

PE1662/OO

Petitioner submission of 6 October 2020

In response to the Royal College of General Practitioners submission, we are in regular contact with Dr. Anne Cruikshank, the lead GP on the Lyme Disease Spotlight Project. She has told us that, although the project was intended to run until June 2020, it was suddenly shelved in December 2019. At that point, although GP training courses had been designed, none had been run in Scotland. There has therefore been no education provided within Scotland as a result of this project. There are no current resources within the RCGPs to ensure those courses are run in future and no other RCGP initiative to improve education at present.

In response to the Scottish Government submission, we are told that a patient representative has been appointed to the Scottish Health Protection Network (SHPN) Tick Borne Diseases subgroup. A member of an English charity has been appointed who is not resident in Scotland, is not a patient of NHS Scotland, does not have Lyme disease, and does not have regular contact with Scottish patients that we are aware of. We are not aware of any patient of NHS Scotland with Lyme disease or other tick-borne illness that is a member of the committee. Nobody has contacted the main group of Scottish patients to indicate that they are representing our views. We have made representations to the committee to allow a petitioner to represent patient views but this has been declined.

The Scottish Lyme Disease and Tick-borne Infections Reference Laboratory uses an internationally recognised 2-tiered testing protocol. However, the test may be internationally recognised but it has the same issues that were found for testing for COVID-19: antibody testing is an outdated test methodology which was meant for surveillance and not diagnosis. No acknowledgement is made of the variability of antibody response found in infected hosts¹, meaning a test can be negative when there is ongoing infection. In a recent meta-analysis of test kits², it was found that "sensitivity of an individual test was as low as 7.4%. The mean sensitivity of all test kits with all samples was 59.5%, and ranged from 30.6% to 86.2%".

In a related study³, it was found that "using clinically representative LD test sensitivities, the two-tier test generated over 500 times more false-negative results than two-stage HIV testing". Another study concluded that "In the serology of EM in Europe, C6 ELISA does not seem to cover all cases"⁴. Much better tests have been developed but are not used in Scotland. The Phelix Phage Borrelia test is a new test, developed in conjunction with Leicester University, which is designed to test for bacterial presence and is not dependent

¹ Variable manifestations, diverse seroreactivity and post-treatment persistence in non-human primates exposed to *Borrelia burgdorferi* by tick feeding by Monica E. Embers, Nicole R. Hasenkampf, Mary B. Jacobs, Amanda C. Tardo, Lara A. Doyle-Meyers, Mario T. Philipp and Emir Hodzic. Published 13 December, 2017

² [Commercial test kits for detection of Lyme borreliosis: a meta-analysis of test accuracy](#) by Michael J Cook and Basant K Puri. Published 18 November 2016

³ [Application of Bayesian decision-making to laboratory testing for Lyme disease and comparison with testing for HIV](#) by Michael J Cook and Basant K Puri. Published 10 April 2017

⁴ [Antibody responses to borrelia IR\(6\) peptide variants and the C6 peptide in Swedish patients with erythema migrans](#) by Ivar Tjernberg, Heidi Sillanpää, Ilkka Seppälä, Ingvar Eliasson, Pia Forsberg and Pekka Lahdenne. Published 9 January 2009

on host antibody production⁵. We would like to see this test assessed for routine use in Lyme disease testing in Scotland.

No acknowledgement seems to be made that patients who are ill after a tick-bite may have multiple infections. Research has found that polymicrobial infection is the rule not the exception⁶. The Scottish Lyme and Tick-borne Disease reference Laboratory has no ISO accredited tests for any tick-borne infections other than *Borrelia*⁷. A test for *Anaplasma* has been developed but it is not ISO accredited and is only intended for use in the first 4 weeks after a bite, a timescale in which many patients have not even attended their GP.

Many patients are being diagnosed in private testing for *Babesia*, *Bartonella*, *Anaplasma*, and *Rickettsiae* species but test for many of these infections are impossible to get via NHS Scotland. Many GPs have never heard of these infections, and yet they have been found in abundance in animals. For example, a recent study found *Anaplasma* in 73% of sheep and 40% of deer in Scotland, *Babesia ventorum* was detected in 9 % of healthy sheep, and *Babesia divergens* was found in 11 % of wild red deer⁸. These diseases seem to be better understood in animals than in humans. We would therefore like to see testing for all co-infections in Scotland. We would also like to see education of GPs and consultants to ensure they know about all the co-infections which can affect humans and the fact that polymicrobial infection can increase the length and severity of illness⁹.

It is suggested in the petition papers that the petition might be closed. We wish to draw attention to the title of our petition: Improve Treatment for Patients with Lyme Disease and Associated Tick-borne Diseases. Our main request for this petition is that Scotland establish a specialist treatment centre for tick-borne diseases and that all clinical staff who work there are educated on the [International Lyme and Associated Diseases Educational Foundation Physician Training Program](#). Until this has been discussed and evidence provided, it would be unfair to even consider closing the petition.

Patients are being given only a few weeks of treatment and then being discharged while still ill and told it is all in their heads. There is a growing body of research evidence that *Borrelia* is a very persistent infection and this is not being taken into account¹⁰. We need doctors to be educated in the latest research which demonstrates that *Borrelia* can survive years of antibiotic treatment and can result in death¹¹.

⁵ <https://redlabs.be/phelix-phage-borrelia/>

⁶ [Co-infection of Ticks: The Rule Rather Than the Exception](#) by Sara Moutailler, Claire Valiente Moro, Elise Vaumourin, Lorraine Michelet, Florence Hélène Tran, Elodie Devillers, Jean-François Cosson, Patrick Gasqui, Van Tran Van, Patrick Mavingui, Gwenaél Vourc'h and Muriel Vayssier-Taussat. Joseph M. Vinetz, Editor. Published 17 March 2016

⁷ [Schedule of accreditation for NHS Highland. Issued 10 June 2019](#)

⁸ [An investigation of endemic and emerging tick-borne Protozoa and Rickettsia in Scottish livestock](#). PhD theses of Alexander Geoffrey Gray (May 2017), University of Glasgow.

⁹ [Concurrent Lyme disease and babesiosis. Evidence for increased severity and duration of illness](#) by P J Krause, S R Telford 3rd, A Spielman, V Sikand, R Ryan, D Christianson, G Burke, P Brassard, R Pollack, J Peck, and D H Persing. Published 5 June 1996

¹⁰ [Persistent Borrelia Infection in Patients with Ongoing Symptoms of Lyme Disease](#) by Marianne J. Middelven, Eva Sapi, Jennie Burke, Katherine R. Filush, Agustin Franco, Melissa C. Fesler and Raphael B. Stricker. Published 14 April 2018

¹¹ [The Long-Term Persistence of Borrelia burgdorferi Antigens and DNA in the Tissues of a Patient with Lyme Disease](#) by Eva Sapi, Rumanah S. Kasliwala, Hebo Ismail, Jason P. Torres, Michael Oldakowski, Sarah Markland, Gauri Gaur, Anthony Melillo, Klaus Eisendle, Kenneth B. Liegner, Jenny Libien and James E. Goldman. Published 11 October 2019

We suggest that the following be invited: Dr. Cruikshank as the lead GP of the RCGP Spotlight Project; Prof. Lambert who submitted evidence PE1662/DD; and Prof. Perronne who helped develop the National Plan for Tick-borne Diseases which is used in France and which has resulted in the establishment of specialist regional treatment centres.

We do not feel that any of our requests have been addressed in the petition discussion so far. The highest priority request in our petition are:

Testing:

- Provide a test for Lyme disease which tests for more strains of *Borrelia* and does not rely on antibodies.
- Provide tests for all co-infections in Scotland, particularly *Bartonella* (multiple species), *Babesia* (multiple species), *Anaplasma*, and *Rickettsiae*.
- Understand the full extent of tick-borne pathogens in Scotland.

Treatment:

- Establish a specialist treatment centre involving a multi-disciplinary team of specialists.
- Develop SIGN Guidelines for all tick-borne infections, covering the complexities which arise when ticks carry multiple pathogens.
- Provide resources for research and development into the treatment of chronic tick-borne infections in Scotland.

Education:

- Educate all consultants working at the specialist treatment clinic in persistence and the complexity of multiple co-infections by using the ILADEF Physician Training Program.
- Require GPs to undertake mandatory training on tick-borne infections.
- Comprehensively cover all tick-borne infections in student medical training.
- Run a public awareness campaign including easily digestible printed leaflets, web-based resources, an online Facebook and Twitter campaign, and a TV campaign, directed at human health.
- Require landowners to display information notices at visitor centres and car parks throughout Scotland.

Tick Control

- Provide funds for research into effective tick control methods.
- Increase measures for tick control.