

# Citizen Participation and Public Petitions Committee

6th Meeting, 2022 (Session 6), Wednesday  
20 April 2022

## PE1723: Essential tremor treatment in Scotland

### Note by the Clerk

**Lodged on** 4 July 2019

**Petitioner** Mary Ramsay

**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.

**Webpage** <https://petitions.parliament.scot/petitions/PE1723>

### Introduction

1. The Committee last considered this petition at its meeting on [19 January 2022](#). At that meeting, the Committee agreed to write to the Scottish Government 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 Scottish Government and the Petitioner 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](#).

## Action

7. 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 19<sup>th</sup> January 2022

**The Convener:** Our second agenda item is the consideration of continued petitions. The first of those is PE1723, on essential tremor treatment, which was lodged by Mary Ramsay and calls on the Scottish Parliament to urge the Scottish Government to raise awareness of essential tremor and support the introduction and use of a focused ultrasound scanner for treating people in Scotland who have the condition.

I am delighted to welcome Rhoda Grant MSP back to the committee to speak to the petition. Before I come to Rhoda, I will provide a little more background. When it last considered the petition in September of last year, the committee agreed to write to the University of Dundee to seek an update on the magnetic resonance-guided focused ultrasound—MRgFUS—scanner system.

A response from the University of Dundee has now been received, which confirms that its focused ultrasound system has been used to treat five patients with essential tremor. Funding approval has been obtained from individual national health service boards for patients to be treated in Dundee over the coming months.

The committee also wrote to the Cabinet Secretary for Health and Sport requesting an update on plans to submit a proposal to the national specialist services committee to allow the treatment to become a standard form of care. Applications to the committee have now been halted due to the pandemic. At present, the majority of those wishing to access the treatment are forced to travel long distances to access care in England.

Although I sometimes tease that she is with us more than some of our committee members, it is a pleasure to have Rhoda with us again this morning. Would you like to update the committee on anything in relation to the petition?

**Rhoda Grant (Highlands and Islands) (Lab):** Thank you, convener. If I seem to be here a lot of the time, it simply shows how important the committee is to my constituents. It makes a real difference to people's lives, and I hope that this petition will also have that impact.

Since the committee last considered the petition, I have spoken to and met Mary Ramsay virtually on a number of occasions. Following some of those meetings with Mary, and with other stakeholders who have an interest, I wrote to Ralph Roberts, who is chair of the national specialist services committee.

He told me that the national services division is due to meet the clinical team in Dundee towards the end of this month to discuss how a formal application for designation and the relevant paperwork can be prepared for consideration by both the national patient, public and professional reference group and the national specialist services committee. He told me that the next meetings of those groups are

scheduled for February and March, but that it is unlikely that they will discuss focused ultrasound at those meetings. The issue is more likely to be discussed at the May or June meetings, and there is no guarantee that a conclusion will be reached at that time.

It feels to me that there is still no real recognition of the issues that people with essential tremor face in having to travel to London for assessment and again if they are assessed as suitable for the procedure. There is also no acknowledgement of the waiting times that people face and the impact on their lives. There are real fears that the decision will be further delayed beyond the spring or summer.

The committee knows how long the petition has been before it and the previous committee. I share Mary Ramsay's frustration that we appear to be moving at a snail's pace in bringing this much needed treatment to patients in Scotland. Patients have to consider joining a waiting list in London, where the treatment is available. However, that is a long waiting list; indeed, NHS England is looking to create another centre to deal with the demand.

It makes no sense whatever to me that we have the equipment and knowledge in Scotland but we are not using those for our patients, who are forced to travel to access the treatment. That is not good for them, and it is certainly not good for the public purse. I am not sure whether the committee is aware that 80 patients were referred for assessment in Dundee last year from their health boards, and that around 25 per cent were considered to be appropriate for treatment.

I urge the committee to keep the petition open and to put pressure on the bodies that I mentioned to ensure that the treatment is approved as quickly as possible. I think that the committee already knows that Mary Ramsay and Ian Sharp, who has had the treatment, are happy to give evidence on their experience and show at first hand the difference that treatment can make to those with essential tremor. Perhaps the committee could also contact the NPPPRG and the NSSC to ask them to give priority to their consideration of the treatment and to do so at their earlier meetings. As you said, convener, because of Covid, those bodies have not met for a long time.

**The Convener:** Thank you, Rhoda. That was helpful, and quite disappointing in some respects.

**David Torrance (Kirkcaldy) (SNP):** I would like us to keep the petition open, based on the evidence from the University of Dundee and the success of the treatment there. I would like us to write to the Scottish Government to highlight that success of the MRgFUS treatment in essential tremor patients and to ask for clarification as to when the pause on NSSC applications is likely to be removed. I would also like us to ask the Scottish Government whether it intends to provide funding for the MRgFUS treatment to be made available to more essential tremor patients in Scotland, and how it will raise awareness of the treatment among the profession.

**The Convener:** As no other member wishes to come in, on the basis of David Torrance's suggestions and the contribution from Rhoda Grant, I think that we are proposing to write to the Scottish Government to highlight the success in Dundee and to ask when the pause is likely to be removed. We will also ask the Scottish

Government whether it intends to provide dedicated funding to ensure that ultrasound scanning can be made available to more patients in Scotland and how it plans to raise awareness of essential tremor among patients and healthcare professionals.

I would also like us to take on board Rhoda Grant's suggestion that we write to the two organisations that she mentioned. I am sorry, but I did not actually catch the acronyms, but they will have been noted by the clerks. She mentioned two bodies that she was keen for the committee to write to, so I would like to include them in our further submissions.

Are members content with that approach?

*[Members indicated agreement]*

## Annexe C

### Scottish Government submission of 18

February 2022

### PE1723/R– Essential tremor treatment in Scotland

Thank you for your letter of 24 January 2022 on behalf of the Citizen Participation and Public Petitions Committee regarding further questions in relation to Petition PE1723 - 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.

I note that the Committee, in consideration of evidence from the University of Dundee following its meeting on 19 January 2022 is interested to know:

- When is the pause on NSSC applications likely to be removed?
- Does the Scottish Government intend to provide dedicated funding to ensure the MRgFUS service can be made available to more ET patients in Scotland?
- What plans are in place to raise general awareness of Essential Tremor amongst patients and healthcare professionals?

With regard to the first question, NSSC are currently only considering applications that directly relate to patient safety whilst NHS Scotland continues to support the COVID-19 recovery agenda and remobilisation of services. However, NSD advise with agreement from the NHS Scotland Board Chief Executives that they will resume applications for commissioning of new services in April 2022, but are mindful that we remain in a pandemic state.

Meanwhile evidence continues to be gathered on the effectiveness of the technology available. NSD continues to engage with the clinical team in Tayside to fully understand what would be required to commission a national designation in Scotland should there be a decision to do so.



Moving now to the second question, I can confirm that the Scottish Government has not committed funding to the MRgFUS service in 2022/2023. The evidence base gathered on the effectiveness of the technology will inform consideration on any future financial investment.

Specialist services are commissioned to support patients living with a rare condition or who have highly specialised needs. They are likely to be hosted by only one or two NHS Health Boards, with all Boards agreeing to pay a share of the nationally-hosted service.

In regard to the final question, I want to assure you that the Scottish Government is committed to working with patients and healthcare professionals to continue raising awareness of neurological conditions in Scotland like Essential Tremor. In December 2019, we published a [Neurological Care and Support – National Framework for Action](#) with a vision to ensure everyone with a neurological condition, including tremor-causing conditions, can access the care and support they need to live well on their own terms. Over five years we will invest £4.5 million of funding to implement the Framework's 17 commitments.

Implementation of the Framework has remained supported and prioritised throughout the pandemic. Key priorities for delivery in 2021-22 focus on improving information for patients and carers, better options to support self-management, developing improved care pathways, workforce, accurate data gathering, and use of digital health to support improvements in services.

The Scottish Government have commissioned Healthcare Improvement Scotland (HIS) to support quality assurance of the implementation of the HIS General Standards for Neurological Care and Support. This will support the delivery of the Neurological Framework and help to drive up standards of care.

We are actively engaging with NHS Inform on addressing gaps in patient information about neurological conditions via their website, following a prioritisation survey which was conducted with patient organisations.

I hope this reply is helpful to the Petitioner and the Citizen Participation and Public Petitions Committee.

# Petitioner submission of 25 February 2022

## PE1723/S – Essential tremor treatment in Scotland

I have just been informed that the figure for people with essential tremor in Scotland is 100,000. That does not count people waiting to see a neuro specialist or people who have been misdiagnosed. I have also been advised that we could do with more neuro specialists and surgeons.