

**An open letter to MND researchers from a patient with motor neurone disease who has been a valued member of the Sheffield MND Research Advisory Group (SMND RAG). He has taken the decision to step back from the group due to his deteriorating condition but wants to leave researchers with a final message:**

Dear MND researcher

Our researchers are of exceptional importance in the MND world and I have been fortunate enough to meet a number of them in our centre of excellence in Sheffield. However, I would suggest to you, that of paramount importance are the MND patients, to whom the research community should continually feel accountable. Every time they apply for or receive grant funding. Indeed every day they turn up for work.



When I was diagnosed with MND nearly 4 years ago, my first class neurological team could not tell me why, as an otherwise healthy man, I had developed this disease. They had no meaningful treatment to offer me. They informed me that my deterioration, whilst random to the individual, would be relentless and told me that general life expectancy was 1-5 years after diagnosis.

My sincere wish is that within the foreseeable future, patients newly diagnosed with MND can be told a more encouraging story. One of explanation, treatment and hope.

For that to happen, with the fullest support of the wider MND community, our researchers have to deliver these answers.

So, on those days when people are telling you how clever you are, remind yourself that you need to be cleverer still. When you are making progress with your research project, see if you can speed up delivery, to bring benefit to more MND patients before they die. And throughout everything that you do, please remember at all times to hold yourself fully accountable to those that are unfortunate enough to follow me.

I wish you all the greatest success.

Martin Kelly

**A group of Martin's school friends are fundraising for research into a cure for MND, through the MND Association, by doing a charity walk "Walking back to school for MND" in August 2021. Details can be found here: <https://www.justgiving.com/fundraising/MNDMartinspage>**