

# Stop MS Q&A

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### 1. About the Appeal

## 1.1. When we say stop MS, do we mean find a cure?

The Stop MS Appeal aims to find treatments that slow or stop disease progression for everyone living with MS. That doesn't mean finding a cure right now, but it does mean a future where nobody needs to worry about disability getting worse.

In the future, we believe people with MS will be prescribed a combination of therapies that work on multiple aspects of the condition, stopping immune attacks and relapses, protecting nerves from damage, and regenerating lost myelin. Finding these treatments will prevent disability progression, prevent the need for a wheelchair, and could transform the lives of people living with MS.

### 2. Supporting the Appeal

### 2.1. What fundraising materials are available?

There are <u>fundraising packs available</u> for My MS Walk and Cake Break, and there is a range of other resources available to support fundraising efforts for the Stop MS Appeal. For more ideas of ways to get involved, head to the <u>Team Stop MS</u> section of the website, email our fundraising team at challenge@mssociety.org.uk, or call 0300 500 8084.

# 2.2. What other materials are available to help share the Appeal?

On the <u>Team Stop MS</u> webpage you'll also find a range of resources to use on social media. And on <u>VolWeb</u>, you'll find our '<u>Research Story</u>', a short document explaining the research we are funding through the Appeal and why we are confident that with the right investment, we can set the course to revolutionise MS treatment.

# 2.3. What merchandise will be available and where can I get it?

There is some merchandise available through the <u>online shop</u>, such as collection boxes and lanyards, to help you get involved. Head to the online shop and log in with a local group account to access them.



# 2.4. Does the money my local group raises have to go to research?

No, you don't have to specifically raise money for research, and you don't have to restrict funds unnecessarily. We understand that our groups will need to continue fundraising to support their day to day activities, so retaining flexibility on how funds are used is important.

If your group is able to support the Stop MS Appeal at some point, you could do this in two ways:

- 1. Raise money specifically for the appeal
- 2. Give excess reserves towards research

# 2.5. Can my local group give money from our bank account to the Appeal?

Yes, absolutely. People give money to the MS Society for it to be used, not to be left in a bank account. So we would love you to use them! If you feel you are meeting the local needs of people living with MS then any additional funds should be returned to the national office, so they can be used on research or other national projects.

#### 3. About the research

To find out even more about the MS research we are funding through the Stop MS appeal, take a look at the 'Research Story' on VolWeb that explains everything you need to know.

### 3.1. Why are we so confident we can stop MS?

Over the past 20 years MS research has led to major advances in treatment. No other neurological condition has made such great strides. We're now in a position to build on that success and change what it means to live with MS.

Until now we've been able to use our expanding knowledge of the immune system to help people with relapsing MS. But to help people at every stage of MS we need to stop MS progression, which is far more complex. Research in recent years has transformed our understanding of progression and how the body responds to MS damage. Knowing exactly what goes wrong in MS is enabling us to develop strategies to stop that from happening – meaning treatments that slow or stop disability for everyone with MS, including those with all progressive forms of the condition, are now a very real prospect.



We're confident that, with the right investment, we can set the course to revolutionise MS treatment. By the year 2025 we will have new treatments for progressive MS in end stage clinical trials. We do believe we can stop MS.

# 3.2. Why are we calling the campaign 'Stop MS' if we haven't found a cure?

When we talk about stopping MS, we are talking about our goal of stopping the build-up of progression and disability that happens over time. This means potentially preventing the need for a wheelchair and helping people with MS keep their independence. We believe finding treatments for everyone – including everyone living with progressive MS – will be a major development, which is why we're really excited to share our plans to achieve this. We are not suggesting that we have found a cure.

### 4. About the advertising campaign

### 4.1. How did you choose the people in the advert?

The advert is designed to show people the realities of living with MS, including the daily struggles and challenges, so we can highlight the importance of this major investment in research. It features four people living with MS, who are all at different phases of their life and the condition – some live with relapsing MS, and some with progressive. We did not want to use actors.

We also wanted to focus on telling powerful stories about MS progression that would help us convey the impact MS can have.

We are producing a range of other videos and blogs as part of the appeal that we'll be promoting on our channels over the coming months. These aim to represent a range of symptoms and experiences, and include Charlotte, who has been recently diagnosed with MS.

#### 5. Finances

### 5.1. Where will my donation go?

We need to raise £100 million over a ten year period to find treatments for everyone with MS. The money will fund critical research projects including:



- A first-of-its-kind MS clinical trials platform to find new drugs for people with progressive MS, quickly and effectively. This is currently being designed and developed by an Expert Consortium of the brightest minds in science
- Funding more innovative and ground-breaking projects in the UK through our responsive grant round and fellowships, created to support the best MS researchers
- Supporting vital research infrastructure and programmes like the MS Society
  Tissue Bank, the MS Society Cambridge Centre for Myelin Repair, the MS
  Society Edinburgh Centre for MS Research, and the UK MS Register, which
  enable amazing MS research to happen

# 5.2. What difference has been made by the money raised so far?

The money we've raised so far has provided vital research funding. This includes trials to help determine what kind of treatments are most effective to treat progressive forms of MS, and new research projects looking at ways to repair myelin.

The money we have raised so far has been crucial in bringing about important advances in our understanding of MS, and could have a tangible impact on the experience of people living with the condition.

Thanks to the Stop MS Appeal, we've been able to co-fund an exciting multimillion pound phase 3 trial of the drug Simvastatin. The trial will recruit over 1,000 people with secondary progressive MS across the UK and if it is successful, Simvastatin could be among the first treatments available for secondary progressive MS.

We've also been able to invest in important projects that will enable us to deliver a first-of-its-kind MS clinical trials platform. This includes supporting the UK MS Register which will support recruitment to the trial.

# 5.3. Can I choose what research project my money is spent on (e.g. stem cell therapy)?

To enable us to have flexibility on how funds are used we would prefer they were only restricted to research or broad areas of work (such as myelin repair or stem cells, for example). Restrictions to specific projects will be available for larger donations exceeding £5,000. If the project you would like to fund is already being funded, you will need to tell us what other projects you would like funded.



# 5.4. Is money that would normally be raised to support other activity being diverted to research as a result of the appeal?

We are still investing in policy work and campaigning, and continue to provide support through our helpline, grants, and local groups. We don't plan to divert any money from existing activities, and plan to keep the amount of general funds we would normally spend on research each year (about £3 million) at the same level.