

Citizen Participation and Public Petitions Committee
Wednesday 10 December 2025
19th Meeting, 2025 (Session 6)

PE1952: Specialist services for patients with autonomic dysfunction

Introduction

Petitioner Jane Clarke

Petition summary Calling on the Scottish Parliament to urge the Scottish Government to instruct Scotland's NHS to form specialist services, training resources and a clinical pathway for the diagnosis and treatment of patients exhibiting symptoms of autonomic nervous system dysfunction (dysautonomia).

Webpage <https://petitions.parliament.scot/petitions/PE1952>

1. [The Committee last considered this petition at its meeting on 11 December 2024.](#) At that meeting, the Committee agreed to write to the Minister for Public Health and Women's Health.
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 the Minister for Public Health and Women's Health, and a joint submission from the Petitioner and Lesley Kavi, 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.](#)
5. [Further background information about this petition can be found in the SPICe briefing](#) for this petition.
6. [The Scottish Government gave its initial response to the petition on 29 August 2022.](#)
7. Every petition collects signatures while it remains under consideration. At the time of writing, 2,108 signatures have been received on this petition.
8. [At its meeting on 24 September 2025, the Committee took evidence on thematic healthcare issues](#) that have been raised in multiple petitions, including this petition.

Action

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

CPPP/S6/25/19/5

**Clerks to the Committee
December 2025**

Annexe A: Summary of petition

PE1952: Specialist services for patients with autonomic dysfunction

Petitioner

Jane Clarke

Date Lodged

18 August 2022

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to instruct Scotland's NHS to form specialist services, training resources and a clinical pathway for the diagnosis and treatment of patients exhibiting symptoms of autonomic nervous system dysfunction (dysautonomia).

Previous action

I have spoken with Mr Daniel Johnson MSP on 09/05/22 regarding the current gaps in NHS services for dysautonomia. Mr Johnson offered to submit a motion for a members' debate and to table written parliamentary questions.

Others have raised questions within Scottish Parliament and Westminster. On 1, 4 and 21 Jun 2016, MSP Ms Aileen Campbell's responses to parliamentary questions revealed existing national gaps in diagnosing and treating autonomic dysfunction's many conditions.

Background information

Autonomic nervous system disorders are common. Some cause mild symptoms, but many severely impact upon quality of life or significantly reduce life expectancy. Despite this, Scotland has no clinical pathway for dysautonomia and no specialist hub to diagnose and treat patients. Dysautonomia is a common complication of Long COVID.

With no autonomic clinics in Scotland, most patients do not have access to local or regional healthcare. A fortunate few may be referred to specialists via NHS England, but many are declined referral despite clinical need. Diagnosed patients returning to Scotland can find themselves unable to access necessary medication or follow-up. Treatment may be delayed for years, leaving sufferers unable to work or attend education. It is especially difficult for children to access dysautonomia healthcare.

As many doctors are untrained to recognise and manage symptoms of autonomic dysfunction, dedicated training resources are also needed.

The aims of this petition align with the commitments of the Neurological Care & Support Framework & the UK Rare Disease Strategy.

CPPP/S6/25/19/5

Further key info: <https://dysautonomiapetition.wordpress.com/>

Annexe B: Extract from Official Report of last consideration of PE1952 on 11 December 2024

The Convener: PE1952, which was lodged by Jane Clarke, calls on the Scottish Parliament to urge the Scottish Government to instruct Scotland's national health service to form specialist services, training resources and a clinical pathway for the diagnosis and treatment of patients exhibiting symptoms of autonomic nervous system dysfunction—dysautonomia.

We last considered the petition on 6 March, when we agreed to write to the Scottish Government. We have since received a response from the Minister for Public Health and Women's Health, stating that there are no current plans to develop a dedicated specialist autonomic nervous system service in Scotland. It also says that most people with autonomic nervous system symptoms experience them as part of other underlying conditions, and that they are cared for within existing pathways for their underlying condition.

The minister also explains that she has been advised that it is well within the remit of neurologists to diagnose and manage such symptoms as part of their routine practice, in the majority of cases. The submission also states that cardiologists might also see people with autonomic nervous system symptoms for assessment and investigation, including in circumstances when symptoms do not occur as part of a separate neurological disease.

The petitioner and Lesley Kavi, who is a trustee and chairperson of PoTS UK, have provided a joint submission to the committee. The submission states that PoTS UK has seen no evidence of investigations into the needs of people with postural tachycardia syndrome and related dysautonomia. They are confident that the majority of general neurologists in Scotland would not want to accept referrals for PoTS and they are keen to receive evidence from the minister that would prove otherwise.

The submission also provides personal testimonies from across Scotland that highlight the difficulties that individuals have faced when seeking appropriate treatment for their condition.

The petitioner's submission and the testimonies that we have received contradict the view of the minister, as expressed in her earlier submission. Do colleagues have any comments or suggestions for action?

David Torrance: Would the committee consider writing to the Minister for Public Health and Women's Health to highlight the petitioner's recent written submission and to ask what information is available and what monitoring takes place that gives the Scottish Government confidence that people are receiving satisfactory care, despite the individual experiences that are noted in the petitioner's recent submission? What information does the Scottish Government have on the number of clinicians who are currently treating or willing to accept patients with PoTS, and what steps will the Scottish Government take to improve understanding of autonomic dysfunction among general practitioners?

The Convener: I would be happy to draw to the minister's attention the testimonies that we received as an illustration that she might find useful in challenging any advice that she might be being given on what everybody thinks, because obviously not everybody does think that way.

Are members content with that?

Members *indicated agreement.*

Annexe C: Written submissions

Minister for Public Health and Women's Health written submission, 16 January 2025

PE1952/J: Specialist services for patients with autonomic dysfunction

Thank you for the Committee's correspondence to the Scottish Government of 16 December 2024 regarding petition PE1952: '*Specialist services for patients with autonomic dysfunction*', and the opportunity to respond to the Committee's queries following its meeting of 11 December 2024.

The Committee states that it is keen to understand what information and monitoring is in place regarding standards of care for people affected by dysautonomia, including information on the number of clinicians who are currently treating or willing to accept patients with PoTS.

It may be helpful for the Committee to note that the Scottish Government provides core funding and is responsible for setting the strategic policy for the NHS in Scotland, however, responsibility for the delivery of care rests locally with NHS Boards who configure services taking into account local circumstances and the reasonable needs of their patient populations.

The Committee will therefore appreciate that the Scottish Government does not hold information on the number of clinicians employed by NHS Scotland who are providing, or are willing to provide, care for people affected by PoTS. If you have not already done so, you may wish to contact territorial NHS Boards, which would be best placed to provide the information you have requested.

We do, however, expect NHS Boards to provide high quality, person-centred care and support for everyone, including people with dysautonomia.

As we have previously stated to the Committee, we understand that a majority of individuals with autonomic symptoms experience them as part of other conditions, such as Parkinson's Disease and related movement disorders, neuropathies and Multiple Sclerosis. Autonomic disorders are part of the neurology specialty training curriculum and it is within the remit of neurologists to diagnose and manage these symptoms as part of their routine practice in the majority of cases.

The Committee has also asked what steps the Scottish Government will take to improve understanding of autonomic dysfunction amongst GPs. We recognise the importance of clinician awareness and can confirm that NHS Education for Scotland's learning platform 'Turas' contains training resources on autonomic nervous system dysfunction. These resources are accessible to a multidisciplinary audience, including GPs and are highlighted below.

- 14 June 2022 – PoTs UK webinar '[Long Covid and the autonomic nervous system - a top - down and bottom - up approach](#)'.
- 17 July 2023 – NHS Education for Scotland slide pack learning bite '[The autonomic nervous system and long COVID](#)'.

Additionally, through our [Neurological Care & Support Framework](#) we have funded Action for ME and partners to disseminate an online learning module on ME/Chronic Fatigue Syndrome for GPs and health professionals in Scotland, which incorporates information on PoTS within the context of ME/CFS.

I hope this provides the Committee with the information it requires.

Yours sincerely

Jenni Minto MSP

Petitioner and Dr Lesley Kavi written submission, 24 November 2025

PE1952/K: Specialist services for patients with autonomic dysfunction

Lack of needs assessments and healthcare provision

The Minister again incorrectly assures the Committee that there is sufficient expertise in neurology clinics for PoTS patients; however the national charity (PoTS UK) is not aware of any neurology specialists in Scotland who manage PoTS and related conditions.

PoTS is not generally part of conditions listed in the Minister's response, not part of neurology specialty training curriculum, and not within the usual remit of neurologists in Scotland. In a recent survey only 1.63% of PoTS patients in Scotland were diagnosed by a neurologist, likely based in England.

We have asked repeatedly for details of these specialists: instead, the Minister has recommended that the Committee contact territorial NHS Boards. In fact, PoTS UK made FOI requests to all Health Boards. The 2022 results were [reported previously](#) and the 2024 findings revealed that:

- only 2 of the 14 Health Boards see PoTS patients in neurology clinics (these may not be specialist clinics), and one board rejects or redirects **all** neurology referrals for PoTS.
- 4 Health Boards had no idea where patients with PoTS are seen. Western Isles refers all patients to Glasgow, and Grampian refers all patients to Inverness. However, the Inverness clinic was recently closed.
- No Board could name a specific clinic into which patients could be referred.

If Health Boards and Trusts do not know where patients are seen, how can GPs possibly know where to refer when patients need secondary care support?

The Government expects Boards to:

- ‘take into account local circumstances and the reasonable needs of their patient populations,’ but the 2024 FOI requests show that no Boards know the numbers or needs of their PoTS patients.
- ‘provide high quality, person-centred care and support for everyone, including people with dysautonomia’, but shows little concern for our strong evidence of extremely poor healthcare.

The size of the problem

There were an estimated 9400 people in Scotland with PoTS pre-pandemic. It is thought that 7-14% of people with Long COVID have PoTS i.e. there may be an additional 16,800 affected. The socioeconomic impact of this is enormous as autonomic dysfunction is one of the most debilitating aspects of Long COVID. COVID infections and reinfections continue to increase the number of patients with autonomic dysfunction and cardiological conditions.

Specialist care provision

PoTS patients who can access healthcare are mostly seen by cardiologists because patients present with cardiac-type symptoms, often need cardiology tests and medication.

However, there are no cardiologists known to us in Scotland who manage PoTS patients. Additionally, Lothian’s PoTS guidance tells GPs **not** to refer to cardiology unless the patient faints; these patients likely have vasovagal syncope, not PoTS. <https://apps.nhslothian.scot/refhelp/guidelines/cardiology/postural-tachycardia-syndrome-pots/>

Training

The training mentioned by the Minister is focused on the underlying conditions — Long COVID and ME/CFS — and does not significantly impact GP learning (see below).

Evidence from patients: new survey results

A large 2025 survey of people with suspected and diagnosed PoTS revealed that:

- 90% of patients in Scotland experienced difficulty in accessing NHS healthcare.
- 59% said their GP has not heard of PoTS or does not believe it exists.
- Almost half were misdiagnosed, with their physical symptoms inappropriately attributed to mental health conditions.
- 50% have to seek ongoing private healthcare.
- 14% travel to England to access healthcare.

Most affected patients are children or young adults under the age of 50.

- 38% cannot attend school and many more are off long term
- One third of students had to drop out of college/university

- 38% lost their job due to PoTS
- One third had to reduce working hours due to PoTS

These statistics paint a shameful picture of inequitable access to healthcare and its impact.

A recent Parliamentary drop-in session in Westminster was attended by many interested MPs from Scotland. They had received large numbers of emails from constituents on this issue, one having never received so many individual emails on one subject before.

Scotland has no clinical pathways for dysautonomia and no specialist hubs. PoTS patients, for example, need a care pathway for PoTS in every Health Board, a named service in secondary care that GPs can refer into, and national clinical guidelines. These measures are in place for most other conditions as common and disabling as PoTS.

We sense the Citizen Participation and Public Petitions Committee is repeatedly ‘fobbed off’ by the Government’s responses. We urge you to consider our evidence and encourage the Government to make an urgent assessment of the numbers and needs of patients with dysautonomia in order to address the inadequacy of current services.