

Edinburgh International Science Festival – Gordon Aikman calls for a cure to MND

Dying Motor Neurone Disease campaigner [Gordon Aikman](#) will today make a speech at the Edinburgh International Science Festival where he will outline his thoughts on what is needed to ensure that Scottish scientists and doctors find the cure for MND.

He will make a “direct and personal plea” to party leaders to promise to double MND research funding, pointing out this is likely to be his last General Election.

Gordon has already raised over a quarter of a million pounds for MND research through his Just Giving page.

Gordon Aikman is expected to say:

“Half of people with MND die within 14 months of diagnosis. The odds are stacked against me. This is likely to be the last General Election I will see.

So with just weeks until we go to the polls I am making a direct and personal plea to all the party leaders.

My plea is simple and is this: double MND research funding.

The more we invest the quicker we will find that cure.

When millions of people from around the globe poured ice cold buckets of water over themselves their message was clear: its time to create a world free from MND.

It’ll be too late for me, but we can and we must find a cure

for future generations.

David, Ed, Nick and Nicola – the ball is in your court. This is it. This is our chance. I won't be here next time round.

Don't tell me it can't be done. Let's dare to dream. With the political will we can make the dream of a world free from MND a reality.

And you know what, we are poised to find the cure here in Scotland.

We have a unique opportunity for medical research here in Scotland. Let me explain why:

- *We have world-class universities that are home to world-leading MND researchers.*
- *Scotland's population of 5 million is the perfect size: a large enough sample to be globally relevant and yet small enough to be traceable.*
- *Healthcare is overwhelmingly delivered under a unitary NHS care system.*
- *We have a unique 'patient identifier' – a number that seamlessly links records of all health and social contacts from cradle to grave.*
- *The existing MND patient register means we already have a rich clinical understanding of the Scottish MND population.*
- *The doubling of MND specialist nurses will allow deeper and more comprehensive tracking of patient progress.*

Together this makes a for a very powerful, real-world human resource that should, over time, enable:

- *earlier diagnosis;*
- *improved multidisciplinary patient care; and*
- *most importantly, the development and testing of new treatments*

– and yes, ultimately that means a cure.

In short, success requires comprehensive monitoring of each and every patient, together with a model where care is seamlessly integrated with research.

Scotland is the ideal place to drive both the discovery science, as well as deliver a stratified medical approach for individual patient care and ultimately better-focused clinical trials.

What we need to do is this:

FIRST: We need to deepen the information we gather about MND patients. *That means creating a common pro-forma data capture system. It needs to be online, secure, mobile and user-friendly. That way we can gather clinical information that is accurate and consistent across all of Scotland's MND patients. Then we would be perfectly placed to measure care and ensure a fairer, equitable and uniformly high standard of care.*

SECOND: Create a flexible and ongoing trial model. *Much of the intellectual underpinning is in place. All that is required is modest resourcing and a shared commitment that this is a priority that will be integrated into standard*

clinical care.

THIRD: Market Scotland to the world as the “go to” hub for MND clinical trials. *This would involve informing drug companies and researchers – through existing and developing new relationships – of the rich data and huge opportunity that we have here in Scotland.*

The opportunity could not be greater.

Yes, I am dying but I am confident and excited about what the future of MND research holds.

This is it. This is our chance.

With the political will and modest investment we can and we MUST find a cure for future generations.”

[Follow Gordon’s fight here on his website.](#)