

PE1723/J

Petitioner submission of 1 December 2020

I have lived with essential tremor all my life. It will not kill me, but it can be fatal to quality of life. There is no cure, only treatment, and even then, only if your symptoms are 'severe'. Try waking up one day with 'mild' tremors. Try brushing your teeth, making yourself a cup of tea – watch the boiling water, mind you – or driving your car. Try living with people too often assuming your tremors are 'the shakes'; that you're drunk, or on drugs, or in withdrawal. I discovered very quickly that 'mild' is profound, and that 'severe' can be a waking nightmare.

For 'severe' essential tremor, the current treatment is deep brain stimulation (DBS), where electrodes are implanted in your brain while you're still awake, as if you're watching and starring in a horror film both at once. Though DBS works, it is by its nature high risk. The odds of something going wrong during the procedure, and that something being critical, remain substantial. There's also the risk of problems with what is left behind – the electrodes themselves. If a wire loosens or moves out of place, you can't just call an electrician, it's back under the knife to do it all over again.

Magnetic resonance focussed ultrasound (MRgFUS) is a non-invasive alternative to DBS. Instead of jamming wires into the parts of the brain identified with essential tremor, they are precisely targeted with focussed ultrasound to relieve the onset and progression of tremors. MRgFUS has been trialled in sixteen countries around the world, including in England. Scotland could be the seventeenth.

Evidence on the benefits of MRgFUS is strong and growing. We already know MRgFUS extends the possibility of care to those with 'mild' symptoms not eligible for DBS, making it not just an alternative treatment for some but a flat-out new hope for many others. And that there is more to be learnt isn't a reason not to invest in its discovery, anymore than I should have discouraged my children from going to primary school because they haven't left secondary yet. Maybe they'd have liked that, but would it have done them any good?

MRgFUS is less invasive for patients but also for the NHS. Those treated through focussed ultrasound spend less time in recovery, freeing up that additional time for staff to assist other patients. It also frees financial resources. When I received DBS fifteen years ago, the then £70,000-plus expense had to be approved by the Health Board. In England, where MRgFUS has already been trialled, it's estimated at about half the cost of DBS. If an investment in MRgFUS provide essential tremor patients with better, less invasive treatment, while also saving money which can then be spent to help other patients in need elsewhere, this is surely a price worth paying.

I neither ask for nor expect sympathy. I cannot rearrange the path my life has already taken anymore than I can reorder the stars at night, nor can you. But your choice on this matter can make a difference for many others with essential tremor, including children who now have an opportunity to grow up without the same stigmas and abuse I faced when I was younger, and adults who now have the chance to live better, more fulfilling lives for themselves, and as more productive members of society, because they will be relieved of the worst impacts of their tremors. I believe we have now proven the medical, financial, and moral arguments for the provision of

MRgFUS in Scotland, and we ask that you join us in supporting this. We have come a long way and are almost at the finish – but without your help to get us over the line, 'almost' is still 'left behind'. Your decision here can make a positive change to so many lives.

All that is left now is for someone to say 'yes'.