

Citizen Participation and Public Petitions Committee
Wednesday 11 September 2024
13th Meeting, 2024 (Session 6)

PE1723: Essential tremor treatment in Scotland

Introduction

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>

1. [The Committee last considered this petition at its meeting on 25 October 2023.](#) At that meeting, the Committee agreed to write to NHS Tayside.
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 written submissions from NHS Tayside. The first submission is an initial response from NHS Tayside and the second submission is an updated response. The written submissions are set out in **Annexe C**.
4. The Petitioner has indicated to the clerks that she wishes to give oral evidence to the Committee.
5. [Written submissions received prior to the Committee's last consideration can be found on the petition's webpage.](#)
6. [Further background information about this petition can be found in the SPICe briefing](#) for this petition.
7. [The Scottish Government gave its initial response to the petition on 9 December 2021.](#)
8. Every petition collects signatures while it remains under consideration. At the time of writing, 818 signatures have been received on this petition.

Action

9. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee
September 2024

Annexe A: Summary of petition

PE1723: Essential tremor treatment in Scotland

Petitioner

Mary Ramsay

Date Lodged

4 July 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 25 October 2023

The Convener: Agenda item 2 is consideration of continued petitions. I am delighted to say that we are joined by our very good supporters and petition champions, Rhoda Grant and Monica Lennon.

Rhoda Grant joins us in relation to the first continued petition, PE1723, on essential tremor treatment in Scotland. The petition, 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.

In her written submission, the petitioner states that the current treatment for essential tremor—deep brain stimulation—costs a minimum of £30,000, whereas the magnetic resonance-guided focused ultrasound service costs £10,000. Twenty-five patients were treated in Dundee with the MRgFUS over 18 months, with 14 of them being eligible for DBS but facing a two-and-a-half-year waiting list.

The national services division has shared that it received an updated application from the lead consultant neurologist working in NHS Tayside for a new MRI-focused ultrasound functional neurosurgery service to treat patients with essential tremor. The NHS Tayside executive leadership team advised that it was supportive in principle of the application but that a paper outlining the proposal in detail had not yet been submitted for executive approval so could not be progressed. The NSD advised that an application should be resubmitted for consideration in 2024-25.

I have to say, before I ask Rhoda Grant to speak, that I am quite sympathetic to what the petitioner said in her most recent submission. She does not put it in this way, but, as has been the case with other health-related issues, those affected being able to present evidence to the committee can sometimes be a powerful additional stimulant in our seeking to progress the aims of a petition.

Rhoda, over to you.

Rhoda Grant (Highlands and Islands) (Lab): Mary Ramsay and others stand ready to present to the committee, and I think that that would be powerful. She has had deep brain stimulation and is not eligible for the new treatment because of that. However, others are willing to give evidence, so you would see the contrast and hear the different experiences that people have faced. It would be powerful for the committee to hear that. The petition has been running for some time, so those who gave evidence previously did so to a previous Parliament and committee. It would be good for members of this committee to hear that evidence, so I very much back Mary Ramsay's proposal.

It is really frustrating, because we thought that we were there. We have the machine in Scotland, and there are individual patient applications to get the treatment in Scotland, but we are still stalled in relation to the treatment becoming available to all as par for the course. I do not totally understand what happened in NHS Tayside.

The stage 1 application was put in, but something delayed or prevented the stage 2 application from going in. I do not understand that, given that the equipment and staff are there already.

I wonder whether the committee would write to the chief executive of NHS Tayside to find out what happened and whether it stands ready to make a substantial application at the next round, which, I understand, is next year. It might also be helpful if the committee could write again to the national services division to clarify the timescale for applications—when it would need applications—so that we are all clear as to what is required to get this as an NHS treatment in Scotland as in the rest of the United Kingdom.

Those are the two things that I recommend, and I back Mary Ramsay's offer for her and others to give evidence to the committee, because I think that that would be really helpful.

The Convener: The very actions that the committee was considering taking are the ones that you have just proposed, so thank you very much for those suggestions. Are we happy to incorporate Rhoda Grant's suggestions in relation to NHS Tayside?

Members *indicated agreement.*

The Convener: We will hear what NHS Tayside has to say, but we will do that on the presumption that, having heard what it has to say, we might very well seek to have the petitioner or others who have been affected by the condition give evidence to the committee, so that we have that on the record, with everyone able to see what the condition has led to and the difficulties that people have had in finding a way forward. Are colleagues content to proceed on that basis?

Members *indicated agreement.*

The Convener: Thank you very much. You came, you asked, you got.

Rhoda Grant: I hope that the rest of the day is like that. [Laughter.]

The Convener: If only Government ministers were like that.

Annexe C: Written submission

NHS Tayside submission of 1 December 2023

PE1723/AA: Essential tremor treatment in Scotland

Thank you for your correspondence relating to 'PE1723: Essential tremor treatment in Scotland' and your inquiry relating to NHS Tayside's application for a designated MRgFUS service.

We should like to provide the following update to the Committee:

- A Stage 1 application to National Services Division (NSD) was submitted in March 2023. However it was not possible to move to a fully developed business case at Stage 2 at that time due to a challenge relating to workforce support to develop the detailed business case required.
- We can confirm that a new registration will be submitted to NSD by 28 February 2024 in line with the required timescale. If this is approved, we can also confirm that the necessary additional support is in place to progress to the full application by 31 March 2024.

We trust this provides the Committee with assurance relating to NHS Tayside's commitment to progressing a designated MRgFUS service.

NHS Tayside submission of 27 August 2024

PE1723/BB: Essential tremor treatment in Scotland

The original plan was to submit a funding application to NSD in March 2024. Due to the current financial position across all Boards in Scotland we were advised by NSD of a change to the funding available in 2024/25 which impacted on the usual annual submission process. As a result no bid was submitted for 2024/25 funding.

However, NHS Boards across Scotland are able to access the service currently through the out-of-area referral process and the procedures are being delivered/coordinated through Clinical Research Imaging Facility (CRIF) based at Ninewells Hospital.

Should the normal annual NSD submission process recommence in 2025, we will progress with a bid as planned.