

Citizen Participation and Public Petitions Committee

7th Meeting, 2021 (Session 6), Wednesday
17 November 2021

PE1662: Improve Treatment for Patients with Lyme Disease and Associated Tick-borne Diseases

Note by the Clerk

PE1662: Lodged 28 June 2017

Petitioners Janey Cringean and Lorraine Murray on behalf of Tick-borne Illness Campaign Scotland

Petition summary Calling on the Scottish Parliament to urge the Scottish Government to improve testing and treatment for Lyme Disease and associated tick-borne diseases by ensuring that medical professionals in Scotland are fully equipped to deal with the complexity of tick-borne infections, addressing the lack of reliability of tests, the full variety of species in Scotland, the presence of 'persister' bacteria which are difficult to eradicate, and the complexities caused by the presence of possibly multiple co-infections, and to complement this with a public awareness campaign.

Webpage <https://petitions.parliament.scot/petitions/PE1662>

Introduction

1. The Committee last considered this petition at its meeting on [Wednesday 8 September 2021](#). At that meeting, the Committee agreed to write to the Scottish Government to seek an update regarding points raised at the Committee's evidence session with the then Minister for Public Health and Sport, Mairi Gougeon on 24 February 2021. Namely—
 - the outcome of the round-table event that was due to be held to bring together clinicians, patient representatives and public health experts to discuss testing, treatment and raising awareness;

- any progress that has been made in establishing an Infectious Diseases Managed Clinical Network; and
 - what steps the Scottish Government has taken to encourage more research into Lyme disease, including what is causing longer-term symptoms in some patients and the possible impact that Lyme Disease has on other conditions.
2. Responses have since been received from the Scottish Government and the Petitioner.

Scottish Government submission

3. The Scottish Government's submission of 8 October 2021 confirms that roundtable events were held in April and June of this year and, as a result, two sub-groups were established to look at the education of healthcare professionals and public awareness raising. Both groups met for the first time recently.
4. The education of healthcare professionals sub-group is chaired by the Scottish Government and includes representatives from both primary and secondary care, including experts in infectious disease in general and Lyme Disease in particular. Initially, this group will look at current resources being used by GPs and consider options for additional learning and development. The group has also committed to exploring the implementation of Lyme Disease 'champions' to spread messaging in healthcare settings, as well as linking in with community pharmacies.
5. The second sub-group, which looks at public awareness, includes representation from the Lyme Resource Centre and is looking at options for strategies to implement messaging around Lyme Disease to targeted groups and the wider public.
6. The Scottish Government notes that given the complexity of work these sub-groups are undertaking, they are likely to meet on a long-term basis.
7. The Minister for Public Health, Women's Health and Sport has also recorded a video message highlighting the need to be tick aware which will be used by the Scottish Government on their social media channels.
8. Work to establish an Infectious Diseases Managed Clinical Network has been delayed due to Covid-19, although the Scottish Government states it is still committed to this work and is collaborating with NHS National Services Scotland on this.
9. Finally, in relation to research, it was agreed at the most recent roundtable discussion that the Scottish Government will work with the Scottish Lyme Disease and Tick-borne Infections Laboratory at Raigmore Hospital to consider potential improvements in testing methods and processes.

10. The laboratory is currently undertaking significant research relevant to this petition, including looking at the development of Babesia testing methods.

Petitioners' Submission

11. In response to the latest Scottish Government submission, the petitioners state that at least one petitioner was involved in the Scottish Government roundtables held in April and June, as well as the awareness-raising sub-group meeting, which was held in October. They have also met with the Minister. However, whilst the petitioners describe this as 'promising', they note that they were not invited to the other sub-group session (on the education of healthcare professionals) and have not seen the minutes from that meeting.

12. The petitioners reiterate that the key aim of their petition is to ask the Scottish Government to address:

- currently limited treatment for Lyme Disease and associated tick-borne diseases
- education of medical professionals
- the lack of reliability of tests
- the full variety of species in Scotland
- the presence of 'persister' bacteria which are difficult to eradicate
- the complexities cause by the presence of possibly multiple co-infections
- the need for a public awareness campaign.

13. The petitioners also note that whilst the sub-groups cover both the education of healthcare professionals and public awareness raising, that it is public awareness raising which 'has received by far the greatest attention', despite this being 'a complementary request in our petition'. They go on to state that the key focus of the petition was to improve treatment for those currently ill after a tick bite and for whom treatment according to the current NICE guidelines has not been successful.

14. This included a request for Scotland to establish specialist treatment centres for tick-borne diseases and for all clinical staff to be educated on the ILADEF Physician Training Program and consultants who treat tick-borne illnesses to undertake training on the evidence for persistent Lyme disease and new treatments for this.

15. The petitioners suggest that nothing has been done to address these requests and, as such, even when patients have a history of a known bite, when tests come back negative, they are told they have another condition and therefore can't access treatment that would cure them. They note that whilst 'there has been some discussion about testing, neither that nor consultant education has been tackled enough to make a difference to chronically ill patients.'

16. In relation to the petitioners' request for specialist treatment centres, they point out that the promised Managed Clinical Network for Infectious Disease does not meet their needs, stating that patients 'want to be treated by specialists who are immersed in the topic' and access 'holistic treatment at a multi-disciplinary centre covering all the specialities involved in such a complex disease'.

17. The petitioners also point out that whilst there is some research underway on testing, this does not 'include treatment research or our request to implement existing tests'.

Action

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

Clerk to the Committee

Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting -

- [PE1662/TT: Scottish Government submission of 8 October 2021](#)
- [PE1662/UU: Petitioner submission of 8 November 2021](#)

The Scottish Parliament launched a new website at the end of Session 5. All written submissions received on the petition before May 2021 can be viewed on the petition on the [archive webpage](#). Written submissions received on the petition after May 2021 can be viewed on its [new webpage](#).