enormous amount, but there are many different elements that go into that total, such as the cost of a Project Engineer, laboratory equipment, chemicals etc. In addition we fund Fellowships, which are usually for 2 years and any amount raised can make a big contribution to those costs.

So thank you again for all that you do. Don’t forget to let us know what you’re doing and remember that we’re here to help in any way we can.
A-2 of Fundraising ideas

A Abseil, Aerobics, Afternoon tea party, Air Miles, Arts & crafts stall or exhibition, Auction

B Ball, Balloon race, Barbeque, Barn dance, Battle of the bands, Beer festival, Bike ride, Bingo, Boat race, Book sale, Bring & Buy sale, Burns Night

C Cake stall/sale, Car boot sale, Carol concert, Car wash, Casino evening, Clay shoot, Cocktail & canapé party, Coffee morning, Collection tins & buckets, Concert, Cookery demonstration, Cotswold Way Challenge, Cricket match

D Dance, Disco, Dog show, Dragon Boat race, Dress down day

E Easter egg hunt, Egg & spoon race, Expedition

F Face painting, Fashion show, Fete, Film night, Fireworks, Flower arranging demo, Flower show, Football match, Fun Day, Furniture sale

G Garage sale, Garden party, GIVE AS YOU LIVE, Go-karting, Golf tournament, Gymkhana

H Halloween party, Happy hour party, Head shave, Hippy day, Hoopla

I Ice skating, Iron-a-thon, It’s a Knockout

J Jazz festival, Jelly in the welly, Junk stall

K Karaoke, Kite race, Knitting competition

L Ladies lunch, Line dancing

M Marathon, Medieval evening, Mile of pennies, Monkey march for kids, Murder Mystery, Music concert

N Name the..., Nature trail, Non-uniform day

O Onesie Challenge Open garden, Opera night, Outward bound/ climbing

P Paintballing, Pantomime, Parachute jump, Parties, Personalised gifts, Pet show, Plant a tree

Q Quiz night

R Race night, Raffle, Ramble, Recipe book, Recycle cartridges/mobile phones, Road run

S Safari Supper, Salsa night, Scavenger hunt, Silly sports day, Sit in a bath, Skittles day, Skydiving, Slimming, Space Hopper racing, Swap shop, Swear box, Swimathon

T Table-top sale, Talent show, Toddle, Tombola, Toy sale, Treasure hunt, Treks

U Underwear party, Unwanted gift sale

V Variety show, Vehicle rally

W Walks, Water sport, Waxing, Welly throwing, Wine tasting

X X-factor evening, Xmas fairs

Y Yacht race, Yard of Ale, Yogathon

Z Zorbing, Zodiac evening, Zumbathon

get in touch

For further advice and information contact us at info@smatrust.org or phone 01789 801155.