



mnda

motor neurone disease  
association

A gift in your Will could  
help create a world

free

from MND.

Gifts in Wills help support  
David and Helen while  
researchers look for a cure.

Gifts in Wills

# Let's be the generation that beats MND.



**Our vision is a world free from MND – and that's a goal I believe we will one day reach.**

As CEO of the MND Association, I have been privileged to see the selfless dedication of the MND community and their determination to find a cure.

Those who have remembered the MND Association in their Will have made a huge difference to the work we have been able to fund – and this year we are funding more research than ever. But the fight continues, and we must do more.

We must build on this work to drive forward the research that will deliver effective treatments; to collaborate to ensure people have the coordinated care and support they need; to campaign for better quality of life and to amplify the voices of people affected by this brutal disease.

No one person or organisation can do this on their own – thank you for joining the community and for making the incredible decision to include the MND Association in your Will. We couldn't do it without you.

Thank you.

A handwritten signature in black ink, appearing to read 'Tanya Curry'.

Tanya Curry, CEO

MND Association funded researcher Dr Guillaume Hautbergue who is developing a potential new therapy for people with C9orf72 MND.

**We understand the challenges ahead. Let's take them on together.**

**5,000+**

people in the UK are living with MND at any one time. There is currently no cure.

**6**

people receive an MND diagnosis every single day in the UK.

**1/3**

of people living with MND lose their life within one year of diagnosis and more than half within two years.

**100+**

research projects funded each year to help beat MND. It's working, we're making so much progress.

**Gifts in Wills form over a third of the income we spend on research, care and campaigning. A gift in yours could help us do so much more.**

# “You could help beat MND, with a gift in your Will.”

David was diagnosed with MND in 2012. He and his wife Helen have faced the diagnosis head on, while raising funds and campaigning for others with MND.

“Even in the early 2010s, it was hard to get a definitive MND diagnosis. I'd been asking questions about my health for two years. My arms and hands went first. My neck muscles got increasingly weaker until I couldn't lift my head.

I was referred to my neurologist around mid-2011 which was when the alarm bells started to ring. They thought MND was a possibility, so they began the process of excluding other conditions. By September 2012 it was official. I was referred to King's MND Care Centre.

The support I received has been amazing. The Association helped fund the specialist nurse who visits me at home. They even funded the equipment that helps me maintain my independence.

In fact, gifts in Wills help fund much of the support the MND Association offers. One day, gifts in Wills will help fund the research that beats MND too. Until then, I'm determined to give something back to help fight this disease.

I fundraise, I take part in research. I've been involved in campaigns ranging from access to communication equipment and securing much-needed benefits.

Now I'm sharing my story with you. Because if it helps convince you to include a gift in your Will – you'll be bringing that day closer. Believe me, I know what that would mean to the next generation of families affected by MND.”

Thank you.  
David.



**With a gift in your Will, you could help make sure that one day nobody has their life cut short by MND.**



**“Please consider leaving a gift in your Will today. You'll help bring hope to those diagnosed with MND in the future.”**

**David**

Dr Tatyana Shelkvnikova is investigating a molecule which is thought to be abnormal in MND. Her work could lead to new possible treatments for MND.

With

research

we'll find a cure...

**“Researchers have learnt more about MND in the past five years than in the previous century. We must sustain this momentum.”**

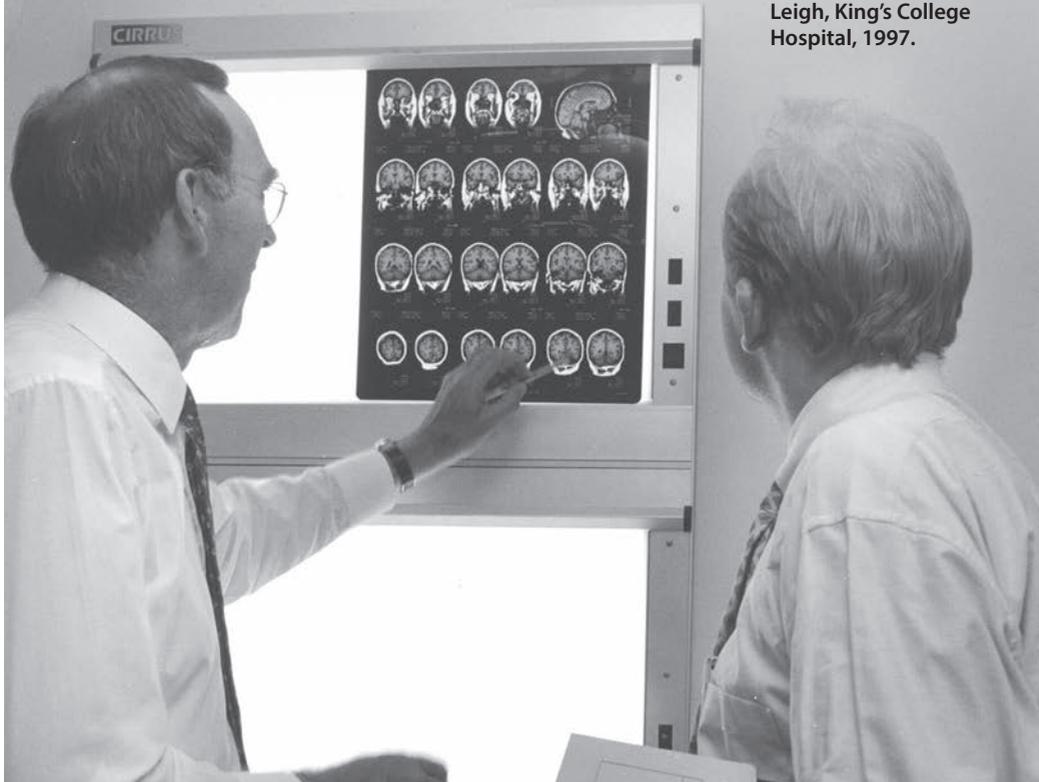
“The MND Association has a longstanding commitment to research since our first research project in 1980, less than a year after the charity was founded. We now support over 100 vital research studies in the UK and around the world, with a funding commitment of over £20 million. This has helped propel MND from a relatively unknown disease to the forefront of neurodegeneration research.

The pace is accelerating and this gives the research community real confidence that we are entering a new era of being able to turn the vast amount of new knowledge gained into effective treatments.”

**Dr Brian Dickie, Director of Research Development.**



Below: Dr Brian Dickie and Prof Nigel Leigh, King's College Hospital, 1997.



**“Our work in the lab will provide more than hope. I firmly believe we will find a treatment in my lifetime.”**



Professor Ammar Al-Chalabi is Director of our MND Care and Research Centre at King's College Hospital.

**Professor Ammar Al-Chalabi has been a driving force behind our increasing knowledge of MND over the past 30 years.**

“In the early days, if you'd asked me if we would ever effectively treat MND, I would have said 'No'. I feel very differently now.

People often ask me 'Are we really making

progress?'. The answer is yes, we really are. But future funding is vital.

UK science has excellent people with the ideas, skills, and drive to push research forward. Research is however very expensive. A gift in your Will is one of the most effective ways to make sure that MND research can continue until we find an effective treatment.”

# A generation of research

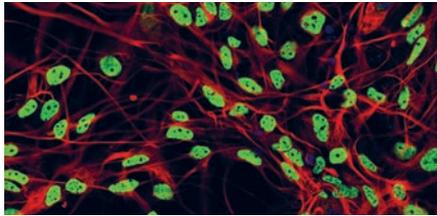
We're building towards a future where the gift you leave could save so many lives.

**1979**

The MND Association is founded.

**1985**

By the mid-eighties we were already spending around £1m a year on research.



**1980**

We awarded our first MND research grant to a project at The Charing Cross hospital.

**1990**

We held the first ever International MND Symposium. It brought MND researchers from around the world together to share their findings. This annual symposium has since grown into the world's leading regular gathering of MND experts.



**1993**

A major advance – the discovery of the SOD1 gene that we now know causes 30% of inherited MND cases.

**2003**

The MND Association's DNA Bank began collecting over 3,000 blood samples from people living with MND, family members and others. It gave us a valuable supply for future research projects.

**2006**

We joined forces with the Department of Health to fund a trial in Non-Invasive Ventilation (NIV) to help people living with MND to breathe.

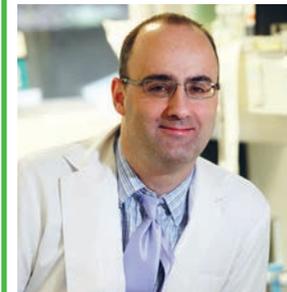


**2010**

NICE (the National Institute for Health and Care Excellence) issued guidance for the use of NIV in MND. That formed the foundation for the eventual NICE guideline on treating MND.

**2011**

Mistakes in the C9ORF72 gene were found to cause up to 40% of all inherited cases of MND. Prof Huw Morris, pictured, was in the team that made the discovery.



**2016**

AMBRoSIA, our biggest-ever research project, began its search for MND biomarkers in 1,500 participants to help us better understand the various types of MND and how each type affects those living with it.



**2023**

The Virtual UK MND Research Institute (UK MND RI) was launched. The Institute is a national network of MND centres and researchers working together to accelerate the search for a cure. We are a founding funder in the Institute.

**Today**

Today we are funding more than 100 research projects each year, more than at any other time in our history – bringing us closer to a cure for MND.



**2022**

We launched the first MND EnCouRage UK event. The annual event aims to retain, encourage and train the next generation of MND researchers, as one of them may hold the cure in their hands – they just don't know it yet.

# Write your Will for free.

You could write or amend a simple or mirror Will for free using our Will writing service via The National Free Wills Network.

This is a great opportunity to ensure your family is protected and your wishes will be followed, without having to worry about the costs involved.

There's no obligation to include a gift to the MND Association in your Will, but if you choose to, you'll help us beat MND, sooner.

**“We had been wanting to make a Will for some time and this seemed an excellent opportunity. The free Wills service was very good.”**

**Ian lives with MND and has included a gift in his Will.**



To find out more visit  
[www.mndassociation.org/free-wills](http://www.mndassociation.org/free-wills)  
or contact us using the details on  
the next page.



**“Please consider leaving a gift in your Will today. Your continued commitment to the fight against MND will help bring hope to those diagnosed with MND in the future.”**

## Thank you.



# Achieving our vision together

Our vision is of a world free from MND.



## Our legacy promise to you

- If you remember MND Association in your Will we promise to spend your money wisely so it achieves the greatest possible impact for people living with MND.
- We understand that your family and loved ones come first.
- We won't put you under any pressure – it's a decision you will want to make in your own time.
- You don't have to tell us your decision – we completely respect your right to privacy (although we'd love to have the opportunity to say thank you).
- We will share news of the vital work gifts like yours make possible. You could transform the lives of people with MND, their families and carers by providing support, or by funding research which brings us closer to a cure.
- You can change your mind about a gift in your Will at any time and any gift you leave will be handled sensitively and respectfully.

## Our mission

We improve care and support for people with MND, their families and carers.

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND.

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

**We will always be here for you. If there is anything you want to know about your legacy, please contact our legacy team on 01604 611799 or e-mail [legacies@mndassociation.org](mailto:legacies@mndassociation.org)**

**“When it came to my Will, the MND Association was always going to feature.”**

Wendy hopes her gift will mean we can beat MND.



**Fellow MND Association supporter Wendy has already included a gift in her Will. Here she explains why she did so, and how she hopes it will help find a cure for MND.**

“My uncle Ray was the life and soul of our family, the glue that held us together. Just six months after his MND diagnosis, he was gone. Without the MND Association, the short time we had would have been unbearable for us all. They helped Ray get the equipment he needed to make his final days as comfortable as possible.

I've included a gift in my Will to help fund the research that stops other

families going through this. It's like my final wish being granted. What more could we wish for than a cure for MND?

“When I first decided to do this, research wasn't in the position it is now. Potential treatments are starting to emerge, it feels like there's a lot more good news. I know it won't be tomorrow. It might take years, even decades. But I'd like to think my gift will one day help create a world free from MND.”

**Will you join Wendy and include a gift in your Will too?**

# Your questions answered

**Helping create a world free from MND with a gift in your Will is simpler than you might think. Here we answer a couple of key questions.**

## What kind of gift can I leave in my Will?

Once you have provided for your loved ones in your Will, there are three main types of gift you can choose to leave to the MND Association.

### A residuary gift

This is a percentage share of what remains after all other gifts and expenses have been paid. An advantage of a residuary gift is its value could rise if the value of your estate increases.

### A pecuniary gift

This is a gift of a set amount that allows you to specify exactly how much you would like to leave in future. These gifts do not increase with inflation.

### A specific gift

This is a gift of any form such as a house, car, property or jewellery.

## How do I make a gift in my Will?

We highly recommend you consult a solicitor when making or amending your Will. They can make sure that your wishes are recorded correctly, preventing future complications for your loved ones.

Your solicitor will require the name, address and charity number detailed below, so please keep this information safe.

Motor Neurone Disease Association  
Francis Crick House  
6 Summerhouse Road  
Moulton Park  
Northampton  
NN3 6BJ

Registered Charity No. 294354

# Your next step matters most



**If you plan to include the MND Association in your Will, or you have already, you don't need to tell us, but by letting us know you could help us plan ahead. We would also love the opportunity to thank you and keep you up to date on our progress.**

- I intend to include a gift to the MND Association in my Will
- I am considering including a gift to the MND Association in my Will
- I have questions about leaving a gift to the MND Association in my Will

Please contact me on \_\_\_\_\_

- I have already included the MND Association in my Will
- I do not plan to include the MND Association in my Will

**If you have any further questions, or there's anything you would like us to know, please use the space below.**

### Your personal details

Title \_\_\_\_\_ First name \_\_\_\_\_ Surname \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_ Postcode \_\_\_\_\_

Email \_\_\_\_\_ Phone \_\_\_\_\_

It is vital that we can communicate with our supporters. We would like to keep you up to date about the work we are doing, to tell you about the amazing difference you have made, and how your financial support in the future can help more people. For further information on how we use your data please read our updated privacy policy at [www.mndassociation.org/privacy-policy](http://www.mndassociation.org/privacy-policy)

**Please fill in this form, save it and email to [legacies@mndassociation.org](mailto:legacies@mndassociation.org) or alternatively call our legacy team on 01604 611799. We will always be here for you.**

**Please help us  
create a world free  
from MND, with  
a gift in your Will.**

**Thank you.**



Registered with  
**FUNDRAISING  
REGULATOR**

Francis Crick House  
6 Summerhouse Road  
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**[www.mndassociation.org/wills](http://www.mndassociation.org/wills)**

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