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Participants on the LDUK discussion board asked a series of questions about LDA. These were gathered into one document and sent to LDA.  
LDUK text black on white; LDA answers in the green boxes.  
These answers were correct at the date of the document. For current information see the LDA website.

## **Questions posed by LDUK Lyme patients to LDA trustees**

November 4<sup>th</sup> 2015

### **Role of LDA**

“Striving for the prevention and treatment of Lyme disease and associated tick-borne diseases”

The role of LDA is not very clear. On the welcome page patient support is not mentioned, but it is evident as a role in reports of activities. LDA is treated, and allows itself to be treated, as though it is the voice of the Lyme patient community, but does not engage in conversation with Lyme patients. The information gathering and dissemination role is clear and done well but its role with respect to patients and the authorities needs clarification. In practice support of individuals seems unpredictable. We quite understand if LDA feels that some roles are difficult to maintain in harmony with other roles, but this needs clarification.

### **Background and History**

LDA is a registered charity formed in 2003. We are a small group of trustees and regular volunteers. We have no paid staff and no premises. We are funded entirely by public donation. – so far, at least, we have not received any funding from any government agency. By law, trustees of a charity cannot benefit financially from their work. Some of us have full or part-time day jobs, but we all give freely of a lot of our own time to help move things forward. All trustees have experienced Lyme disease ourselves, either as sufferers or as carers, including the negative attitude of many doctors. Many of us still have significant health problems as a result.

“Striving for the prevention and treatment of Lyme disease and associated tick-borne diseases”, is a mission statement, not a definition of our role. Our activities as registered with the Charity Commission are:

Lyme Disease Action is campaigning to improve prevention, diagnosis & treatment of Lyme disease by

- 1) making high-quality information on Lyme disease available, including via publications and conferences
- 2) providing a help desk for public and health professionals
- 3) parliamentary lobbying
- 4) fostering scientific and medical education and research into Lyme disease and its associated diseases.

LDA does not formally represent people so much as work to improve the situation for all stakeholders in Lyme disease. This includes presenting patients' views and experiences to doctors, healthcare agencies, researchers etc, but also presenting doctors' views etc. to patients. The aim is to promote good unbiased evidence to everybody. We distributed 20,000 leaflets in the last year, including to many hospitals and GP surgeries, as well as various outdoor and countryside bodies. We see raising awareness and political lobbying as an essential part of achieving our mission.

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## 1) LDA representation of patients

- a) Is LDA going to engage in any real consultation with Lyme patients and carers? LDA can only claim to represent those whom they consult and this should be public and transparent.

LDA does engage with patients and runs an active support service with thousands of enquiries over the last few years. It is not very visible because it is a confidential service. We receive and respond to many emails outside the help desk as well on many matters concerning ticks and Lyme disease. We have been members of many discussion boards since their inception and listen to patients' views constantly. LDA holds an annual conference every year which is attended by some doctors but primarily by patients. All trustees are approachable and make an effort to talk to patients at the conferences. Patient and carer workshops were included in the 2010 conference. LDA initiated, funded and organised the JLA Partnership which reported in 2013, and which openly sought and collected questions from doctors and patients. The majority of the 69 uncertainties came directly from patients.

- b) Can LDA act in the interests of individual patients whilst also maintaining a close relationship with PHE? Patients and PHE are often in conflict and for the individual patient fighting for diagnosis and treatment there is no "middle path".

Yes; the relationship with PHE has been instrumental in moving things forwards. It is important to note that PHE, or more specifically RIPL (Rare and Imported Pathogens Laboratory), is not the same organisation as the HPA. We have a professional working relationship with PHE. We have regular meetings and are working with them as part of our campaign to bring about improved services.

- c) Does LDA seek to represent all patients, those with +ve NHS tests, those with +ve foreign tests and those with only clinical diagnoses? And how does it interpret "represent"?

LDA aims to work on behalf of everyone who has or may have Lyme disease and other tick-borne infections, regardless of their test results.

## 2) Relationship with PHE

- a) In what respects is LDA dissatisfied with PHE's activities? Will LDA hold PHE to account in public over inadequacies and failings, such as those identified?

Prior to 2012, the HPA refused to engage in any meaningful discussion with LDA about significant concerns. Since 2012, LDA has been invited to engage in ongoing dialogue with RIPL/PHE, who appear to be more mindful of the need for patient engagement. LDA believes it has been able to use its credibility to promote a more open-minded approach to Lyme disease, following repeated discussions of the available scientific evidence base and the pressing clinical dilemmas that are an inherent aspect of the patient helpdesk. LDA would like to see the engagement with PHE translate into an interactive relationship with NHS specialists which benefits Lyme disease patients.

- b) Is LDA happy with the new statement that has appeared on the NHS choices website: *"Chronic Lyme disease" There has recently been a lot of focus on Lyme disease in the media, with much attention on people who've been diagnosed with*

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*"chronic Lyme disease". This term has been used by some people to describe persistent symptoms such as tiredness, aches and pains, usually in the absence of a confirmed Lyme disease infection. It's different to "post-infectious Lyme disease" (see above), which is used to describe persistent symptoms after a confirmed and treated infection. It's important to be aware that a diagnosis of chronic Lyme disease is controversial. Experts do not agree on whether the condition exists, or whether the symptoms are actually caused by a different, undiagnosed problem. In either case, there's no evidence to suggest people diagnosed with chronic Lyme disease can pass the condition on to others, and there's little clear evidence about how best to treat it." If not, has LDA complained about this?*

We hadn't seen that statement on the NHS Choices website, so thank you for bringing it to our attention. We are not happy with it and we will do what we can to get it changed.

- c) Should LDA be doing the public-awareness-raising work for PHE or challenging PHE to do it? LDA may supplement awareness-raising work but if it is doing the work of PHE surely it should be publicly funded, not using its donated funds. Donated funds should be used for work additional to that which is PHE's responsibility. Who funded the HIV campaigns in the 80s?

Raising awareness is part of LDA's remit. If people are aware of the risk and seek treatment as a result, or avoid falling ill in the first place, then we think that is a good use of our funds. That doesn't mean we do PHE's work for them. They have their own channels of communication to the medical profession and the public, and we are pressing them to do more.

- d) If LDA's "information standard" status and helping an individual patient access diagnosis or treatment are in conflict, which is more important to LDA?

There is no conflict between the Information Standard and the need to give the best possible information to patients and doctors. The Information Standard (TIS) was initiated by the Dept. of Health and is now under NHS England, but is independent of them. The system is based on general good Quality System practice such as ISO9001. Accreditation and auditing are overseen by an arms-length company contracted by NHS England. When we started the process the attitude of the DoH and the HPA towards Lyme disease was very negative. We specifically asked if it made a difference whether we agreed with the DoH, and were told emphatically that it did not. TIS requires that information promoted by health organisations is based on good evidence. It does not demand conformity to any specific viewpoint on any particular medical condition. It also does not substitute for guidelines and does not dictate a patient's medical care and treatment.

Accreditation to the Information Standard means doctors cannot justify dismissing us. It is why more doctors are more likely to accept our information and why the RCGP approached us to write their e-learning module for doctors.

### 3) Relationship with BIA

- a) LDA challenged BIA about its guidelines on LDA's website. Infectious disease consultants are often the most difficult barrier preventing Lyme sufferers accessing a diagnosis because the BIA guidelines insist on positive NHS tests and do not admit either to the fallibility of the tests, nor to the possibility of seronegative Lyme

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disease. Does LDA have any plans to challenge BIA more publicly and effectively about this, to ensure that ID consultants do not rule out Lyme Disease solely because of negative antibody tests?

LDA sought a meeting with the BIA in 2013, using a mediator, to discuss concerns with their Position Statement. They declined all requests for a meeting. We are continuing to work with consultants whenever the opportunity arises. We have recently submitted a paper to a medical journal which outlines our concerns.

4) RCGP online course

- a) Producing this was very constructive. The lack of GP take-up (about 1%) is very disappointing and clearly needs action which is not the responsibility of LDA or patients. Is LDA intending to lobby RCGP/BMA/PHE and use the media to make sure that take-up is vastly increased?

Figures to the end of September 2015 show that 845 doctors have taken the course so far. This is a promising start.

LDA is looking at ways to promote the course further through CCGs and professional organisations and has recently paid to continue to make the course open access and not just available to RCGP members. It is important to note here that doctors are free to choose their own CPD and neither the DoH nor PHE has any authority to compel them. Individual patients can also help with this - there is a [flyer on our website](#) that can be printed and taken to GP surgeries and pharmacies to raise awareness of the course.

5) Relationship with LDUK

- a) Does LDA suggest that people who approach them may find further help and support with LDUK, just as LDUK directs people to LDA for the help that they can give? If not, why not?

LDA does not direct people towards on-line patient forums. Although they can be very helpful they are also unpredictable and inconsistent in the ad hoc nature of the advice and information given to patients by individual forum members. LDA is concerned that some contributors on LDUK appear to over-emphasise the inaccuracy of UK serology tests whilst appearing to offer a platform that might steer people towards expensive private overseas tests, without any explanation to patients of the inherent limitations of all such serology tests, and without demonstrating any evidence that it has subjected the overseas tests to a similar degree of scrutiny.

**Public Statements (press, website and presentations)**

It is understood that sometimes organisations are misquoted. These questions are stimulated by website and presentation statements and by frequent comments in the media. Clarification of LDA's position would be useful for all:

- 1) Criticism of "patient support groups", sometimes explicitly LDUK, are frequent and derogatory. How is it consistent for LDA to deride and criticise LDUK in public and then speak of working together? This is only one question but it goes to the emotional and logical heart of the differences between us. Whilst patient support groups may necessarily be filled with people with a range of experience, LDUK is in the main a

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responsible forum with a large number of knowledgeable people keeping an almost round the clock eye on posts and ensuring that no poor advice goes unchallenged, has excellent, sensitive but firm moderation and a warm atmosphere. Many LDUK people appreciate being able to refer sufferers to LDA, and frequently do, but it soils the relationship when we are criticised in public.

We don't think we have specifically mentioned LDUK critically in public, nor that we frequently criticise patient support groups. LDA has published in the peer-reviewed literature a strong objection to patients and their support groups being denigrated and unjustly portrayed as 'Antiscience' or 'Pseudoscience'. The corollary is that we believe we have a duty to speak out when we believe patients are at risk of being misled or misinformed.

- 2) LDA's recent statements criticising patients who go abroad for diagnosis and treatment and saying they are "fuelling the fire" are unacceptable to many and are themselves inflammatory. Please would LDA say what they would recommend to a patient who has negative UK tests, has every possible indication of Lyme Disease and who cannot get treatment in this country? What is wrong with going abroad?

We have looked for the source of the "fuelling the fire" quote to check the context, and it comes from a Huffington Post article on 12th October. That comment was not intended to imply that patients are deliberately creating tension. We do understand why many people go abroad if they are getting no help from their NHS doctors.

Patients with negative test results can look at the self-help pages on our website for suggestions on how to present their case to their doctors. The LDA helpdesk has been able to help a number of people with negative Lyme serology access care and treatment by working collaboratively with their doctors and RIPL, PHE. LDA presented an example of a case of probable seronegative Lyme neuroborreliosis, successfully treated and re-treated with IV ceftriaxone at its 2015 conference.

- 3) Recently, several LDA comments have been seen about the BBC Inside Out West programme concerning so-called false positives. These are inappropriate and inaccurate. Single incidents cannot be valid in an evidence-based context, there are many reasons why an apparently healthy person might produce positive tests (as the Scottish study done by Roger Evans and reported at the March 2015 PHE conference demonstrates) and the quoted details are not accurate. Will LDA recognise this, stop quoting this data and correct it when others do so?

The reporters had false positive results and at the time it seemed to scupper progress LDA had made in attempting reconciliation between IGeneX and RIPL. False positives are as much a feature of the inherent problems in serology as false negatives and LDA does not ignore either.

- 4) LDA's recent statements about foreign labs and their tests have been very all-inclusive. Please would LDA make clear in public which tests and/or labs they accept? A list of labs and tests would be the clearest way to do this. Use of the word accredited is not clear because many of the labs and/or tests which LDA rejects do have accreditation. (This question overlaps with a question in the section on Testing. The emphasis here is on the

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public statements made about foreign labs and tests. The question in the Testing section is more about the detailed views of LDA on specific labs and tests.)

We don't have the resources to compile a list of tests and labs and to give them all a fair analysis. We do not "reject" labs, we simply provide information on why a particular set of tests from a particular lab may or may not be useful and may or may not be accepted by a UK doctor.

### Testing

- 1) Although on their website, LDA give reasons why the NHS testing for Lyme is unreliable, advice to patients seems often to be that NHS tests should be accepted. Please would LDA clarify their position on NHS tests? In particular do they accept that patients who have negative tests may have Lyme disease, that antibody tests can never rule out Lyme disease and will they always point this out to GPs and consultants?

LDA has never said that "NHS tests should be accepted". LDA believes that Lyme disease should be a clinical diagnosis, supported if possible by test results. We explain the limitations of Lyme serology tests and explain why they cannot be used to rule out Lyme disease. Yes, we do point this out to GPs and consultants, both verbally and in writing. When we write a paper for a journal we point this out and it's also in the RCGP module, on our website and in [LDA newsletter articles](#).

- 2) LDA often calls into question the reliability of tests from "unaccredited foreign labs". This blanket statement causes problems for Lyme patients in principle and in practice. As many of the labs which seem to be included in this are fully accredited to international standards (for example Armin labs has Dakks accreditation and all of their tests are CE marked. Igenex have their results accepted by medicaid and medicare and a number of state health boards) please would LDA give more detailed information on their views about foreign testing.

The main body calling these tests into question is PHE which requires in vitro diagnostic test kits to meet certain accepted EU standards and for labs to be accredited, in order to demonstrate quality and proficiency. LDA also regularly calls into question the suitability of the serology test kit currently used at RIPL.

LDA can find no evidence that ArminLabs has DAKKS accreditation. The DAKKS website is easily accessible in English with a list of accredited labs, and ArminLabs is not there. Infectolab, where Dr Schwarzbach used to work, is listed, but their accreditation only applies to their lab. If ArminLabs is accredited they will have a certificate from DAKKS showing which specific tests are included in the scope. If anyone can find evidence of their accreditation then we will be pleased to acknowledge it.

Please could they list:

- a) Any tests which LDA considers should never be accepted from any lab, with reasons.
- b) A list of accredited labs which LDA does not consider to be reliable, with reasons.
- c) A list of accredited labs, tests from which LDA would recommend the NHS should accept, which Lyme patients can rely on and which doctors can regard with interest even if they cannot formally recognise them.

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- d) A list of any individual tests from the above accredited labs which LDA would not accept, with reasons.

CE-marking of a test also does not necessarily mean that it is reliable. To obtain a CE mark a manufacturer has to provide evidence that a test meets their own definition of what the test does. If that definition is narrow and specific enough then it is possible to validate even a relatively poorly-performing test. Nevertheless, if the lab is accredited to a national standard then it at least means they are independently audited to ensure that their procedures for handling samples, avoiding contamination etc. meet the standard. It is then more likely that the results of the test will be accepted by a UK doctor.

There is evidence that Lyme borreliosis which is caught in Europe is picked up less well by American tests which rely solely on *B burgdorferi sensu stricto*. LDA facilitated a meeting with IGeneX (Jyotsna Shah) and PHE/RIPL in 2013 to discuss their respective tests. Both IGeneX and RIPL agreed it would be good to work together and swap samples. Unfortunately that did not progress as LDA had hoped. Recently at a conference in Vienna, LDA's Medical Director, Sandra Pearson, discussed this with Jyotsna Shah who said IGeneX had been really busy but that she hoped to follow-up on the proposal to collaborate with RIPL.

There are so many labs offering tests for Lyme disease that it would be an enormous amount of work to do justice to an analysis of different labs and their tests and to maintain that list afterwards. LDA cannot do that.

- 3) What is the opinion of LDA on the Advanced Labs pure culture test developed by Eva Sapi and Burrascano? Surely culture positivity in patients who have failed standard courses of antibiotics but yet remain ill with Lyme-like symptoms, would be proof of ongoing active infection and the need for further antibiotic treatment. Why does LDA not challenge PHE openly on this?

LDA are not experts in *Borrelia* culture and is aware that it is notoriously difficult and insensitive and we are aware that the claims made about the test have been openly challenged on the grounds of possible contamination. This was disappointing as better direct tests are urgently needed. It is not sensible for LDA to encourage patients to pay for expensive tests like this, when apparently credible doubt has been cast on their validity.

- 4) What is the opinion of LDA on dark field microscopy? Does it have a place in Lyme diagnosis and if not, why not? Why is it used by many doctors abroad? Are they misguided?

Darkfield microscopy has been used in syphilis, but this was used on skin lesions, with more chance of viewing any spirochaetes, and not blood. In later infection particularly, Bb are only found in the blood in small numbers as they have worked their way into body tissues, so it is fairly unlikely that any will be present in a small blood smear. There is evidence that certain specialist microscopy techniques e.g. Focus Floating Microscopy, may be useful in examining tissue samples.

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- 5) What does LDA understand to be the usefulness, significance and limitations of the CD57 test?

LDA is aware of reports about the use of CD57 in some chronic Lyme patients and one case report. More convincing research appears to show no difference in CD57 count between healthy patients and people who continue to have symptoms after conventional antibiotic treatment ([Marques 2009](#)). Please note that LDA does not agree with the use of the term Post Lyme Disease Syndrome (PLDS) as used in this paper, since it is not possible using current tests to know how many of these patients were still suffering from chronic Lyme disease.

CD57 is not specific to Lyme disease. CD57+NK cells have been shown to be reduced in several different auto-immune conditions and raised in several infectious diseases.

- 6) What does LDA understand to be the usefulness, significance and limitations of LTT tests such as, specifically, the Elispot, particularly because it is accepted as of use in the diagnosis of TB?

Usefulness in one infection does not necessarily imply usefulness in another. The organisms that cause LD and TB are very different. The manufacturers of the ELISPOT test are not listed on the DAKKS website. They say they are accredited to ISO13485, but that is a quality system standard for medical manufacturers. On its own it does not entitle them to CE-mark their products. A medical product must have a Declaration of Conformity specific to the product and must show a CE mark including the 4-digit code number of the independent Notified Body that handles the accreditation. The manufacturer does not provide any accessible evidence that they have this. Again, if anyone can provide this evidence we will be happy to acknowledge it

- 7) LDUK often experiences patients who have consulted LDA being given what amounts to a clinical diagnostic decision by the Chair of LDA, especially when a patient is advised that enough treatment has been given or that a diagnosis of Lyme is not correct. Does LDA endorse the ability of the Chair to give this advice?

LDA does not give consultations nor clinical advice and does not endorse any trustee to give it. We are very careful in our wording that we only provide information and evidence. We do not offer an opinion on whether any individual has Lyme. We do always check doses and duration of treatment against BNF, CKS and EFNS guidelines recommendations and comment when they fall short. All correspondence that goes through our help desk is recorded on a secure ticketing system so that the evidence is available should we be challenged. If anyone who has been in touch with the helpdesk has interpreted what we have said as a diagnostic decision then please get in touch again. We are approachable and will be happy to review the wording and explain what was said. It might be helpful to see the presentation that our medical director gave at our last conference about how our helpdesk works.

- 8) LDA liaison with RIPL is on occasion valuable. Can LDA not use its relationship with PHE to
- a) Ensure that the correct guidance is given at the end of test results from RIPL eg it should not say “no further action necessary” in the case of negative tests with a suspicion of late or chronic Lyme?



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We are already working to persuade RIPL to improve the comments provided with the test results.

- b) Ensure advice to doctors on co-infections is not dependent on a +ve Lyme test, given that Lyme tests are not reliable?

We are not aware that doctors are being told that testing for other tick-borne infections is dependent on a positive test for Lyme disease. If anyone has any examples of this happening then please contact us.

- c) Ensure that doctors are helped to interpret Lyme tests accurately? Currently many are confused as to what the tests mean, especially the unusual interpretation of IgG and IgM results in Lyme.

We provide information to doctors to help in interpretation of the test results in the light of the patient's clinical history.

### Diagnosis

- 1) What is LDA's position, and how does it advise doctors, on a flexible clinical approach to diagnosis? LDUK sees many patients, for example, with suspected chronic disease, who have negative UK tests, but history and symptoms consistent with Lyme Disease, a positive Elispot LTT test and a low CD57. Although the latter two tests are not formally accepted in the UK, how would LDA advise or suggest that a doctor deals with such a patient?

LDA provides doctors with information to enable them to take a clinical decision based on the patient's history as much as any test results that are presented to them. We have no evidence that CD57 and ELISPOT are specific enough to enable a diagnosis of Lyme disease.

- 2) Another frequent occurrence is that of Infectious Disease consultants ruling out Lyme solely on the basis of negative UK serology and then making a diagnosis of CFS, all other possibilities having also been ruled out. Does LDA support this pattern of CFS diagnosis and if not, what does it do to support patients in this position?

We do not support a diagnosis of CFS based solely on negative test results for Lyme disease. CFS/ME and Lyme disease both have symptoms overlapping those of other conditions and diseases. We provide support to patients via the LDA help desk and information given on our website.

- 3) Given the diagnosis difficulties of bartonella and babesiosis, does LDA actively support consideration of these two diseases by doctors and encourage clinical diagnosis and empirical treatment?

We support consideration of other tick-borne diseases and they are mentioned in the RCGP course.

- 4) Does LDA think it is wrong to advise those patients with difficult chronic complex disease to go to other doctors, at home and abroad, who use a multi-disciplinary approach to look at nutritional deficiencies, genetic problems, hormonal imbalances, food and

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environmental sensitivities and other infections, in a way which can improve some chronic illness?

LDA deals with tick-borne diseases and cannot comment on other diseases and conditions. LDA supports a holistic evidence-based approach to chronic health problems associated with Lyme disease. We do recognise that people have the right to make their own health choices and aim to provide information to support this.

**Advice to Doctors in primary and secondary care, apart from primary diagnostic and treatment advice.**

- 1) Patients are concerned that advice on the following Lyme-related issues is not being passed on or made available for doctors to allow them to better support patients who are in treatment. It is very difficult for patients to explain these issues to doctors who regard anything which comes from the patient as suspicious and unreliable. If doctors were introduced to these aspects of Lyme by an organisation trusted by the NHS it would considerably ease the relationships between patients and their doctors, especially when the patients are receiving specialist treatment that the doctor does not understand. Can LDA provide this information for doctors?

- a) Herxing – what it is and how to manage it.

The LDA website contains a section on the Jarisch-Herxheimer reaction and a link to NICE Clinical Knowledge Summaries which provides information on the diagnosis and management of this.

- b) Supplements considered generally useful whilst patients are on treatment such as glutathione, magnesium and probiotics.

We can give doctors information on the known pros and cons of probiotics and on supplements that are known to interfere with specific antibiotics. All supplements should be thoroughly investigated before taking them.

- c) Co-infections – what they are, what the symptoms are, how to test for them, when and how to consider making a clinical diagnosis.

We have some information in our leaflets, and can provide what peer-reviewed information we know about. There has been even less research into the prevalence of other tick-borne infections in the UK than into Lyme disease, so there is a huge uncertainty there.

- d) Cyst forms of *Borrelia* and biofilms, which are important features of Lyme disease – what they are and what treatment might involve.

We cannot provide information until research has provided answers on significance and treatment.

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- e) Other medical conditions that may be spin-offs of Lyme disease – thyroid and adrenal issues, yeast infections, SIBO, gastritis, sleeping problems, pain.

We recognise that Lyme disease can affect multiple body systems. Areas such as gastroenterology and pain management are outside LDA's remit and local resources are better known to the GP.

- 2) Does LDA believe that doctors in primary and secondary care need more education on orthodox treatment and these associated aspects? Is it pushing for the relevant authorities to make such education available?

LDA believes that medical awareness and education on Lyme disease and associated tick-borne infections requires improvement and regularly pushes for this, whilst recognising the significant difficulties and obstacles that need to be negotiated in order to achieve marked progress. We are actively lobbying for a network of specialist Lyme clinics to develop and foster much needed UK expertise.

### Treatment

1. UK guidelines appear to have been drawn up with input from LDA – the provenance for the *Map of Medicine* for Lyme, now unavailable to the public, credited LDA as contributors. However these run counter to some information on LDA's website eg dose of 200mg doxy per day compared to 300 or 400mg. UK guidelines are the same as the IDSA not those of ILADS. Please clarify whether LDA regards IDSA or ILADS treatment guidelines as being more appropriate for treating Lyme disease?

The Map of Medicine itself does not mention the dose of doxycycline, but refers to a paper that did. We provided some information, but do not necessarily support every publication that the MoM referenced. We have a history of pointing out the many deficiencies in the IDSA guidelines: see our website. The IDSA are currently reviewing their guidelines, but we believe the proposed process is flawed, and have submitted a [public comment](#) to that effect. ILADS guidelines offer more flexibility to the treating clinician.

2. In individual cases is LDA willing to advise doctors that UK guidelines are not sufficient (even if the doctor may not take that advice)? To take some examples:

The UK only has Lyme disease guidance for primary care, so by definition it is inadequate. LDA regularly informs clinicians of the limitations of current guidance and any recommendations made.

- a. What would LDA's advice be to a doctor treating a small child who had primary and secondary EM rashes, had Lyme symptoms, had 3 weeks amoxicillin started 2 months after the bite and is still symptomatic. Is the advice that the doctor should stop treating?

LDA would provide evidence of the benefit of re-treatment from the medical literature and would also check the dose of amoxicillin. However, as stated above, we are careful not to cross the line into individual treatment advice.

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- b. What would LDA advice be to a person with late disease who has positive UK tests, who has been treated according to UK guidelines but is still symptomatic?

LDA would present evidence of the benefit of repeat treatment where there are ongoing symptoms, which the person could present to their GP for consideration. We would also draw attention to the difficulty involved in assessing any individual patient: whether continuing symptoms may be due to persistent infection, inflammation, damage to nerve tissues, co-infection or a combination thereof.

- c. What would LDA advice be to a person with a strong clinical history of late Lyme disease, but with negative UK serology?

To look at our self help pages for reasons for negative serology, document their history and discuss with their GP. They may have the option of contacting the LDA help desk for further support.

- d. Where does LDA stand with respect to long-term antibiotic treatment in late disease?

There is a lot of anecdotal evidence of the effectiveness of long-term treatment in late disease, although even that does not work for everybody. One of the problems here is that the doctors who treat this way tend not to record and publish their results in peer-reviewed medical journals, and so far there has been a lack of research to quote to doctors. Given the justifiable concerns over the over-use of antibiotics in some applications, LDA's credibility could be at risk if we do anything more than state what evidence there is and what uncertainties there are.

3. Where does LDA stand on the alternatives to abx treatments that have been accepted by many mainstream Lyme doctors, such as herbals and targeted supplements?

LDA knows of no evidence that herbal treatments have an effect on Lyme disease other than in some cases relieving some symptoms. LDA has no evidence on supplements.

4. Is LDA pushing the UK authorities to put money into treatment and testing research as well as/instead of more research into tick distribution and ecology?

The JLA project referred to earlier proved that most aspects of Lyme disease are under-researched and poorly understood. Research into better testing is being carried out by PHE. We are working to convince NIHR to put funding into treatment studies. LDA believes this should be in addition to research into tick ecology and screening ticks for pathogens.

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## Controversies and public safety

These are not so much controversies as difficult areas to research definitively given the inability to experiment on humans.

**LDA argued hard to place the confirmed uncertainties on transmission in the JLA top 10 uncertainties, and that remains our position on all these questions.**

### 1. Congenital/Maternal transmission

- a. Exactly what is the LDA stance on maternal transmission of Lyme and Babesia? We hear various things in press reports and would like to know exactly what is a misquote and what LDA considers to be factually accurate. The statement in the Lords' briefing note says that maternal transmission to living children is unproven but this avoids the issue of what LDA think is actually likely or possible.

LDA has stated that transplacental transmission of Lyme disease has been reported but has no evidence beyond that and will not guess.

- b. Does LDA agree or disagree with the conclusions of Dr Sarah Chissell in her talks, one of which is on the LDA website, where she says she thinks congenital Lyme disease exists (her talk is essentially a literature review)?

Dr Chissell's presentation was primarily a review of the available medical literature. We acknowledge the limited evidence there is, and our answer is as above.

- c. If the LDA position is that congenital Lyme and maternal transmission is possible but not irrefutably proven, what do they consider is the responsible position to take with regard to statements to the media and advice to patients and doctors – to warn that it may be possible and open the door to protective therapy, or to reassure that it is impossible, close that door and risk unborn children being harmed unknowingly by mothers?

Any pregnant woman with Lyme disease should be treated as studies have shown adverse outcomes are more common in untreated cases.

### 2. Sexual transmission

There is too little research to give a definitive answer on this. Ray Stricker and Sam Donta took an hour to debate this issue at the 2015 Lyme Disease Association conference in Rhode Island and the conclusion was "more research needed".

- a. What is the LDA stance on sexual transmission of Lyme disease?
- b. Given that there is evidence that borrelia can be found in vaginal secretions and semen, that some animal studies have shown transfer and that anecdotal evidence suggests that sexual transmission may occur, what does LDA consider to be the responsible position to take with respect to statements to the media and advice to patients and doctors? Protection from sexual transmission is

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relatively straightforward and the implications, both for populations and individuals, of not doing so if transmission is possible, are severe.

### 3. Blood transfusions

- a. There is good evidence to suggest that Lyme could theoretically be transmitted by blood donation. For example studies done in 1990 demonstrated that Lyme could survive blood bank storage conditions. The restrictions on blood donation concerning Lyme disease (taken from [my.blood.co.uk](http://my.blood.co.uk)) are: "You must be completely healed/recovered from any infection for at least 14 days before you give blood. If you are taking antibiotics you must wait for 7 days after your last tablet. If you have hospital or GP appointments pending then you must also wait until these have finished" Considering how many people who develop Lyme do not know about it at the time, considering how many people are told by doctors that their EM rash is nothing, and considering how many people are given 1, 2 or 3 weeks doxy and appear symptom free but develop late Lyme after months or years, does LDA consider the blood supply to be free of significant risk of carrying Lyme and Babesia?

LDA does not consider the blood supply to be free of risk.

- b. Does LDA consider the blood only to be infected with spirochetes for a few weeks after infection, even if untreated, as does the NHSBT?

In later infection there are fewer bacteria in the blood as they tend to move into body tissues, but there is at least a theoretical risk at any stage that some bacteria could be collected in the blood that is drawn. Spirochaetes being passed in this way would not necessarily lead to infection. Donated blood cannot practically be screened for every possible pathogen and Lyme disease is one of many diseases where there may be bacteria in blood before a person feels unwell.

### 4. Other vectors

- a. What is LDA's view on other vectors, such as mosquitoes, sandflies, horse-flies etc. Does LDA consider that it is only ticks which can spread Lyme? Yes, no or possible?

There is a highly evolved relationship between the tick and *Borrelia*. There have been anecdotal reports of cases of Lyme transmitted by other vectors, but as far as we know it has not been proved in animal studies. Everyone is aware of being bitten by a horse fly or a mosquito, and it might be easy to blame that rather than the tiny, unnoticed nymph tick.