

Petitioner submission of 12 January 2023

PE1723/W: Essential tremor treatment in Scotland

Waiting list and costs

MRgFUS provides not only an opportunity for more effective and less invasive treatment but also has an untapped potential for research into other neurological conditions such as Parkinsons. By providing MRgFUS for patients on the NHS it would not only save money, provide better care, but also allow Scotland to utilise and enhance its research in the field. It would allow opportunities for patients out-with Scotland to be referred to and treated here too.

There are several aspects to consider when considering costs and savings by rolling out MRgFUS on the NHS. I have it on good authority that the minimum cost of DBS is £30,000 per treatment, per patient. **The cost of MRgFUS is £10,000. A saving of £20,000 per patient.**

Now, the folk in Dundee treated 25 eligible patients in 18 months. Out of these 25, 14 were eligible for DBS. The waiting list for DBS is some 2 and a half years. If they had not received MRgFUS, they would still be waiting for DBS.

Let's focus on savings though. 4 of these patients would have cost the NHS £420,000. Instead by received MRgFUS they saved £280,000 of NHS funding.

Those that are referred for MRgFUS treatment in England face years of waiting lists, and additional costs burdens to both themselves and the taxpayer for patient travel reimbursement. The English NHS have realised the cost savings and potential in MRgFUS. They have invested in and now have two centres in England that offer MRgFUS and we current refer and send our patients to be treated south of the border when we have the potential and capacity to do so in Scotland.

There is an opportunity sitting right in front of the Scottish Government and there is no time like the present to realise this.

Statement from Ian, an Essential Tremor patient

A bit of my History prior to MIR focused ultrasound procedure (MRgfus).

Where do I start? To begin a brief history of my Essential Tremor.

I am 68 years old and was first aware of a problem in my early 30s when I noticed an issue with my writing in my left hand which was my primary hand. This slowly progressed over the years until my late 40s when I started to find it difficult to carry a cup or glass of liquid without spilling it. I also had difficulty in eating and using cutlery. I was also an avid DIY enthusiast and also tied flies for my hobby of flyfishing, as you can imagine not being able to carry out these activities was extremely frustrating and had a profound impact in my work life as a senior manager in the electronics industry. Furthermore, by my early 50s I started to have tremors in my right hand and this was when I was diagnosed with essential tremor.

I embarked on a course of medication however, this had very little effect on the tremor and had some unpleasant side effects. The tremors continued to get worse until eventually I had to give up my job when I was 55 years old as I was incapable of doing it properly. As you can imagine this had severe impact on my mental health as well my physical health.

This brings me to the benefits of MRgfus

If you believe in miracles, then the benefit of this procedure is up there with the best of them.

The procedure is carried out on only one side of the brain at present. The effect is immediate. Within 5 minutes of the procedure being completed I had no tremor anymore. I could lift a glass of water to drink from it, hold my hand steady and sign my own name for the first time in over 20 years.

The effect of this procedure is life changing for me and everyone else who has had it since.

I am able to socialise again eat and drink properly. Although my right hand still causes issues, I can tie flies go fishing do DIY etc.

The added benefits are that this procedure is extremely cost effective compared to the alternative procedure DBS (Deep Brain Stimulation). Added to this, it is **non-invasive**, requires no surgery, or follow up drugs - just informal check-ups for first year.

I cannot thank the fabulous team at Ninewells in Dundee enough for giving me my life back.

Conclusion

The Committee may wish to note that this treatment follows on from initial development carried out at Glasgow University, Western General Hospital, and Kelvin & Hughes Ltd. This was recognised by the Scottish Parliament on 11 December 2018 in a Members Business Debate, marking the 60th anniversary of the publication in 1958 by Donald, McVicar and Brown, in the Lancet. We would hope that the committee would urge the Scottish Government, the SNHS, and other research bodies to continue Scotland's proud history in the field to be continued to be developed. Part of this development is to make available this treatment to all potential patients on the NHS.