

Briefing for the Public Petitions Committee

Petition Number: [PE1662](#): Improve Treatment for Patients with Lyme Disease and Associated Tick-borne Diseases

Main Petitioner: Janey Cringean and Lorraine Murray on behalf of Tick-borne Illness Campaign

Subject: Calls on the 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.

Background and epidemiology

[Health Protection Scotland](#) monitors the incidence of Lyme Disease in Scotland. Their website provides the following information on the disease:

Lyme disease is caused by infection with *Borrelia burgdorferi* and is transmitted to humans through the bite of an infected tick. Infection is acquired by immature ticks from infected small wild mammals, which act as a reservoir of the organism. Prolonged feeding (>24 hours) of infected ticks on a human can result in disease. Geographical distribution of the disease in Europe closely follows that of the known range of the tick vectors and ramblers and campers are at increased risk of disease due to their greater exposure to the disease vectors. The true incidence of the disease is unknown due to incomplete detection and reporting of cases, but is estimated to be 0.3 per 100,000 in the UK. ¹

(The incidence in Scotland is higher than this. Results from a [study on distribution and presentation](#) of the disease were summarised as follows:

'The number of laboratory-confirmed cases of Lyme borreliosis in Scotland peaked at 440 in 2010. From 2008 to 2013 the estimated average annual incidence was 6.8 per 100,000 (44.1 per 100,000 in

¹ It is important to note that other evidence suggests that incidence is much higher in parts of Scotland. See: https://www.rcpe.ac.uk/sites/default/files/jrcpe_45_3_mavin.pdf

NHS Highland). Of 594 questionnaires from NHS Highland patients: 76% had clinically confirmed Lyme borreliosis; 48% erythema migrans; 17% rash, 25% joint, 15% neurological and 1% cardiac symptoms. Only 61% could recall a tick bite.

Main clinical features

These follow a tick bite (although this may go unnoticed). A rash develops which usually has the appearance of a reddened circle that expands away from the bite and clears in the centre. The skin may be warm but is not usually painful. Early localised disease may be associated with “flu-like” symptoms of malaise, fatigue, lethargy, headache and joint and muscle aches. Other, more severe, manifestations of the disease include arthritis of large joints, meningitis and myocarditis, all of which may occur without the rash. (One in three people diagnosed with Lyme disease have no rash).

Incubation period

Transmission of *B. burgdorferi* does not take place until the tick has been in place for >24 hours. The skin syndrome usually occurs within 1 month of the tick bite. Other manifestations may take several weeks or months to develop.

For people concerned that they have been affected, [NHS Inform's](#) advice is based upon Information from [Public Health England](#), and has information on such areas as: signs and symptoms, testing, how to remove a tick and where ticks are found.

Incidence

The chart below is taken from a scientific paper: [Distribution and presentation of Lyme borreliosis in Scotland – analysis of data from a national testing laboratory](#) in the *Journal of the Royal College of Physicians Edinburgh*, 2015

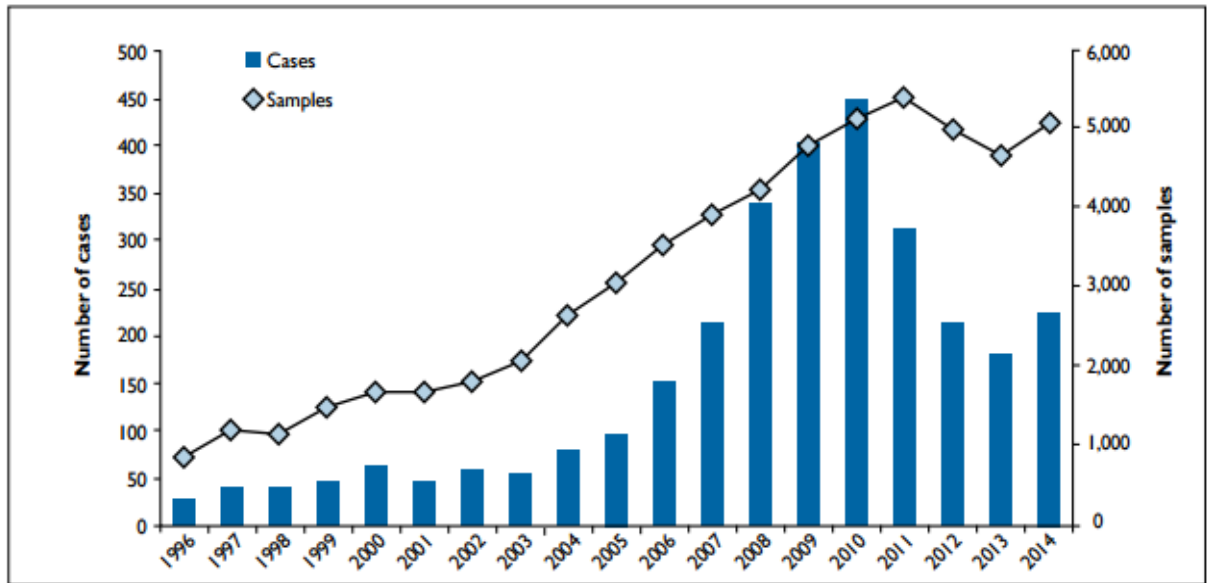


FIGURE 1 Laboratory samples and cases of Lyme borreliosis in Scotland 1996 to 2014

The following table provides data on incidence collected by Health Protection Scotland:

Lyme Disease, Scotland, Annual Totals
as at 28 July 2016

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015*
<i>Borrelia</i> (total) (Lyme Disease) ¹	171	230	285	228	308	229	207	176	224	200
<i>Borrelia burgdorferi</i>	171	230	285	228	308	229	207	176	223	200
<i>Borrelia</i> species	0	0	0	0	0	0	0	0	1	0

¹ includes *Borrelia burgdorferi* and *Borrelia* species

Data source: Health Protection Scotland

*2015 data remain provisional

Testing and Treatment

In Scotland, samples where Lyme disease is suspected are sent to the National Testing Laboratory at Raigmore Hospital in Inverness. This is *not* a [reference lab](#), for Lyme disease, as the Petitioner states, but it is linked to the Toxoplasma reference lab at Raigmore. This means that the Lyme testing lab funding, staffing and status are not equal to that of other reference labs for other diseases in Scotland.

A link to information on the current testing procedures for Lyme Disease can be found via the NHS Inform website, via [Lab-tests online](#). There are a number of tests used in the diagnosis of Lyme Disease:

Lyme disease antibodies by ELISA: The first test done is an [enzyme-linked immunosorbent assay \(ELISA\)](#). The UK Health Protection Agency Lyme Borreliosis Unit (and the Scottish Lyme Disease Laboratory) uses one that detects both [IgM](#) and [IgG](#) antibodies to *B. burgdorferi*. The ELISA is sensitive but has a high [false positive](#) rate

Lyme disease antibodies by Western blot. If the ELISA is positive, an additional test called a [Western blot](#) is used to help doctors confirm a diagnosis of Lyme disease. The Scottish Lyme disease laboratory uses Western blots that test for IgM and IgG antibodies separately.

Lyme disease bacterial DNA by PCR: Another specific test, the polymerase chain reaction (PCR), detects the [DNA](#) of *B. burgdorferi*. It is used to confirm the presence of the [bacterium](#) in joint fluid in Lyme arthritis and in [cerebrospinal fluid \(CSF\)](#) in Lyme meningitis

The Petitioner would like to see testing and education of health professionals improve.

There are issues with testing. Clinical assessment and diagnosis is the first key stage in diagnosis, and if symptoms are clear, then antibiotic treatment should start before testing. Lab Tests Online give the following information on the tests in current use:

‘If the [ELISA](#) test is carried out within a few weeks of a tick bite or possible exposure it may fail to detect antibodies to *B. burgdorferi*, and will usually be repeated a few weeks later. About 30% of tests are positive by two weeks and about 80% by six weeks. The rate increases with duration of infection until more than 99% are positive.

If the ELISA test is positive and both the IgG and IgM [Western blot](#) tests are negative, it is probable that the ELISA result is a false positive and [Lyme disease](#) is not the cause of the symptoms.

If the ELISA and [IgM](#) tests are positive, with or without a positive [IgG](#) test, early Lyme disease is probable and treatment with antibiotics is advisable.

A positive ELISA test with a positive IgG and a negative IgM test can be seen in later Lyme disease. However, it should be born in mind that these results can also be seen when exposure to *B. Burgdorferi* took place a long time ago, and the current symptoms may be unrelated. This is particularly likely in people who have been exposed to tick bites at work (like foresters), during recreation (like ramblers) or because they live near woodlands or heaths’

There is no Scottish Intercollegiate Guidance Network (SIGN) guideline at present, but the UK National Institute for Health and Care Excellence (NICE) has produced a [Clinical Knowledge Summary \(CKS\) for the management of Lyme Disease](#).

Research – public information, ‘persister’ bacteria,

The University of Highlands and Islands has conducted recent research in the Highlands to raise awareness of ticks and Lyme disease. An abstract to [an article](#)² published in the electronic journal Remote and Rural Health describes the prototype design for a smartphone application that uses citizen science data input, earth observation and terrestrial data to map *Ixodes ricinus* ticks, and; secondly to create packages of awareness raising information tailored appropriately for the communities which participated in the study. [Further information and background to the study](#) can be found on NHS Highland’s website.

Since at least 2015, some [research](#) (see [here](#) for further references) has considered the presence of ‘persister’ bacteria. These are bacteria that are not killed off by first line antibiotic treatment in some individuals, leading to people experiencing chronic symptoms of the disease long term. There is not yet a consensus that this is the case with Lyme disease.

Scottish Parliament Action - Scottish Parliamentary questions and answers

[Tuesday 24th July 2012](#)

[Tuesday 13th November 2012](#)

[Monday 27 June 2016](#)

[13 September 2016](#)

[Tuesday 31st January 2017](#)

[Thursday 2nd March 2017](#)

UK Parliament Action

In May 2016, a [petition](#) (now closed) was lodged with the UK Parliament calling for improved testing and treatment protocols. In its response to the petition, the UK Government included the following:

‘The Department is commissioning three separate systematic reviews on the diagnosis, treatment and transmission of Lyme disease to provide evidence to inform future decision making. These will be put into the public domain on completion, which is expected to be in autumn 2017. NICE guidance on diagnosis and management of Lyme

² [Morton, S., Munoz, S-A. & Hall, J.](#) 30 Jun 2016 *Rural and Remote Health (Internet): Abstracts - Innovative solutions in remote healthcare - ‘Rethinking remote’ 23-24 May 2016 Inverness, Scotland, UK.* online, Vol. 16, 4095

disease is currently in development and expected to be published in July 2018.

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12 June 2017

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