

PE1662/I

Petitioners' submission of 1 December 2017

**We are encouraged by the general agreement that more needs to be done about Lyme disease and that it is a complex disease. We strongly support the development of a Scottish National Plan for Tick-borne Infections similar to that developed for France but including co-infections.**

We are particularly grateful for the support given by Lyme Disease UK, Lyme Disease Action, and Scottish Land and Estates, including the open [public support of moorland managers](#).

We are grateful for all work which is done currently by stakeholders in areas of awareness, and shaping of policy and guidelines in relation to Lyme disease. We particularly acknowledge the significant work done in the Highlands. However, much more needs to be done. The establishment of a Lyme Borreliosis sub-group is welcomed by patients but we have not seen significant evidence of change arising yet from the group's existence.

We are encouraged by the statement that, "in order to effectively tackle Lyme Disease the veterinary profession, medical profession, animal keepers and pet owners, Government, local authorities, land owners and other relevant stakeholders must work collaboratively under a 'One Health' agenda to raise awareness of how to prevent the transmission of Lyme Disease and improve the testing and treatment of this vector-borne disease". It is patient experience that vets appear to be better informed about Lyme disease than many GPs and so a combined effort is likely to be most effective.

We are in full support of Lyme Disease UK's urge for development of a Scottish National Plan for Tick-borne Infections similar to that developed for France<sup>1</sup> but including co-infections.

## **Lyme Disease in Scotland**

**Lyme Disease Action state that "there are 4 different genospecies of Borrelia present in Scotland of which 3 are pathogenic." However, we believe there are at least 5 genospecies present in Scotland and all may be pathogenic. Current tests do not include two of these species. Contrary to popular opinion, Lyme infection can occur within a short time of a tick bite.**

Research published in 2016<sup>2</sup> by Dr Caroline Millins, a tick researcher from the University of Glasgow's School of Veterinary Medicine, identified four genospecies: *B. afzelii*, *B. garinii*, *B. burgdorferi* (sensu stricto) and *B. valaisiana*. They found that "Of the infected nymphs across all 19 sites 45.5% of infections were *B. afzelii*, 28.8% were *B. garinii*, 7.6% were *B. valaisiana*, 9.1% were *B. burgdorferi* (s.s.) and 6.1% were mixed *Borrelia* genospecies infections where two or more genospecies were detected in the same nymph."

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<sup>1</sup> Available at: <http://solidarites-sante.gouv.fr/archives/archives-presse/archives-communiqués-de-presse/article/marisol-touraine-lance-le-plan-national-de-lutte-contre-la-maladie-de-lyme-et>

<sup>2</sup> Available at: <https://parasitesandvectors.biomedcentral.com/articles/10.1186/s13071-016-1875-9>

However, in 2017, it was reported that ticks with *B. miyamotoi* were found feeding on competitors of a Scottish mountain marathon.<sup>3</sup> We do not know what percentage are infected with *B. miyamotoi* and we are not aware if research has been done to determine this. As new species have been discovered recently, there may be more as yet unknown.

The Chief Medical Officer (in a personal letter in November 2016) stated that “the assay which is currently being used can detect antibodies to *B. burgdorferi sensu stricto*, *B. afzelii*, *B. garinii*, *B. spielmanii* and *B. bavariensis*”.

In a freedom of information response from Public Health England, they state that *B. valaisiana* may cause disease in man and that *B. miyamotoi* causes relapsing fever (<https://www.whatdotheyknow.com/request/313568/response/773785/attach/2/551%20FOI%20Lyme%20testing%20reply.pdf>). *B. valaisiana* has been found in cerebrospinal fluid and is suspected to have caused the illness described ([https://wwwnc.cdc.gov/eid/article/10/9/03-0439\\_article](https://wwwnc.cdc.gov/eid/article/10/9/03-0439_article)).

Based on this information we conclude that

- The current test assay cannot identify infection with *B. valaisiana* or *B. miyamotoi*
- *B. miyamotoi* exists in Scotland and causes relapsing fever but the proportion of ticks that carry it is not known
- 8% of infected ticks in Scotland carry *B. valaisiana*, though it is not clear to what extent it causes human illness.

We therefore believe that the test used for diagnosis in Scotland does not detect infections caused by all the *Borrelia* genospecies currently known to be present in Scottish ticks.

Although it is commonly stated that a tick must be attached for at least 24 hours before transmission occurs, a “literature review has determined that in animal models, transmission can occur in <16 hours, and the minimum attachment time for transmission of infection has never been established”. A variety of factors including tick and *Borrelia* species “support anecdotal evidence that *Borrelia* infection can occur in humans within a short time after tick attachment”. Recent research concluded that, in the case of *B. miyamotoi*, “transmission can occur within the first 24 hours of nymphal attachment” (<https://www.ncbi.nlm.nih.gov/pubmed/28501504>).

## Improve and extend testing

**We appreciate the work done by the National Lyme Borreliosis Testing Laboratory but more is needed. We had not understood till recently that Raigmore is a Borreliosis Testing Laboratory and not a Reference Laboratory. We strongly support elevation of its status and extension of its scope to cover tick-borne co-infections.**

## Epidemiology

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<sup>3</sup> Use of mass-participation outdoor events to assess human exposure to tick-borne pathogens. Available at: [https://wwwnc.cdc.gov/eid/article/23/3/16-1397\\_article](https://wwwnc.cdc.gov/eid/article/23/3/16-1397_article)

**We are grateful for the acknowledgement of uncertainties around data gathering and collation. We welcome all suggestions for epidemiological studies and wish these to include all co-infections.**

This concurs with NICE who, in draft guidelines issued by NICE on 25<sup>th</sup> September 2017, state “there is a lack of robust epidemiological data on Lyme disease in the UK” (<https://www.nice.org.uk/guidance/indevelopment/gid-ng10007/documents>).

## **Borrelia Test Issues**

**We are grateful that it is acknowledged that there is scientific uncertainty around the laboratory tests for Lyme Disease. We want to see Raigmore being given the resources to do much more research to evaluate alternative tests which do not rely on antibodies and which can distinguish active infection.**

Lyme Disease UK and Lyme Disease Action both raise the issue that patients go to private laboratories for tests and sometimes receive positive results whereas their NHS results are negative. Patients want answers as to why their NHS results are negative and yet they are still seriously ill. Patients believe that either they have a strain of Borrelia or a co-infection which is not being included in testing, or they have Lyme disease but are not producing the antibodies relied on by the tests. Without the research to investigate this question, patients will continue to seek answers. We are therefore pleased to hear that there is collaboration with the University of Leicester on a new research method of blood tests.

In the draft guidelines issued by NICE on 25th September 2017 (<https://www.nice.org.uk/guidance/indevelopment/gid-ng10007/documents>), they recommended several areas for research including identifying “What is the most clinically and cost effective serological antibody-based test, biomarker (such as CXCL13), lymphocyte transformation and ELISPOT for diagnosing Lyme disease in the UK at all stages, including reinfection?”

- CXCL13: a biomarker for acute Lyme neuroborreliosis: investigation of the predictive value in the clinical routine (<https://www.ncbi.nlm.nih.gov/pubmed/24682168>)
- LTT: “The Lymphocyte Transformation Test for Borrelia Detects Active Lyme Borreliosis and Verifies Effective Antibiotic Treatment” (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3474945/>)
- ELISPOT: The ELISPOT (<http://www.elispot.com/>) is a standardised and disclosed test principal acknowledged and approved by the U.S. Food and Drug Administration to diagnose tuberculosis. The only difference when using it for other infections is that a different antigen is used. However, it is not currently approved for use with borrelia infections. We would like research its usefulness in diagnosis and management of Lyme disease and co-infections. LymeSpot (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4406722/>) and iSpot Lyme (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3972671/>) are revised ELISPOTs for Lyme disease. There is further information in Lehman PV et al.: Unique Strengths of EliSpot for T Cell Diagnostics in: Kalyuzhny AE.

Handbook of EliSpot: Methods and Protocols, Methods in Molecular Biology, Vol. 792. 2nd Ed: Springer; 2012: 3-23.

We would like to see Raigmore being given the resources to evaluate these and to include two other tests in the research:

- "Direct DNA sequencing is a valuable tool for reliable molecular diagnosis of Lyme and related borrelioses"  
(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4847596/>)
- Nanotrap® Lyme Antigen test which now has a European licence  
(<https://translational-medicine.biomedcentral.com/articles/10.1186/s12967-015-0701-z>)

We would also like account taken of the European ID-Lyme project to develop a novel test for the early detection of Lyme Borreliosis (<https://www.id-lyme.eu/>).

It is often stated that it can take up to 6 weeks to get positive serology. However, a recent study "disproved that all patients with LNB develop positive serum Borrelia antibodies within 6 weeks after infection" (<https://academic.oup.com/cid/article-abstract/65/9/1489/4079714/Characteristics-and-Clinical-Outcome-of-Lyme>) It has recently been stated by Dr. Steven Phillips (Facebook) that "there are now over 50 medical journal articles documenting Lyme disease despite negative antibody tests. This research spans all stages of illness, including late stage disease". In addition, immune response in European patients has been found to be undulatory and so test results can be intermittently negative during infection (<https://www.hindawi.com/journals/isrn/2012/719821/>).

Lyme Disease Action mention that the study on Scottish blood donors finds 4.2% of donors had had exposure to the bacteria. They suggest they could have had a mild form from which they recovered without treatment or serious disease for which they had treatment and also recovered. However, there is a third option which has not been fully explored: these people may have a very early form of illness which has yet to develop.

Three research groups have now found spirochaete infection including borrelia in the brains of patients with Alzheimer's disease. In the fullness of time, it may be found that addressing Lyme disease also, at least partially, addresses Alzheimer's disease. One study showed that "Borrelia burgdorferi persists in the brain in chronic lyme neuroborreliosis and may be associated with Alzheimer disease."  
(<https://www.ncbi.nlm.nih.gov/m/pubmed/15665404/>).

In a more recent study, researchers duplicated previous findings that demonstrate "that the plaques, which are characteristically found in AD brains, reveal the presence of biofilms. These biofilms are undoubtedly made by the spirochetes present there; further, we have also found that the biofilms co-localize with the  $\beta$  amyloid that is a signature finding in the disease" (<https://www.omicsonline.org/open-access/alzheimers-disease-a-novel-hypothesis-integrating-spirochetes-biofilm-and-the-immune-system-2314-7326-1000200.php?aid=67274>). A recent meta-analysis showed "a strongly positive association between bacterial infection and AD" (<https://www.ncbi.nlm.nih.gov/pubmed/25182736>).

We agree that it is unfortunate that private doctors in Germany and the USA who diagnose patients clinically and treat patients empirically with long term and combinations of antibiotics do not publish outcome studies. However, patients are experiencing significant improvements in their health and quality of life through their approaches. This petition aims to achieve such health benefits for more patients. If that requires more studies to be done on outcomes of such approaches then we welcome those.

## **Co-infections**

**Patients are grateful for the acknowledgement that lack of testing for co-infections is an issue presently in Scotland. They question whether the severity of their illnesses is caused by infection with multiple species of borrelia or additional co-infections which are not currently tested for in Scotland. We want more extensive testing to cover such co-infections and recognition of the complexities that multiple co-infections introduce.**

One recent paper concluded that “exposure to and possibly also infection with multiple tick-borne pathogens in humans seems to be the rule rather than the exception” (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5648423/>). Recent research has also found that co-infections increase the severity and length of Lyme disease infection (<https://www.ncbi.nlm.nih.gov/pubmed/8637139/>). One of the petitioners has tested positive in private tests for babesia microti, ehrlichia, and bartonella henselae as well as borrelia.

As well as Anaplasmosis, mentioned by the Scottish Government, patients tested abroad are often being found to be infected with Babesia, including Babesia microti, Babesia divergens or Babesia duncani (WA-1). There is no test available in Scotland for Babesia duncani (WA-1). Fluorescence In Situ Hybridization (FISH) Assays have been found to be useful in diagnosis, and we request that evaluation of this be done urgently to help in the identification of babesia co-infections. There have also been reports of “Concurrent infection of the central nervous system by Borrelia burgdorferi and Bartonella henselae: evidence for a novel tick-borne disease complex” (<https://www.ncbi.nlm.nih.gov/pubmed/11559306>). Other patients report testing privately for co-infection with chlamydia pneumoniae or mycoplasma pneumoniae, and reactivation of viruses such as EBV, CMV, Herpes, etc., and do not feel that the complexities involved are understood.

We are interested to hear that other vector-borne diseases are being introduced to the UK, including leishmaniosis, ehrlichiosis and babesiosis. Patients want to ensure that all such emerging infections are tested for in humans as well as animals.

## **Improve Treatment**

**We want it understood that patients are often misdiagnosed in the early stages because the Erythema Migrans rash is not present or misdiagnosed. They either do not get treatment or get inadequate treatment. In such cases, patients with early disseminated or late Lyme are finding the current treatment regimes unsuccessful and inadequate. The primary focus of our petition is to get better treatment for those who have been failed by current diagnostic and treatment protocols.**

We understand that the first line 'medical response' to the disease should be public health information on safe tick removal and early detection of the Erythema Migrans rash by patients and their doctors. However, patient experience is that the Erythema Migrans rash is either not present or often misdiagnosed as a condition such as ringworm, cellulitis or lupus. A Scottish study in 2015 found that "the low number of patients with EM (48%) was surprising and is much lower than that documented in other studies (69.1 to 89.3%)." and "only 61% of patients could recall having a tick bite" ([https://www.rcpe.ac.uk/sites/default/files/jrcpe\\_45\\_3\\_mavin.pdf](https://www.rcpe.ac.uk/sites/default/files/jrcpe_45_3_mavin.pdf)). One of the petitioners had a well-documented expanding rash which lasted 14 months and was seen by two GPs and a Dermatologist and yet remained undiagnosed for three years following the bite.

Treatment may be very effective when prompt diagnosis is made. However, in cases where the Erythema Migrans rash is not recognised or not present and Lyme is not suspected, patients do not get such early treatment and many patients are left with other diagnosis. One petitioner was told by an Infectious Diseases consultant that she was "lucky to have the rash, otherwise it would be a diagnosis of MS".

When patients are diagnosed but diagnosis is delayed by several years, patients with early disseminated or late Lyme are finding the current treatment regimes unsuccessful and inadequate. They are then discharged without further help and feel abandoned at a time when they are seriously ill. One of the petitioners was discharged by the NHS while still very ill and has had to pay for private treatment for over 7 years despite continued symptoms of infection, including pus oozing out of the sinuses and eyes. Many patients have similar stories.

## **Guidelines**

**We are very disappointed with the treatment recommendations in the draft NICE Guidelines. We suggest that Scotland should instead adopt the guidelines developed by the International Lyme and Associated Disease Society (ILADS).**

The NICE Guidelines are very narrow in scope, limited in their recommendations, and do not provide help for patients with chronic illness. We understand that their work was significantly hampered by lack of evidence and some recommendations were made without any evidence at all.

When it is known that borrelia is a similar organism to syphilis but with a more complex structure (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC208952/>) and it is understood that syphilis can now be drug-resistant (<https://www.nature.com/articles/nmicrobiol2016245.epdf>), patients are bewildered to understand why the draft guidelines do not acknowledge the complexities of treatment in the case of borrelia.

We suggest that Scotland should instead adopt the guidelines developed by the International Lyme and Associated Disease Society (ILADS), the only approved Lyme disease guidelines currently listed in the US National Guideline Clearinghouse (<https://www.guideline.gov/summaries/summary/49320>).

Dr. John Lambert, a consultant in Dublin, gives a good overview of the problems of the continued reliance on the outdated IDSA guidelines (<https://on-lyme.org/en/sufferers/lyme-stories/item/273-we-don-t-have-perfect-tests-for-diagnosis-of-lyme>) stating “These guidelines are outdated and not evidence based in my opinion. We are sticking to the old traditional view even when the data and the patients in front of us do not fit into the ‘guidelines’” and “I’ve found it very helpful to learn from the ILADS doctors and to bring my knowledge up to speed and also learn about chronic Lyme.” and “To withhold treatment in this clinical scenario is fraught with significant problems, breaching a doctor's responsibility to his patient and also basic human rights legislation”. The human rights violations of Lyme disease sufferers are indeed under international investigation (<https://www.linkedin.com/pulse/human-rights-violations-relapsing-fever-lyme-disease-luche-thayer>).

## Persistence

**The Scottish Government state that their understanding of the presence of ‘persister’ bacteria is developing. The lack of acknowledgement of this persistence by many doctors is a major reason for this petition.**

Lyme Disease Action state that Lyme disease can persist beyond a course of antibiotics. This is definitely the case for both petitioners and other patients.

In draft guidelines issued by NICE on 25th September 2017 (<https://www.nice.org.uk/guidance/indevelopment/gid-ng10007/documents>), they recommend research into “the most clinically and cost-effective treatment options for different clinical presentations of Lyme disease in the UK”, but we feel they have not taken account of the existing mounting evidence of bacterial persistence.

As far back as 2013, it was stated that "accumulating evidence indicates that Lyme disease spirochetes are adapted to persist in immune competent hosts, and that they are able to remain infective despite aggressive antibiotic challenge. ... Credible evidence supports the conclusion that LD can be a recalcitrant and chronic relapsing infection in animal hosts" (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3636972/>).

In 2014, a mouse study confirmed the findings of previous studies there was "resurgence of spirochete DNA in multiple tissues at 12 months [after treatment], with levels nearly equivalent to those found in saline-treated mice" (<https://www.ncbi.nlm.nih.gov/pubmed/24466286>).

In 2015, research at Northeastern University found that "Borrelia burgdorferi, the causative agent of Lyme Disease, forms drug-tolerant persister cells" (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4505243/>). Further research has concluded that there is “substantial evidence that Borrelia burgdorferi is capable of forming biofilm in vitro. Biofilm formation by Borrelia species might play an important role in their survival in diverse environmental conditions by providing refuge to individual cells.” (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3480481/>).

One report from 2015 cites over 700 papers that support the evidence of persistence of Lyme and other tick-borne diseases ([http://www.ilads.org/ilads\\_news/wp-content/uploads/2015/09/EvidenceofPersistence-V2.pdf](http://www.ilads.org/ilads_news/wp-content/uploads/2015/09/EvidenceofPersistence-V2.pdf)). And there has been much more evidence since.

Researchers at John Hopkins University have now published several papers on the persistence nature of borrelia. In 2014, in an article in Nature, they "identified 165 agents approved for use in other disease conditions that had more activity than doxycycline and amoxicillin against B. burgdorferi persisters. The top 27 drug candidates from the 165 hits were confirmed to have higher anti-persister activity than the current frontline antibiotics. ... Our findings may have implications for the development of a more effective treatment for Lyme disease and for the relief of long-term symptoms that afflict some Lyme disease patients". In 2016, they stated that "Borrelia burgdorferi can develop round body forms, which are a type of persister bacteria that appear resistant in vitro to customary first-line antibiotics for Lyme disease" (<https://www.ncbi.nlm.nih.gov/pubmed/27242757>). In 2017, they found that even "ceftriaxone pulse dosing fails to eradicate biofilm-like microcolony B. burgdorferi persisters" (<https://jhu.pure.elsevier.com/en/publications/ceftriaxone-pulse-dosing-fails-to-eradicate-biofilm-like-microcol>). They also found "Eradication of Biofilm-Like Microcolony Structures of Borrelia burgdorferi by Daunomycin and Daptomycin but not Mitomycin C in Combination with Doxycycline and Cefuroxime." (<https://www.ncbi.nlm.nih.gov/pubmed/26903956>).

In a recent letter, it was stated that "There is 16S ribosomal RNA gene sequencing-based evidence of persistent infection by Borrelia burgdorferi and related spirochetes in patients after full courses of antibiotic treatment for Lyme disease. ... These cases proven by gene sequencing cannot be dismissed by the usual suspect of laboratory PCR contaminations." (<https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2623750>).

Recent research found that "Borrelia burgdorferi manipulates innate and adaptive immunity to establish persistence in rodent reservoir hosts" (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5316537/#!po=0.657895>). Another paper reviews the mechanism of persistence via sleeper cells (<http://onlinelibrary.wiley.com/doi/10.1111/1462-2920.13897/full>). Another study has found that extracellular, live spirochetes accumulate in lymph nodes and hypothesises that this tricks the immune system into making an inadequate response (<http://journals.plos.org/plospathogens/article?id=10.1371/journal.ppat.1002066>).

The evidence for proof of chronic lyme and its severity is discussed in a recent review article (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2876246/>).

### **Specialist Treatment Centre**

**We were pleased to hear that Lyme Disease Action has argued for pilot specialist clinics for Lyme disease which would develop a new protocol, co-designed with patients, for assessing and reviewing patients. Achieving a specialist clinic in Scotland is one of the main aims of the petition.**

We had previously stated that it should involve a multi-disciplinary team of specialists in infectious diseases, immunotherapy, functional medicine and nutrition. We have since been informed that the team should include a cardiologist because specialist analysis of ECGs can be used for diagnosis and because of potential cardiac involvement.

We would encourage collaboration with other medical practitioners who have significant experience in this field. As well as doctors who work to ILADS guidelines in the USA, we would encourage collaboration with Dr. John Lambert in Dublin and Prof. Christian Perronne in Paris.

## **Improve Education**

**We are pleased that there is consistent support for increased awareness.**

In draft guidelines issued by NICE on 25th September 2017 (<https://www.nice.org.uk/guidance/indevelopment/gid-ng10007/documents>), they “agreed that raising awareness is of great importance to improve diagnosis and management of Lyme disease”.

## **Public Education**

**We agree that public education on safe tick removal needs to be adequately resourced and that education messages should emphasise positive action to manage the risk and should not discouraged the public from enjoying the benefits of outdoor exercise. However, we do not agree that this should be limited to tick ‘hot-spots’ and wish this to be extended to all areas of Scotland.**

We welcome the awareness generated by the ‘Big Tick Project’ and request that similar awareness, including Facebook and Twitter campaigns, is directed at human rather than animal health. Resources such as webinars and podcasts are useful but they are not sufficient. Also, we are disappointed that the NHS Inform page on avoiding bugs and germs (<https://www.nhsinform.scot/healthy-living/outdoor-health/bugs-and-germs/avoiding-bugs-and-germs-outdoors>) makes no mention of watching out for a bulls-eye rash and flu-like symptoms after a bite.

We do not believe that reliance on online resources is sufficient to provide the public with the education they need to remain safe outdoors. It is not reaching enough of the general public. Many patients had never heard of Lyme disease before becoming ill. Perhaps if they had, they would have modified their behaviour to avoid being bitten, or been able to recognise the signs sooner and get treatment at an earlier stage. What is really needed is physical leaflets and warning notices and perhaps a TV campaign such as that used at the emergence of AIDS. All children should be taught tick awareness lessons in school like some schools in the Highlands.

We are grateful for the support for a public information campaign that takes a joined-up ‘One Health’ approach to promoting awareness of Lyme Disease, that educates the public through easily digestible fact sheets and patient information, and encourages the general public to contribute to tick surveillance through a Tick Surveillance Scheme. All GP and veterinary practices should display such posters and leaflets. We also want to see suitable warning notices at places such as visitor centres and car parks.

We feel significantly more is needed in terms of such public education. As an example, the notice board in the Regional Infectious Disease Unit at Edinburgh Western General has two leaflet holders provided by Lyme Disease Action, but they currently hold leaflets on HIV and rabies. There are no leaflets on Lyme disease present at all. Lyme disease is 4 times more prevalent than HIV (<https://www.ncbi.nlm.nih.gov/m/pubmed/21196901/>) so why is it not given priority?



We agree that education messages should emphasise positive action to manage the risk and should be worded to ensure the public are not discouraged from enjoying the benefits of outdoor exercise. We believe the awareness should educate the public on avoiding tick bites, how to remove ticks, and symptoms to watch out for if they have been bitten.

However, we do not agree that these should be targeted at times and places where a particular risk is known to exist. Maps of tick distribution by Public Health England show ticks distributed throughout the UK, including Scotland (<https://www.gov.uk/government/publications/ticks-distribution-of-ixodes-ricinus-in-england-scotland-and-wales>). This includes green spaces in urban environments (<https://www.ncbi.nlm.nih.gov/pubmed/28089123>). One of the petitioners was bitten in a country park 20 miles from central Edinburgh, and we know of a number of patients who have been bitten in parks within London (Richmond Park and Bushey Park) and even one patient who was bitten in her garden in Haringey. If the public can be bitten in Central London, there is no argument for believing that patients in any part of the UK are not at risk.

The seasonal activity of ticks is changing with climate change. A recent paper found that “high summer temperatures can cause mass transfer of ticks between development cohorts, resulting in increased activity and therefore increased disease transmission in late autumn and early spring. This suggests that in northern temperate regions of Europe global warming is likely to cause changes in the seasonal patterns of tick-borne diseases” (<http://www.sciencedirect.com/science/article/pii/S1438422107001695>). One of the petitioners was bitten in the first week of March, in early Spring, which does not support the traditional view that the risk is only a summer one.

We wish to highlight the work being done currently by Mountaineering Scotland to increase awareness. They are preparing welcome packs as a gift incentive for new members, including insect repellent, a tick removal tool and Lyme disease information leaflet. Encouraging more organisations to do something similar would be helpful.

### **Primary Care Education**

**Despite the current guidance from the British Infection Society stating that laboratory confirmation is not required for a confidently made clinical diagnosis of early Lyme disease, this will not help patients if GPs are not aware of this. We want mandatory education for GPs and nurses throughout Scotland.**

We are grateful for the explanation on the numbers taking the online course delivered by the Royal College of General Practitioners and Lyme Disease Action. We are disappointed to hear that only 2,368 users have registered for the course. With 236,800 registered medical practitioners in the UK ([https://www.gmc-uk.org/doctors/register/search\\_stats.asp](https://www.gmc-uk.org/doctors/register/search_stats.asp)), if all users are medical professionals that equates to exactly 1% of practitioners having registered. However, we know that a number of patients have registered as users and so the percentage of medical professionals is therefore less than 1%. The course has been available for over 3 years and we are therefore disappointed that its appropriateness to Scotland is only now being considered.

We acknowledge that GPs in the Highlands appear to be better trained than those in the rest of Scotland. This is particularly so for early Lyme disease. However, patient experience is that disseminated and late Lyme disease is not well understood. We are not convinced that GPs in other geographical areas have refreshed their knowledge of the recognition and management of the condition. If that were the case, the RCGP course would have had far more registered users and patient experience would be better than it is.

We are disappointed that reference is made to GP education in tick 'hot-spots'. A person's home location will often not be the location they were bitten, and so we require GPs throughout the country to be educated. However, with 4.2% of blood donors throughout Scotland having positive borrelia serology, we believe that there is no argument for considering 'hot-spots' for GP or public education.

### **Consultant Education**

**It is not just GPs who need education in the persistence of Lyme disease. We suggest that it would be very helpful to patients if consultants were provided specialist Lyme education through the ILADEF Physician Training Program provided by the International Lyme and Associated Disease Society (<http://www.ilads.org/education/physician-training.php>).**

One petitioner has a letter from a senior neurologist stating “Personally. I have never been persuaded by the concept of chronic Lyme disease. ... Nevertheless, I accept that this condition has become somewhat popular on Internet websites and in the lay Press recently. ... At times during the consultation it became clear that she has been significantly distressed by her symptoms over the years. I was not persuaded that she had fully explored all the psychological angles”. If the severity of patient symptoms is not believed, the complexity of diagnosis is misunderstood, and the research proving persistence is ignored, how are we supposed to get treatment?

### **Tick Control**

**We very much support all attempts to reduce tick numbers as mentioned by Scottish government Land and Estates, Scottish Natural Heritage, and NFU Scotland. We support the re-introduction of tick treatment under the Pet Travel Scheme.**

We are disappointed to learn that the removal of the requirement for tick treatment under the Pet Travel Scheme has increased the risk of tick-borne diseases entering the UK and support the re-introduction of tick treatment.

### **Other**

Mention is made of the LymeMap Project. This project was awarded £250,000 of funding from the European Space Agency in 2015. A new mobile app, announced in 2015, was reported as being intended to ‘stop the spread of the disease’ (<https://www.express.co.uk/life-style/science-technology/577129/LymeMap-Scottish-Highlands-New-App-UK-Lyme-Disease-Ticks-Hotspots-Tracking>). The one-year study was intended to test the technical and commercial feasibility of LymeMap and if successful the project was expected to move to a demonstrator phase before being commercialised. However, we have not heard of the outcome and no app has ever been available to the public to our knowledge.

We also have reservations on the use of a vaccine for control of Lyme disease in dogs without further research. A vaccine for use in humans had to be withdrawn very soon after reaching the market because of reports of adverse effects (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2870557/>).

## Suggested Actions

We suggest that actions should include publication and implementation of a **Scottish National Plan for Tick-borne Infections** similar to that developed for France (<http://solidarites-sante.gouv.fr/archives/archives-presse/archives-communiqués-de-presse/article/marisol-touraine-lance-le-plan-national-de-lutte-contre-la-maladie-de-lyme-et>) but including co-infections. This should include:

### Testing

1. Elevate Raigmore to Reference Laboratory status and extend its scope to cover all tick-borne infections.
2. In order to help understand the extent of the problem, make all forms of borreliosis and emerging co-infections notifiable, whether diagnosed through testing or clinically.
3. Comprehensively evaluate borrelia diagnostic methods: DNA, antigen, LTT, Elispot, etc. for all genospecies found in Scotland, including borrelia miyamotoi and borrelia valaisiana.
4. Evaluate and introduce testing for all co-infections, to include multiple species of the common co-infections bartonella, babesia (including babesia duncani), and anaplasmosis.
5. Undertake epidemiological studies.

### Treatment

6. Establish a specialist treatment clinic involving a multi-disciplinary team of specialists in infectious diseases, cardiology, immunotherapy, functional medicine and nutrition, and collaborating with Lyme disease specialists in other countries. Ensure patients are followed up after treatment and treatment outcomes at the clinic are documented and analysed.
7. Require GPs and consultants working in Scotland to follow the guidelines of the International Lyme and Associated Disease Society (<https://www.guideline.gov/summaries/summary/49320>), currently the only approved Lyme treatment guidelines in the US National Guidelines Clearinghouse.
8. Provide GPs with a standardized assessment, based on the questionnaire developed by Dr. Richard Horowitz (<http://www.cangetbetter.com/symptom-list>), describing the list of examinations allowing a complete diagnosis in anyone with symptoms suggestive of a tick-borne infection.
9. Provide resources for research and development into the treatment of chronic tick-borne infections in Scotland.

### Education

10. Educate consultants working at the clinic in persistence and the complexity of multiple co-infections by using the ILADEF Physician Training Program designed by the International Lyme and Associated Disease Society (<http://www.ilads.org/education/physician-training.php>).
11. Require GPs to undertake mandatory training in tick-borne infections.
12. Communicate to all medical professionals, including GPs and nurses, to ensure they are aware of the lack of reliability of tests, the lack of markers of current infection, the emerging research on persistence, the possibility that ticks can transmit multiple infections from the same bite and the added complexity this introduces, and to provide clarity about existing and new testing procedures for all tick-borne diseases.

13. Ensure all tick-borne infections are comprehensively covered in the training of medical students.
14. Run a public awareness campaign including easily digestible leaflets, web-based resources, an online Facebook and Twitter campaign, and possibly a TV campaign, directed at human health, to include information on tick bite avoidance, tick removal and initial signs of illness to look out for after a bite.
15. Require landowners to display information notices at visitor centres and car parks throughout Scotland.

**Tick Control**

16. Establish further methods for tick surveillance.
17. Increase measures for tick control.
18. Reintroduce the requirement for tick treatment under the Pet Travel Scheme.