MS Society

# We're stopping MS

Our short guide on our **Stop MS Appeal**, from the research to the people who are making it happen.

STOP

Today is the most of has ever been for the second s management of r We know what peo — no relapses, r of disability and — and we kno Help us raise for ground-bre and we can m Together, we are to sto

- exciting time there the treatment and nultiple sclerosis.
- ople with MS want to accumulation I no uncertainty w how to do it.
- £100 million aking research ake it happen.
- e strong enough p MS.

# More than 100,000 people in the UK have multiple sclerosis, and many hundreds more have a friend or family member with the condition.

#### **Stop MS Appeal Board members:**

Sir David Walker

Sir Vernon Ellis, Chairman
Kate Hely-Hutchinson, Deputy Chairman
Sir David Bell
Donald Cameron of Lochiel
lain Conn
Josh Krichefski
Nicholas Maclean
Sir Peter Middleton
Sir Geoffrey Owen

#### MS Society leadership:

Nick Winser, Chairman of the Board of Trustees Nick Moberly, Chief Executive

Dr Emma Whitcombe, Executive Director of Fundraising

Over the past 20 years, MS research has led to major advances in treatment development. No other neurodegenerative condition has made such great strides and we're in a unique position to build on that success to continue to transform the lives of people with MS.

We can build on the significant achievements we've made, but to do so requires a major financial investment in research."

#### **Professor Jeremy Chataway**

**Consultant Neurologist** 

MS researcher and co-leader of the ground-breaking MS SMART clinical trial

Over 100,000 people live with multiple sclerosis (MS) in the UK, and many hundreds more have a friend or family member with the condition. In the UK alone, there are 14 new diagnoses every day — that is 5000 people a year. MS damages nerves in your body. It's unpredictable, and different for everyone. It can cause problems with how people walk, move, see, think and feel.

If someone close to you has MS, you already know there is no cure for this chronic neurodegenerative condition. It destroys lives. It devastates families. It hits people in the prime of life, and shatters dreams for the future.

Research has got us to a critical point, and we must act now. Today we have treatments that can reduce relapses and slow the worsening of disability in relapsing forms of MS. But that is not enough. We want to stop MS in its tracks for everyone, including those with progressive MS. Research successes — many funded by us — mean that we now have an unprecedented opportunity to develop a programme of effective treatments that could slow or even stop the damage caused by MS. But we simply do not have the money to make it happen.

Our Stop MS Appeal needs to raise £100 million to find treatments for everyone with MS. We can see a future where nobody needs to worry about MS getting worse.

Your support can dramatically improve the management of MS symptoms and potentially bring the condition to a halt. By 2025 we plan to be in the final stages of testing a range of treatments for everyone with MS.

Today, nothing can stop MS. Tomorrow, we will. We believe we can stop MS, and you can help.

# The impact of MS

There is currently no cure for MS. Yet the toll it takes on those with the condition and their families is almost immeasurable.

These are the statistics that put MS in the UK into perspective:

# 100,000+ people living with MS

one of the highest rates of MS in the world

# £3.3 to £4.2 billion

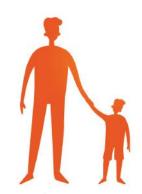
the estimated cost of MS to the UK economy each year

# 125 children each year more children experience an MS-like attack than anywhere else in the world

## 27% employed

only about a quarter of those with MS are in employment five to nine years after diagnosis

#### Chances of having MS if you...



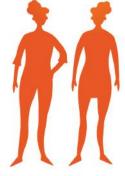
...have a parent with MS

1 in 67



...have a brother or sister with MS

1 in 37



...have an identical twin with MS

1 in 5

# 3 times higher

— triple the number of women develop MS compared to men

# 14 every day

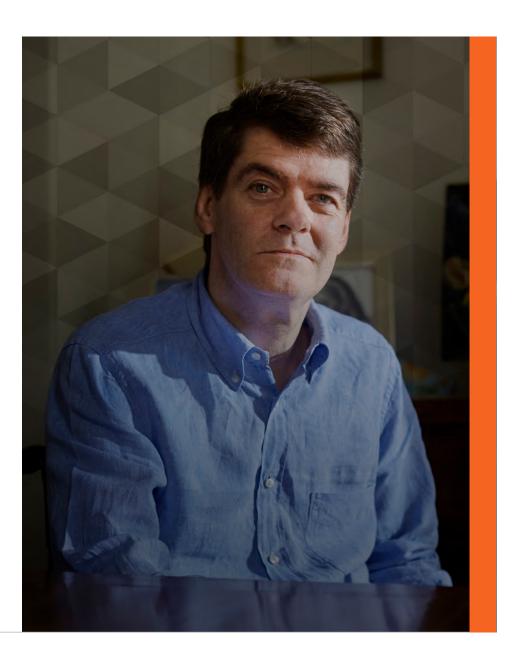
the number of people diagnosed with MS

"To do nothing now would mean missing a unique moment in history when we have a real opportunity to change people's lives."

## Nick's Story

Nick is 60 years old and is from Kent. He is Kate's husband, and dad to Rosie, Harry and Lily. He battles MS every day, a disease that has robbed him of the life most of us take for granted.

Our Stop MS Appeal will pay for research into new treatments to prevent debilitating nerve damage.



"Fifteen years ago, when I was 45, I started to lose control of my body. It was a shock, but nothing could prepare us for what lay ahead. The unpredictability and resulting anxiety made even the most mundane family activity fraught.

It robbed us of all spontaneity and changed all of our lives forever. I felt the profound effects of isolation as I was confined to a wheelchair and felt frustrated as I lost control of my body. Be in no doubt about the corrosive and destructive effects of MS.

I know from personal experience that MS is cruel. It attacks at random, and at first the symptoms can be invisible. Gradually your body becomes less able to perform, and mobility is increasingly limited.

It's common for MS to ruin relationships, cause family breakdowns, lead to unemployment and have a serious impact on mental health. I'm grateful for the support of my family, but regardless of how you cope, the effects are devastating.

The message is clear and simple: Stop MS. The time is now for a significant step change in funding, to bring an end to the pain and psychological damage so many people are suffering. You have the power to keep our hope alive, and the hope of thousands of other families like us.

To do nothing now would mean missing a unique moment in history when we have a real opportunity to change people's lives. Please help." "He used to stand so proudly, so confidently, so blissfully unaware. Things couldn't be more different now. My dad used to soar over me like a shield. Now, I am his.

The spontaneity has gone, replaced with times of doubt and despair.

But he has hope."

Nick's 20 year old daughter, Lily



## Our plan to stop MS

"With a dramatic increase in investment over the next 10 years, there is a genuine prospect to transform treatment for everyone with an unprecedented approach."

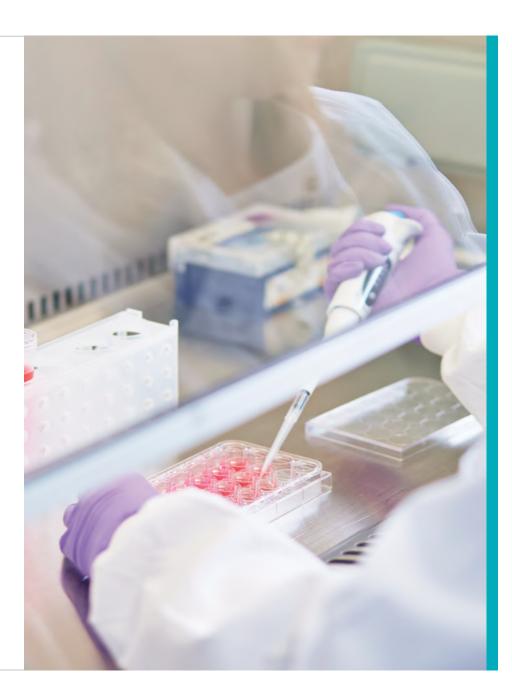
We can deliver therapies that will work together to stop immune attacks, protect nerves from damage, and regenerate lost myelin."

#### **Professor Alan Thompson**

**Consultant Neurologist** 

Chair of Scientific Steering Committee of the Progressive MS Alliance and Chair of the Stop MS Ambassadors Group







#### Research focus

\_

## Progression

Together we will slow and stop progression of MS with advanced techniques that repair myelin and protect nerve cells from damage.

This research is pivotal to our drive to stop MS.

We are developing a radical new approach to run the most innovative clinical trials programme for MS in the world. We will build rolling, adaptive clinical trials focused on neuroprotection and techniques to repair myelin. This will allow us to test several repurposed drugs at once. The trial will be the first of its kind in the world and will enable researchers to maximise resources, truly work collaboratively and accelerate research results.

This approach will help find treatments to slow or stop the progression of MS sooner.

"Here in the UK we are among the world leaders in myelin repair thanks to the investment that the MS Society has made."

**Professor Robin Franklin**Director of the Cambridge Centre for Myelin Repair

We must investigate whether aggressive drugs given earlier are more beneficial in the long term, and determine if vitamin D supplements are an effective and safe treatment.

#### Research focus

\_

### **Treatment**



Some evidence suggests that early treatment with aggressive disease modifying therapies (DMTs) improves outcomes for people with relapsing MS. But we do not yet know whether this is more beneficial in the long term.

Aggressive therapies have a greater risk of serious side effects and people with MS need to know if these are worth it. We will fund underpinning research to answer these questions, which could lead to building a clinical trial.

We know that vitamin D plays a role in regulating the immune system, but we do not know if supplements are an effective treatment for people with MS. We want to find out:

- if it could reduce relapses or slow the progression of disability
- what levels are necessary for a worthwhile effect
- whether long-term supplementation would be safe



#### Research focus

## Prevention

Your generosity will help unravel the mystery of what causes MS. It is vital we understand the many different factors that influence someone's chance of developing the condition.

There are many theories about the underlying cause of MS, but we simply do not know for sure.

It is believed to be due to a complex interaction between genetic and environmental factors. In the past five to ten years, research has made significant progress in understanding the genetics of MS: we now know that at least 110 genes are linked to the condition. This has given us important insight, but it is not the whole story.

Studies in identical twins have proven that environmental factors also play a role.

Research into environmental factors is ongoing, but several have been implicated already, including infection with a virus like Epstein-Barr and lifestyle factors such as smoking. More needs to be done to understand how these factors fit together and influence an individual's risk of developing MS.

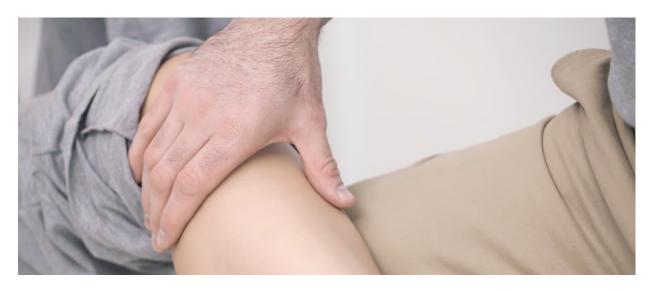
We need to learn more before we can develop and test prevention strategies. We must continue supporting research into the causes of MS, funding work through our open grant round and programmes such as the MS Society Tissue Bank. We will also hold an international symposium on prevention to develop research recommendations in the area.

#### Research focus

\_

# Symptom management

We must give those with MS the support and treatments they need to manage pain and other symptoms, including hugely debilitating fatigue.



People affected by MS tell us they want more research into mobility, physiotherapy, pain, memory and thinking, so they can manage their lives.

Fatigue is the most commonly reported MS symptom and often the most disabling. Some say it is like 'an elephant sitting on your chest.' We have had success with practical fatigue management programmes, but the causes are poorly understood. We must improve the way we define and measure fatigue to help evaluate the effectiveness of treatments, and improve access to them.

Helping people manage their MS requires training and support, and a health and social care system that recognises patients as true partners in their own health. Our strong links with research communities, health professionals and people affected by MS have already created a multidisciplinary approach to tackling this.

But we must do more. We have established a multidisciplinary working group through our Clinical Trials Network to further develop research plans in this area, with the potential of commissioning research within the year.



# Why now and why us?

Today we have 11 licensed treatments that can reduce relapses and slow the worsening of disability in relapsing MS. What we have achieved is incredible. But it is not enough. We must now capitalise on this progress and stop MS.

There is no proven treatment for progressive MS, where symptoms develop unpredictably and disability increases. Finding an answer is urgent and vital.

As the largest not-for-profit funder of MS research in Europe, we have the track record to make it happen. We can build on previous successes including:

- funding Professor Ian McDonald, who revolutionised diagnosis with the 2010 McDonald MRI criteria
- investing in an early stage trial of Lemtrada, now one of the most effective disease modifying therapies for relapsing remitting MS
- backing a clinical trial of botox for bladder management in MS, now licensed in the UK, USA and 13 European countries
- supporting UK researchers involved in the International MS Genetics Consortium, which has discovered around 110 genes linked with MS.



This work has created an unprecedented opportunity that means the next breakthroughs could be transformational. It is time to act.

#### Commitments

# Quality research

We are at the forefront of bringing together the best scientists from around the world.

We have invested in key institutions led by world-renowned researchers, including the MS Society Cambridge Centre for Myelin Repair, the MRI unit at the Institute of Neurology and the MS Society Edinburgh Centre for MS Research. These will be central to delivering the Stop MS research programme.

All research funded by us is subject to rigorous peer review and processes that ensure the highest standards. Each project, even those from world-class institutions, is reviewed for quality and relevance by international, independent experts and people affected by MS.

Our research strategy has been set by people affected by MS and health care professionals, so we will address the areas that are most important to people living with MS today.





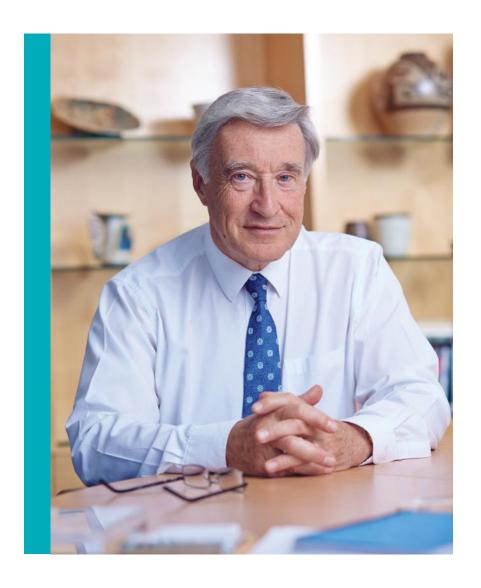




"An end to the devastating impact of MS is within our grasp.

To put it quite simply, raising £100 million for MS research will change the course of the disease, transforming the wellbeing, outlook and quality of life for everyone affected by MS."

**Sir Vernon Ellis,** Stop MS Appeal Board Chairman



"I am personally dedicated to this important cause and excited about the possibilities that lie ahead. The scientists, the MS community and the MS Society are ready to deliver a step change in the treatment and management of the condition. But we also need exceptional people like you, philanthropic visionaries, to come on this incredible journey with us.

By supporting Stop MS, you will be helping to find answers to the most important questions in MS science and give the 2.3 million people across the world with the condition the hope of a better future.

With your help we can make medical history. Together we can Stop MS."





## To discuss how you can transform the lives of people with MS, please contact:

**Supporter Care Team** 

Tel: 0300 500 8084

Email: supportercare@mssociety.org.uk

MS Society, MS National Centre, 372 Edgware Road, London, NW2 6ND

#### mssociety.org.uk

