

## Lyme Disease UK Response to Lyme Disease Government Petition Response

A petition demanding better testing and treatment protocols for Lyme disease was signed by over 10,000 people, resulting in a government response. Lyme Disease UK is a support network with over 4000 members and some responses from patients and carers were collated and are presented in the table below. We would be grateful for any government answers to comments and queries – please email [lymediseaseuk@gmail.com](mailto:lymediseaseuk@gmail.com)

The petition and government response can be found here:  
<https://petition.parliament.uk/petitions/113475>

Government Statement	Lyme Disease UK Response and Further Questions
<p>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 disease is currently in development and expected to be published in July 2018.</p>	<p>1. The quality of the reviews will depend entirely on the evidence that is called on and the scientific rigour with which it is examined. Professor Whitty who is commissioning the reviews says he wishes to exclude people with “entrenched views” and it is to be hoped that the pruning will not be selective or prejudicial. We also hope that he will fulfill the commitments made in a meeting with Caudwell Lyme Disease</p> <p><a href="https://caudwell-lyme.net/2016/06/03/the-uk-governments-independent-lyme-disease-reviews-a-discussion-with-prof-chris-whitty/">https://caudwell-lyme.net/2016/06/03/the-uk-governments-independent-lyme-disease-reviews-a-discussion-with-prof-chris-whitty/</a></p> <p>2. If the reviews reach the public domain only on completion, with the evidence called and heard behind closed doors, there is a risk that relevant research will not be included. Professor Whitty mentioned in his meeting with Caudwell Lyme disease that the review findings may be able to feed into the NICE process. We are concerned that Autumn 2017 will be too late and that the review findings won't be taken into account by NICE when guidelines are expected to be published in July 2018.</p> <p>3. The Lyme disease community is aware of, and is trying to be involved in, the NICE guidelines development process, but is very concerned by the indications so far. Over half of the comments submitted on the draft scope are from stakeholders representing patients and individual patients. Concerns surround the exclusion from the scope of large groups of patients who may have Lyme disease (e.g. those with CFS), the exclusion of consideration of co-infections, of methods of transmission, of prevention of infection, and of significant strains of Borrelia. Due to conflicts of interest, private doctors specialising in Lyme disease treatment are not permitted to be on the NICE guideline committee, however the doctors with the most experience of Lyme disease are in the private sector.</p>

	<p><b>Questions:</b></p> <p>a) How will evidence be selected?</p> <p>b) Will the substantial canon of current research on Lyme disease be fully represented?</p> <p>c) Will the evidence selected be made public prospectively or only retrospectively?</p>
<p>We are not aware of any evidence that very large numbers of cases are undiagnosed and untreated. Current tests rely on detecting an antibody response and as this often occurs after symptoms appear, General Practitioners (GPs) are advised to treat patients empirically using their clinical judgment rather than relying on a laboratory test. Thus treatment can start immediately and does not depend on a laboratory result.</p>	<p>The evidence exists in many forms, but is not looked for or accepted by the government. Delays in diagnosis often happen when months or years later, patients present to Lyme support groups with ongoing symptoms and then discover that they do in fact have the illness according to private, overseas laboratories. These groups endeavour to present numbers to the government and the government is welcome to reach out to patient groups.</p> <p>It is the patient experience that far too much emphasis is being placed on NHS blood tests which are not 100% accurate and that many people are not benefiting from GP's clinical judgment as they are being told that they can't possibly have Lyme disease even with a history of tick exposure. Whilst testing is poor, and government only accepts positive serology tests for an immune-suppressive disease, this statement cannot be justified.</p> <p>The scale of the problem is emphasised by:</p> <ol style="list-style-type: none"> <li>1. The large number of people contacting support groups such as Lyme Disease UK and the newly established charity Caudwell Lyme Disease for support. Please see <a href="https://caudwell-lyme.net/patients-speak-out/">https://caudwell-lyme.net/patients-speak-out/</a> for examples of patient experiences.</li> <li>2. Recent estimates of the actual number of people infected with the disease are more than 10 times higher than published figures. <a href="https://caudwell-lyme.net/2016/05/18/how-many-people-in-the-uk-really-have-lyme-disease/">https://caudwell-lyme.net/2016/05/18/how-many-people-in-the-uk-really-have-lyme-disease/</a></li> <li>3. A study reported by Roger Evans at a PHE Open Day in March 2015, showed that 4% Scottish blood donors have positive antibodies for Lyme disease. This argues a greater prevalence for infection and therefore lack of diagnosis than thought.</li> <li>4. Official figures for Lyme disease incidence in the UK are considerably lower than in the rest of Europe with no good explanation. See</li> </ol>

	<a href="http://www.counsellingme.com/VIRAS/UKLymeIncidence2.pdf">http://www.counsellingme.com/VIRAS/UKLymeIncidence2.pdf</a> for more information.
<p>All cases of Lyme disease confirmed by laboratories in England are reportable under legislation. Following consultation, legislation does not require notification of clinically diagnosed infections apart from very rare cases of encephalitis. As only a proportion of infected individuals present to GPs with symptoms, the actual incidence of infections would remain unknown even if reporting of probable cases based on clinical observations was complete.</p>	<p>Only reporting cases with positive serology severely impacts the understanding of the number of people contracting Lyme disease in the UK. This statement also suggests that cases ARE left undiagnosed and is a contradiction to what has been said above.</p>
<p>Tests used in the National Health Service (NHS), Public Health England (PHE) and national laboratories across Europe are well established, and are highly reproducible between laboratories. International External Quality Assurance schemes are in place to ensure consistency between different tests centres. Commercial manufacturers and international academic groups have research programmes into improved tests, and PHE with the Liverpool University Health Protection Research Unit also has a small research programme. PHE also have links with groups in the United States and Europe investigating new diagnostic techniques.</p>	<p>Results being highly reproducible between laboratories does not mean that are accurate, nor fit for purpose.</p> <p>There are examples where someone has a negative ELISA from one accredited UK laboratory and a positive from another, also accredited UK, laboratory.</p> <p><b>Questions</b></p> <p>a) Is it possible to provide details of the International External Quality Assurance schemes including details of methodology, tick and Borrelia species used and test kits involved?</p> <p>b) What is the small research programme referred to? Are these the PhD projects announced in 2013? Please give details of the subjects under study, as these projects should be reaching completion.</p> <p>c) Please give details of the 'links' with US and European groups which are investigating new diagnostic techniques.</p>
<p>All medical training includes elements on infectious diseases and their mechanisms of transmission, and in the United Kingdom (UK) the medical revalidation programme ensures that specialists are up to date in their field. A number of infectious disease clinics across the UK see cases of Lyme disease, as do neurology and rheumatology specialist centres. In addition, PHE have appointed a new consultant who will be working with selected regional clinics as well as opening a new service to support the management of Lyme disease.</p> <p>The National Institute of Health and Care Excellence (NICE) and Lyme Disease Action produce guidance and training modules for General Practitioners, and PHE has a helpline for doctors as well as running GP training days. Specialist doctors have access to the literature on Lyme disease and are trained in the recognition and management of the disease within their higher professional training and continuing professional development.</p>	<p>The usefulness of the “revalidation programme” depends entirely on what is included in this “revalidation programme”. The BIA has a very outdated understanding of Lyme disease, consistent with the flawed and outdated US guidelines of 2006. If this is what is being “revalidated” then it increases, rather than decreases, concern. There is no consultant known to be experienced in treating Lyme disease successfully in this country and patients are not aware of the new service set up to support the management of Lyme disease.</p> <p>If the training module for GPs referred to is the RCGP online course launched in 2014, it has a very low participation rate (at last check this was 2% of GPs). It does not, as far as we know, address the problems of persistent Lyme disease.</p> <p>The RIPL at Porton Down does have a helpline which is accessible to GPs. Two problems appear to exist- most GPs are not aware of the helpline's existence and if they do access it, then it is not made clear that those manning the helpline are experts in testing and not clinicians. They are therefore not qualified, over the telephone, to make a</p>

	<p>clinical diagnosis or dismiss the possibility of Lyme disease.</p> <p>Patients also have access to original research on Lyme disease as a lot of it is published online. Patients continually find that doctors are less familiar with the research than they are.</p> <p>a) Is the medical training based on the same inadequate and inaccurate material which forms the basis of current guidance?</p> <p>b) Is it possible to provide details of compulsory Lyme disease education and training in Infectious Disease modules?</p> <p>c) Is it possible to give details of the Lyme disease component in revalidation schemes.</p> <p>d) Who is the new consultant? What is his/her experience of treating Lyme disease?</p> <p>e) Is it possible to provide details of the new service set up to support the management of Lyme disease?</p> <p>f) Is it possible to confirm how many people have completed the training module and how many of these were GPs rather than other health professionals to whom the course is also accessible?</p> <p>g) Is the helpline referred to by PHE in the petition response, the RIPL helpline? Please confirm that those operating this helpline are qualified in testing procedures and are not clinically qualified doctors. Do doctors know about this facility and do they understand its limitations?</p> <p>h) How many of these GP training days have there been? How often are they run? How many doctors, of the approximately 64 000 GPs have so far been trained?</p> <p>i) What guidance do doctors receive to navigate the enormous amount of research on the subject? Are they guided to material which supports the views of PHE and BIA? Are they guided to papers that represent the full range of research in Lyme disease? Or, are they left to navigate it on their own?</p>
<p>Services for the treatment of Lyme disease are commissioned locally and are the responsibility of Clinical Commissioning Groups. NHS England expects commissioners to provide services based on local population needs.</p>	<p>Ticks are common all over the UK and Lyme disease can be contracted in London gardens and urban parks as well as Lake District fells. People travel extensively within the country. Local population needs are not predictable. Services need to be uniform and comprehensive across the country, not subject to a post-code lottery.</p>
<p>All treatment for Lyme or other conditions should be</p>	<p>In an ideal world, this would be the case but in an area of</p>

<p>evidence based, and targeted at the disease mechanisms underlying those symptoms. Each patient should be treated according to the pathological process giving rise to those symptoms. If there is no evidence of active infection, long term antibiotics are not appropriate and in many cases have caused significant harm.</p>	<p>medicine that is still so misunderstood and where more research is desperately needed, the reality is, many patients are not receiving any care. Refer again to <a href="https://caudwell-lyme.net/patients-speak-out/">https://caudwell-lyme.net/patients-speak-out/</a> for patient testimonies. People are being denied treatment despite having serological evidence of Lyme disease and symptoms consistent with the illness. Often, an alternative diagnosis is not forthcoming or symptoms are attributed to CFS for which there is no blood test.</p> <p>The risks of antibiotic therapy should be weighed up against potential benefits in patients who have a chronic infection which renders them unable to work or function in society. Occasionally, diarrhoea and increased antibiotic resistance are cited but modern treatment methods, not practised by the NHS, seek to avoid the latter and uncomfortable side effects are rarely given as a reason for denying cancer sufferers chemo- or radio- therapy.</p>
<p>The National Institute for Health Research (NIHR) welcomes funding applications for research into any aspect of human health, including Lyme disease. These applications are subject to peer review and judged in open competition, with awards being made on the basis of the scientific quality of the proposals made.</p>	<p>A lack of bias is unprovable and The Big Tick Project, <a href="http://www.bigtickproject.com">www.bigtickproject.com</a> which is looking at infection rates in ticks has had to be privately funded. The PHE project surveying ticks is not looking at infection rates and so will show nothing about Lyme disease prevalence or risk.</p>
<p>Lyme Disease Action, the local authorities in the New Forest and other areas, together with PHE already provide website information and leaflets on Lyme disease and tick-borne illnesses. Public awareness materials produced by PHE are available on GOV.UK and NHS Choices. PHE is also involved in a number of local and national tick awareness campaigns that are run annually at the start of the tick season, including coverage on national television.</p>	<p>Information should be available countrywide and funded by the government, not by charities. Website information is of limited use – you have to know about Lyme disease to look for it. One MP, with young children, told a constituent she had never heard about ticks and Lyme disease. Social network surveys of ordinary people revealed almost uniform lack of awareness of any campaigns run by PHE. (One person collected 395 responses of which only 3 had seen government-sponsored information) No-one has seen coverage on TV that has not been stimulated by the patient community. If PHE is doing this, it's not reaching the public.</p> <p><b>Questions</b></p> <p>a) Can we please have details and examples of PHE campaigns?</p>

### A Small Selection of Relevant Scientific Papers:

Demonstrating the issue with using ELISA and Western Blot (current UK method) as diagnosis criteria:

<http://www.ncbi.nlm.nih.gov/pubmed/12422608>

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4042490/#B60>

<http://www.ncbi.nlm.nih.gov/pubmed/21271270>

Demonstrating that the Lyme Disease bacteria is persistence and hence Chronic Lyme Disease does require treatment:

<https://www.ncbi.nlm.nih.gov/pubmed/27141311>

<https://www.ncbi.nlm.nih.gov/pubmed/26014929>

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2786795/>

<http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0048277>

<http://www.ncbi.nlm.nih.gov/pubmed/23479042>

<http://ije.oxfordjournals.org/content/34/6/1439.full>

<http://www.ncbi.nlm.nih.gov/pubmed/9266264>

Covering the importance of considering other pathogens ‘coinfections’:

<http://www.ncbi.nlm.nih.gov/pubmed/8637139>

<http://journals.plos.org/plosntds/article?id=10.1371%2Fjournal.pntd.0004539>

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3565243/>

<http://bmcmusculoskeletdisord.biomedcentral.com/articles/10.1186/1471-2474-3-15>

<http://www.ncbi.nlm.nih.gov/pubmed/15938513>

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3565243/>

<http://www.ncbi.nlm.nih.gov/pubmed/9266264>