**Name of petitioner**

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

**Petition title**

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

**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.

**Action taken to resolve issues of concern before submitting the petition**

- Asked my MSP, Angela Constance, to get information from the Scottish Health Secretary, Shona Robison, on plans to improve outcomes for Lyme disease patients.
- Written a report for discussion with the Chief Medical Officer to highlight the issues in diagnosis and treatment.
- Met with the head of Healthcare Improvement Scotland to raise the issues in diagnosis and treatment.
- Discussed the issues in diagnosis and treatment with Neil Findlay MSP.
- Established the website “Tick-borne Illness Campaign Scotland” (www.ticscotland.org.uk) to raise awareness of the issues.
- Asked my local councillor to ensure signs were placed prominently in the country park where I was bitten.

**Petition background information**

**Lyme Disease in Scotland**

Many patients in Scotland are being failed by current medical practice regarding Lyme Disease (also known as borreliosis) and related tick-borne co-infections.
If the disease is caught early, patients recover with standard treatment. However, 10-20% of patients go on to develop a debilitating chronic condition referred to by some as Post-Treatment Lyme Disease Syndrome. Currently, many patients are then abandoned without further help, left to seek private help or self-medicate.

On average, 5% of ticks in Scotland are infected with borrelia. The number of cases of Lyme Disease in humans has increased in the last decade: in 1996 there were fewer than 30 new cases in Scotland; in 2015 there were around 220. However, GPs estimate that only 20-40% of cases are referred, so the numbers are likely to be much higher. Analyses are very rough because the real figures are unknown.

Tests in donated blood have concluded that 4.2% of blood donors have positive borrelia serology. With the estimated 2015 mid-year population of Scotland standing at 5.373 million, that equates to 225,666 blood donors of Scotland having been infected. The number of infected people is likely to be higher as those who are ill are less likely to give blood. Not everyone who is infected has current symptoms.

We want to see significant improvements in treatment for Lyme Disease, particularly addressing the needs of those with chronic illness.

**Improve and extend testing**

There are numerous issues with testing and diagnosis. Current practice is to rely on diagnostic tests, but these are unreliable. According to Lyme Disease Action, “there are no conclusive tests for Lyme Disease currently in routine use in the UK that will accurately diagnose Lyme Disease or distinguish from past infection”. The National Lyme Disease Reference Laboratory at Raigmore acknowledges that “traditional testing is expensive, lacks sensitivity, cannot distinguish between current and past infection and cannot be used as a marker for treatment response”.

We wish to see guidelines produced which ensure doctors are aware of the lack of reliability of tests and the lack of markers of current infection, which provide clarity about the testing procedures for all tick-borne diseases, and which require all forms of borreliosis and emerging co-infections to be notifiable.

Currently there are no tests which cover all tick-borne infections found in Scotland. For example, there are at least two species of borrelia which are found in Scotland but not tested for. We want to see testing extended to cover all borrelia species found in Scotland. As some patients have no detectable antibodies, we wish tests to be introduced which do not rely on antibody response. Testing for co-infections should also be comprehensive and include multiple species of the common co-infections bartonella and babesia.

**Improve treatment**

The current guidelines used for treatment in Scotland were developed in 2006 by the Infectious Diseases Society of America (IDSA). These guidelines have been removed from the US National Guidance Clearinghouse because they are considered out of date.

Recent research has shown that the bacterium which causes Lyme Disease forms dormant ‘persistor’ cells, which are known to evade antibiotics. Borrelia has been described as “one of the most complex bacteria known to man”. Treatment protocols need to be modified to address the complexity of borrelia infection.

Current treatment, based on these outdated IDSA guidelines, normally involves antibiotics for up to one month, but this regime does not acknowledge persistence of borrelia infection, or the presence of possibly multiple co-infections. Patients with continued symptoms should be followed up regularly and not abandoned as at present. Treatment, which could include IV, high dose, pulsed, combination or long-term antibiotics, should be extended for as long as symptoms persist. Also, until tick-borne diseases are clearly understood and up-to-date guidelines developed, where uncertainties exist doctors should be professionally supported in decisions they take to prescribe unlicensed medication to their patients.

A Scottish vector-borne illness treatment centre should be established to deal with complex cases, involving a multi-disciplinary team of specialists in infectious diseases,
immunotherapy, functional medicine and nutrition. This should be supported by full training of staff in the most up-to-date clinical methods for dealing with persistence and the associated complexities of co-infections, along with the provision of resources for research and development into the treatment of chronic tick-borne infections in Scotland.

**Improve education**

Doctors need to be taught to recognise a collection of symptoms of Lyme disease, many of which mimic other illnesses, irrespective of the presence of the characteristic rash or positive blood test. Education should be improved to ensure that consultants are fully up-to-date on the complexity and persistence of borrelia, including the added complexity when co-infections are involved. GPs and medical students also must be aware of the complexities of the illness, and the urgent need for prompt diagnosis and appropriate treatment.

Education should extend to the public, so that they are aware of the dangers and have information on how to protect themselves. This can be achieved partly by landowners being required to display suitable warning notices at, for example, visitor centres and car parks.

**Unique web address**

http://www.parliament.scot/GettingInvolved/Petitions/lymedisease

**Related information for petition**

A full background with links to peer-reviewed literature, news articles and patient stories is available at: http://www.ticscotland.org.uk/

**Do you wish your petition to be hosted on the Parliament’s website to collect signatures online?**

YES

**How many signatures have you collected so far?**

0

**Closing date for collecting signatures online**

28 / 06 / 2017

**Comments to stimulate online discussion**

What is your view of the current testing and treatment regime for Lyme Disease and associated tick-borne diseases? Have you been failed by inadequate current treatment?

Do you agree that it is essential to improve testing and treatment and to ensure that guidance and training are developed for medical professionals?

Please add any other comments you feel will contribute to highlighting this issue.