

**PE1723/G**

Petitioner submission of 8 April 2020

Firstly, I realise the Scottish Government and health service have been tackling the Coronavirus crisis over the past weeks and months and thank every NHS worker and key worker during difficult times.

I also thank the committee for asking further questions from the Scottish Government about this important issue.

However, I am hoping when this current crisis abates, it will not impede the innovative work that is going on in Scotland to make available new treatments which, I firmly believe, will save the health service money in the long run, as well as being of great benefit to patients.

The longer a decision is stalled to fund MRI-guided focused ultrasound (MRgFUS) in Scotland the harder it is for fundraisers as the price tag for the equipment and initial setting up increases. I believe the extra funding needed now is an added £100,000 which, in the current climate, is very hard to achieve. And that figure will be increasing day by day.

As someone with Essential Tremor, I cannot accept that there is a need for further research and evidence into the effectiveness of MRgFUS before it receives Scottish Government backing.

MRgFUS is a treatment for Essential Tremor currently available on Medicare in the USA, the NHS in Japan, and in other countries around Europe.

Essential Tremor is a movement disorder that usually affects the hands, but can also affect the head, voice, and legs. It is characterised by a tremor, an involuntary rhythmic movement of a body part.

It is not a life-threatening disease but is often described as a “life-taking” condition, in that it has progressive and hugely debilitating effects on those people whom it affects, rendering the accomplishment of everyday tasks extremely difficult, embarrassing or in some cases impossible. Simple tasks such as using a mobile phone, driving, and eating and drinking become extremely difficult or not achievable at all. This has a huge impact on mental health and the confidence to participate in social activities in public.

Currently, the most common non-pharmacological treatment for Essential Tremor in the UK is Deep Brain Stimulation, an invasive procedure which, although very effective, involves the surgical opening of the skull, permanently implanted hardware requiring surgical battery replacements for the remaining lifetime of the patient, as well as a long recovery period and hospital stay.

Deep Brain Stimulation is the treatment I have undergone for many years and I see MRgFUS as non-invasive and the way forward for many, many patients.

NHS (National Health Service) England has recently published its draft commissioning policy on the use of transcranial MRgFUS for the treatment of medication refractory Essential Tremor.

NHS England sought public consultation in the form of an online survey on its draft commissioning policy, prior to making a final commissioning policy this summer.

The consultation period provided an opportunity for individuals and groups to show their support for ensuring patients can access MRgFUS on the NHS when the country is able to do so after the challenges of COVID-19. The consultation closed on 12 April 2020.

Only one hospital in the country (St Mary's, in London) has the equipment necessary to treat people with MRgFUS. Good news for those living nearby to London, and NHS England now has a proposal to commission the treatment from a second provider, but there is a campaign for it to consider three or four centres to make the treatment reasonably accessible across the whole of England.

While England is proceeding a pace with providing this treatment, unfortunately Scotland is falling behind as the costs for bringing it to Scotland are increasing.

I ask this committee to keep pushing for this to be available here, as it is available in England and in other countries across the world.

I will repeat what I said earlier to the committee: "If there is a will and determination to fight Essential Tremor, and to understand its causes, it can be overcome for the generations that will come after me.

"It is for those determining the outcome of this consultation to decide whether their will, and their determination, is sufficient for Scottish doctors and Scots with essential tremor to have the best opportunity to fight this fight. For me, and my part, if focussed ultrasound helps someone avoid what I went through, I will fight to my last breath to get it."