

# Citizen Participation and Public Petitions Committee

15th Meeting, 2023 (Session 6), Wednesday  
25 October 2023

## PE1723: Essential tremor treatment in Scotland

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| <b>Lodged on</b>        | 4 July 2019  |
| <b>Petitioner</b>       | Mary Ramsay  |
| <b>Petition summary</b> | Calling on the Scottish Parliament to urge the Scottish Government to raise awareness of essential tremor and to support the introduction and use of a focus ultrasound scanner for treating people in Scotland who have this condition. |
| <b>Webpage</b>          | <a href="https://petitions.parliament.scot/petitions/PE1723">https://petitions.parliament.scot/petitions/PE1723</a>  |

### Introduction

1. The Committee last considered this petition at its meeting on [8 February 2023](#). At that meeting, the Committee agreed to write to NHS Tayside and the National Services Division.
2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.
3. The Committee has received new responses from the National Services Division, which are set out in **Annexe C**.
4. Written submissions received prior to the Committee's last consideration can be found on the [petition's webpage](#). All written submissions received on the petition before May 2021 can be viewed on the petition on the [archive webpage](#).
5. Further background information about this petition can be found in the [SPICe briefing](#) for this petition.

6. The Scottish Government's initial position on this petition can be found on the [petition's webpage](#).
7. Every petition collects signatures while it remains under consideration. At the time of writing, 818 signatures have been received on this petition.

## **Action**

The Committee is invited to consider what action it wishes to take on this petition.

**Clerk to the Committee**

## Annexe A

# PE1723: Essential tremor treatment in Scotland

## Petitioner

Mary Ramsay

## Date lodged

04/07/2019

## Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to raise awareness of essential tremor and to support the introduction and use of a focus ultrasound scanner for treating people in Scotland who have this condition.

## Previous action

I have raised this issue with Rhoda Grant MSP who held a debate in the Parliament on this matter.

## Background information

I have essential tremor and have been to hell and back for the past 62 years. The effects of essential tremor can have a serious impact on a person's life, with lack of understanding and awareness of the condition leading to ineffective treatment but also bullying. I want to prevent any child or adult going through verbal and physical abuse like I did.

There are over 4000 people in Scotland with essential tremor. The main treatment at the moment is brain surgery or deep brain stimulation (DBS) which some people with the condition do not want to endure. DBS is expensive. The cost to the NHS in Scotland is approximately £30,000. The cost of a focus ultrasound scanner is approximately £10,000. The focus scanner is also a much less invasive procedure.

The introduction of a focus ultrasound scanner together with an awareness raising campaign of essential tremor could help Scotland take the lead in looking at innovative, more effective treatments for the condition.

## Annexe B

### Extract from Official Report of last consideration of PE1723 on 8 February 2023

**The Convener:** PE1723, which was lodged by Mary Ramsay, calls on the Scottish Parliament to urge the Scottish Government to raise awareness of essential tremor and to support the introduction and use of a focused ultrasound scanner for treating people in Scotland who have the condition.

At our previous consideration of the petition, the committee agreed to write to the Scottish Government and the national specialist services committee on a number of outstanding issues. We have considered the petition on a number of occasions and we are quite engaged with it.

In response, the Scottish Government has provided information about the role, membership and operation of the national professional, patient and public reference group. The national services division has now responded to the committee, setting out the current service provision and how it operates with the national specialist services committee. The response states that, at the time of writing, no formal application for a national magnetic resonance-guided focused ultrasound service had been submitted by NHS Tayside.

We are joined for our discussion of the petition by Rhoda Grant. I ask her whether she would like to say anything before we consider the various representations that we have recently received.

**Rhoda Grant (Highlands and Islands) (Lab):** Thank you, convener. I appreciate your allowing me to speak again on the petition. It is really disappointing that, since Mary Ramsay started her campaign, there is still no nationally recognised treatment centre for focused ultrasound in Scotland. In England, there are already two centres offering treatment on the NHS. Since Mary started her petition, we now have the facilities here, in Dundee, but we appear to have made little progress on making the treatment universally available on the NHS.

Scottish patients are being sent south and treated in England, which is difficult for them given the travel involved. It adds to their distress and their time away from home. It also adds a cost to the Scottish NHS. Some health boards are sending their patients to Dundee, because they know that the facility is there, but it would be much better if all health boards had a clear pathway to send people to Dundee.

I understand that an application has been submitted to the national services division—it has obviously crossed with its information to the committee—from NHS Tayside, which is looking to have the treatment adopted nationally. I am not clear when that will be considered and what the timeframe for it is, so could the committee raise that matter with the national services division and the Scottish Government? It would be good if we could pin them down as to when that will be considered, what the stages will be and a likely timeframe for them to reach a decision. It would also

be useful to try to find out why the treatment has been assessed as useful and is available in the rest of the UK but not here in Scotland.

10:45

Mary Ramsay asked me to say that she stands ready to give evidence to the committee. She believes that the committee should hear directly from people who are affected by essential tremor and the impact that it has on their lives.

We hope to have a drop-in event on 16 March at 1 pm in committee room 3. That is a plug, but I would like to extend an invitation to committee members, because Mary Ramsay will be there, along with other campaigners and people who have been treated for essential tremor by both treatments available and clinicians. That should be very informative, and you will be very welcome.

**The Convener:** Given that this is very much in connection with a petition that is open and under consideration, it is perfectly in order for the committee to actively promote that event. There will be an opportunity for committee members to drop in to meet Mary Ramsay and, in the first instance, to engage with that drop-in event, which I think would be a productive thing to do.

In your evidence, Rhoda, I think that you have taken us slightly further forward. Did I hear you say that an application has now been lodged—you assume—by NHS Tayside?

**Rhoda Grant:** Yes.

**The Convener:** I think that we might want to confirm that with NHS Tayside. Do members agree to that?

**Members** *indicated agreement.*

**The Convener:** The submissions that we have had have all been about how that might happen but, now that it has happened, we might want to know, from all those who have an active part in the resolution of the matter, about the timescale and likely progress of the application. Do members agree to that approach?

**Members** *indicated agreement.*

**David Torrance:** I am extremely disappointed by the progress that has been made on the petition, so could we ask whether there are any barriers that will prevent the application from progressing?

**The Convener:** I think that we are all disappointed, which is why the petition has stayed open. There seems to have been quite a curious bureaucratic process and almost obfuscation, given the opportunity and the benefit that there would clearly be to patients in Scotland. We heard how the alternative has been so disappointing historically.

I think that we want to try to clarify those points. I thank Rhoda Grant, because that has taken forward the committee's understanding of the current situation.

We will keep the petition open and write to the various organisations, including the Scottish Government, after confirming with NHS Tayside that the application has now been submitted.

## Annexe C

### 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 Deep Brain Stimulation (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.

## National Services Division submission of Submission of 1 March 2023

### PE1723/X: Essential Tremor Treatment in Scotland

Thank-you for your recent correspondence in relation to the petition which calls on the Scottish Parliament to urge the Scottish Government to raise awareness of essential tremor and to support the introduction and use of a focus ultrasound scanner for treating people in Scotland who have this condition.

We are glad to hear that the previous update that we provided was helpful to the Committee. NHS Tayside continue to provide such a service at present in Dundee in conjunction with the University of Dundee and not a nationally designate service. The provision of this service has reduced the requirement for patients from Scotland to travel to the NHS England commissioned services in London or Liverpool for assessment or treatment. In the event that a patient required to travel to one of the English providers for treatment this would be funded using the risk share funds which NSD hold and administer on behalf of the territorial Health Boards.

#### NSD/ NSSC Process Update

NSD require applicants to register their proposal/application and submit an outline Stage 1 application which will be reviewed by the Clinical Strategic Management Group within NSD. Such applications need to be submitted to NSD by the end of March for progression during the next financial year. Such an application requires the sponsorship of either the Board Chief Executive or their designate within the Health Board in which the proposed service is to be provided.

Following such scrutiny if the proposal is considered successful at this stage, NSD will work in conjunction with the applicants to develop a formal specification for a service over the following months. It is then the responsibility of the applicant to detail how they will meet the requirements of the specification and implement this should their application (formal business case) be prioritised and endorsed towards the end of the year by the National Specialist Services Committee.

#### Specific Update in Relation to This Clinical Service

Whilst NSD has been in regular correspondence with NHS Tayside over a number of years in this regard and an application has been registered, at the present time NHS Tayside have not as yet submitted a BCE sponsored fully worked up Stage 1 application for designation. Without such sponsorship NSD are unable to progress this further. NSD have contacted NHS Tayside recently once again to remind them of the requirement that their formal Stage 1 application requires to be submitted by the end of March to allow for this to be considered by SMGC in April.

If a Stage 1 application were to be received, this would enter the NSD annualised commissioning process for designation which aims to prioritise the formal business cases in late 2023 with a view to potential designation and commissioning from the beginning of financial year 2024-2025. Such scrutiny by NSSC is in the latter half of 2023.

Regarding potential barriers and challenges, as a result of the Covid-19 pandemic NHS Scotland remains under significant pressures in terms of resources in terms of people and finances as well as finite capacity to meet the needs of the population. Any potential new services require to be prioritised, considering the competing demands across the system as well as Scottish Government Policy and the strategic priorities for the Board Chief Executives. Each year NSD receive several requests for designation of potential new services and NSSC will consider these applications together with a view to prioritising in order to meet the needs of the population.

We hope that this further update is of help to the Public Petition.

## National Services Division submission of 15 October 2023

### PE1723/Y: Essential Tremor Treatment in Scotland

Thank you for your enquiry regarding an application for a national MRgFUS service. Earlier this year, NSD received an updated application from the lead Consultant Neurologist working within NHS Tayside for a new MRI Focussed Ultrasound Functional Neurosurgery service to treat patients with Essential Tremor. Confirmation was sought that the NHS Tayside Executive Leadership Team was supportive of the application and that it was within their planning and financial assumptions, as the application would be considered by Chief Executives and the NSSC in December this year for commissioning in April 2024.

In May, the NHS Tayside Executive Leadership Team advised they were supportive in principle of developing an MRI Focused Ultrasound

service; however, a paper outlining the proposal in detail had not yet been submitted for Executive approval and so could not be progressed at this time. On this basis, we advised that the application for a national service could not be progressed within this year's NSD work plan and should be resubmitted for consideration in 2024/25 once the NHS Tayside Executive Leadership Team has approved the application.