

## PE1662/C

Royal College of General Practitioners submission of 27 October 2017

Thank you for your letter dated 04 October 2017 following the Public Petitions Committee meeting held on 14 September 2017 at which the above petition was considered. RCGP Scotland have been asked to provide views on issues raised during this meeting and in particular, the suggestion that only 3% of GPs have undertaken the available training on Lyme disease provided by RCGP, in conjunction with Lyme Disease Action. I am happy to provide the following response for the Committee's consideration.

By way of background, let me firstly provide some information on the disease and its prevalence in Scotland and the rest of the UK. Lyme disease or Lyme Borreliosis was first described in 1975 in Old Lyme, Connecticut, USA. It is a disease spread by *Ixodes Ricinus*, the hard-bodied tick, which has a two year parasitic life cycle. Up to 10% of ticks in 'hot-spot' areas may carry the causative *Borrelia* bacteria.

In Scotland, it is agreed that the main '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. It is recognised that a proportion of patients with early disseminated Lyme or late Lyme may not recall a tick bite or rash.

The exact prevalence of Lyme disease in the United Kingdom remains uncertain beyond the number of sero-positive blood tests in reference laboratories. As raised during the Committee's meeting, there is scientific uncertainty around the laboratory tests for Lyme disease as testing can only pick up previous exposure with an antibody test.

The problems regarding data-gathering around Lyme disease are also considerable. There exists significant scientific uncertainty around understanding of the natural history and management of Lyme disease. Problems of collating accurate data at GP level due to poor IT infrastructure means that despite GPs in 'hot-spot' areas reporting an increase in Erythema Migrans cases to Public Health Scotland, there is no accurate data to support this.

RCGP Scotland has been key to the shaping of policy and guidelines in relation to Lyme Disease. I have, for ease of reference, listed these actions below:

- on 9 May 2013 RCGP Scotland published a strategic planning document on Lyme disease.
- RCGP Scotland has been represented on the 2017 NICE Guidelines by Dr David Stephens, North of Scotland Faculty Representative
- RCGP Scotland has been presented on Health Protection Scotland Gastrointestinal and Zoonoses (GIZ) Working Group on Lyme Disease since 2015 and therefore helped to shape strategic policy in this area since this time
- RCGP Scotland was represented at the UK Research Strategy meeting on Lyme disease held on 01 June 2017 and presented the clinical aspects at that meeting.

Given the increased prevalence of Lyme disease in rural areas, RCGP's North of Scotland Faculty, and particularly Dr Jim Douglas, RCGP North of Scotland Faculty Provost, have been particularly proactive on the issue of Lyme disease. Please see

below a list of activities that have been implemented and contributed to by RCGP North of Scotland Faculty:

- RCGP Scotland has initiated and implemented the Highland guidelines on Lyme disease on behalf of NHS Highland for the GPs, Out of Hours and A&E services within Highland
- RCGP, via Dr Douglas, has established new collaborations with the University of Leicester on a new research method of blood tests
- the European Space Agency Lyme App Project required community engagement with regard to public information on tick removal and stakeholders including Occupational Health groupings in communities. This was facilitated by the University of Highlands and Islands in collaboration with Dr Douglas. The outputs include websites and educational material on tick removal
- RCGP Scotland has contributed to collaboration on data extraction for general practice computer systems with Sam Holden, NHS Highland Research Officer
- Dr Douglas facilitated the initiation of the Lochaber GP Cluster prospective study on Lyme episodes during 2017 across general practice, Out of Hours and A&E in Lochaber in order to improve the data sets.

RCGP has also provided and contributed to a range of educational outputs, with a number of these are listed below:

- YouTube videos on tick removal and the early diagnosis of Lyme disease
- Forestry Commission videos on prevention and recognition of Lyme disease for outdoor workers
- educational material for pharmacists at the centre of Lyme disease prevention through their advice and sale of plastic tick removers
- NHS Education for Scotland podcasts and webinars for multi-professional education on Lyme led by Dr Douglas
- collaboration with NHS 24 on their material for public facing advice on tick removal and early detection of Lyme disease.

Additionally, and crucially for the purposes of the evidence requested by the Public Petitions Committee, RCGP alongside Lyme Disease Action, delivers an e-learning course. The course went live in September 2014 and is designed to navigate the GP to recognising the rash, early symptoms and late manifestations of Lyme disease in primary care. The course aims to equip GPs to be able to offer advice on prevention of Lyme disease and to begin appropriate treatment to minimise the complications of the condition. Since launching, the course has registered 2,368 users. (Data covers usage up to 30<sup>th</sup> September 2017) Crucially, this online course can be accessed by both RCGP members and non-members. This is neither restricted to a GP nor a Scottish only audience and it is therefore incredibly difficult to ascertain the exact percentage of GPs in Scotland who have completed this training. However, this is just one of many educational resources available to GPs on Lyme disease. In Lyme disease 'hot-spot' areas where GPs are more commonly presented with symptoms suggestive of possible Lyme disease, it is extremely likely that the percentage of GPs trained in Lyme disease is considerably higher than 3%. Indeed, in such areas GPs are the current experts on Lyme disease and the work carried out by RCGP Scotland to raise awareness of the clinical challenges of Lyme disease has undoubtedly prompted GPs in other geographical areas to refresh their knowledge of the recognition and management of the condition.

RCGP Scotland recognises the distress and complications that Lyme disease can cause for those who contract the disease. Lyme disease is just one of the broad range of infectious diseases which form part of the extensive GP training curriculum and most importantly the training aims to equip GP trainees to identify and address their learning needs in all relevant clinical areas.

Public education on safe tick removal does, however, need to continue and to be adequately resourced in terms of the provision of tick removal devices in all outdoor nurseries, primary and secondary schools in tick 'hot-spots'. The positive advantages of well-being by use of the countryside and outdoor sports far outweighs any small risk of Lyme disease. However, all participatory sports and outdoor activity groups should also be aware of the simple prevention of Lyme disease by tick removal. Simple steps, such as ensuring that the correct plastic tick removal devices, are available from pharmacists should also be taken, given that pharmacists remain the key group in the front line of Lyme disease prevention.

I hope that this information serves to clarify the position of RCGP Scotland on the issue of Lyme disease and associated-tick borne diseases. Should you require further clarification or information on any of the points raised within this letter, please do not hesitate to contact me.