

## LDA position statement on HPA information on Lyme Borreliosis

2<sup>nd</sup> edition, October 2007

HPA information taken from their website

[http://www.hpa.org.uk/infections/topics\\_az/zoonoses/lyme\\_borreliosis/default.htm](http://www.hpa.org.uk/infections/topics_az/zoonoses/lyme_borreliosis/default.htm)

### General

Science tries to make sense of the world by creating theoretical models of how it works. In most cases there is some simplification involved in order to make the model workable in practice, but as long as any resulting error is small enough the model is considered acceptable.

And this is the fundamental test for any model – that it is a reasonably close match to observed reality. In the case of Lyme borreliosis the observed reality – whether laboratory research or clinician and patient experience – is often quite different from the model put forward by the HPA. In such a case we can only conclude that the model is incomplete.

The following is a page by page assessment of the information from the HPA website. Some information is repeated in more or less detail on different pages on the website, so to avoid repetition here some points are referred to other paragraphs. Paragraph headings in bold text are reproduced from the HPA website.

### 1 General Information

#### **1.1 Background**

1.1.1 LDA broadly agrees with this paragraph, although it should be emphasised that deer populations are not an essential prerequisite for the presence of infected ticks.

#### **1.2 Transmission**

1.2.1 This information is not disputed. LDA welcomes the statement that tick bites may easily be overlooked.

#### **1.3 Symptoms**

1.3.1 It may not be true that the erythema migrans rash is the most common symptom (see also paragraph 7.1.1). Studies variously show that between 35 and 59% of patients exhibit the rash[1]. Even if a rash is present it may go unnoticed or vary in appearance from the classic definition[2]. It is stated that Lyme disease is easiest to treat when recognised early. This statement is not disputed, but implies that treatment for later cases should be different. The information provided on treatment does not adequately address this.

#### **1.4 Occurrence**

1.4.1 There have been confirmed cases across a much wider area than is described[3]. As stated in the **Background** paragraph, infected ticks can be found in suburban environments as well as upland areas. The whole of the UK should be regarded as endemic (see also paragraph 2.6.4).

1.4.2 It is recognised that a proportion of cases are acquired outside the UK. However, this raises the question that testing for antibodies matching known

UK strains may not be sensitive to strains acquired elsewhere.

## 1.5 Prevention

1.5.1 LDA broadly agrees with this section, although the statement that “*Infection can be prevented altogether ... by removing ticks at an early stage*” is not adequately supported by published research. Rapid removal of ticks may significantly reduce the risk of tick-borne disease, but does not eliminate it[4,5]. It is likely that the majority of tick bites, especially of the smaller nymphs, are not noticed [6]. (See also paragraph 2.7.1)

## 2 Frequently Asked Questions

### 2.1 What is Lyme borreliosis?

2.1.1 This section is largely factual, although “*The infection is not transmitted directly from person-to person, nor from the bites of other types of insect, nor from animals.*” is not entirely true. It has been known since 1985 that *B. burgdorferi* can be transmitted from mother to unborn child[7]. Viable *B. burgdorferi* have also been cultured from urine and breast milk[8], and there is at least a theoretical risk that it could be transmitted sexually. It is also possible that other biting insects could act as vectors, with at least one confirmed case[9].

### 2.2 What symptoms can it cause?

2.2.1 It may not be true that the erythema migrans rash is the most common symptom (see paragraphs 1.3.1 and 7.1.1).

2.2.2 The more serious symptoms cover a wide range. It is true that, other than the classic erythema migrans, none of the symptoms in isolation are unique to Lyme borreliosis, but many sufferers have a large number of symptoms at the same time involving multiple body systems. Few other conditions present with a similar range of concurrent symptoms, therefore non-specific symptoms are a part of differential diagnosis, provided that clinicians are adequately trained.

### 2.3 What are the complications?

2.3.1 There is little evidence for the existence of a post infectious syndrome caused by *Borrelia*, yet it is presented as fact. This hypothesis is based on the assumption that a short course of antibiotics will remove the infection, so any ongoing symptoms must be a separate, aseptic condition with an assumed autoimmune or psychological cause. This is illogical.

2.3.2 We do not dispute that minor symptoms remain in some patients even after long term treatment. However, little research has been carried out on such patients, so it cannot be stated with confidence that these symptoms are not due to ongoing infection by *Borrelia* or other pathogens. The overwhelming balance of evidence shows that *Borrelia* can survive even after months of antibiotic treatment[10]. With any other condition, if a patient is treated, but symptoms are slow to respond and return when treatment ceases, you would conclude that the treatment was ineffective or insufficient. Why not with Lyme?

2.3.3 The statement that “This condition does not respond to prolonged or

repeated courses of antibiotics.” has little supporting evidence, and is contradicted by clinician and patient experience. Little research has been carried out on long term treatment. The single reference study commonly used to support this view has been widely criticised as being poorly designed (see paragraph 11.2). Other studies have directly contradicted this view[11,12,13,14]. The existing research shows that short courses are often ineffective, but suggests that increased length of treatment gives better results in some patients.

## **2.4 Can Lyme Disease be treated?**

2.4.1 *“Repeated or prolonged courses of antibiotics have been shown not to help the small proportion of patients with post-infection syndrome.”* Existing research is limited, but tends not to support this view (see paragraphs 2.3.2 and 8.4.1). There are a great number of Lyme patients who find that “repeated or prolonged courses of antibiotics” have been essential to their recovery. The existence of an aseptic, post-infection syndrome itself is highly controversial and has little supporting evidence.

2.4.2 There is little evidence of “serious or life threatening side-effects” of repeated or prolonged courses of antibiotics, apart from in patients with contraindications such as allergy (see also paragraph 4.4.3).

## **2.5 Are laboratory tests available to help in the diagnosis of Lyme disease?**

2.5.1 There is considerable evidence that the tests have a high false negative rate [15]. There is no doubt that testing is useful, but it must be used to support a clinical diagnosis, not to supplant it.

## **2.6 How common is Lyme Borreliosis?**

2.6.1 The concept of an average number has little relevance in the face of numbers that are growing rapidly, and tends to understate the true nature of the figures.

2.6.2 It is stated here that the HPA estimate that 1000 to 3000 cases occur in the UK each year. Elsewhere on the website it is stated as 1000 to 2000. This estimate appears not to have changed significantly in the last few years, despite large increases in the number of confirmed cases. It is not stated how this estimate is derived. The US CDC estimate the total number of cases as six to twelve times the number of laboratory-confirmed cases[16], with many sources suggesting even this is an underestimate.

2.6.3 Reported incidence rates across Europe vary from 16/100,000 in France to 120/100,000 in Slovenia[3]. Applying the French figure to the UK would give an incidence close to 10,000 cases each year. The true incidence in the UK is unknown, and may be lower than that in France, but the quoted figures were published in 1998, and, from the HPA's own figures, laboratory-confirmed cases have risen by approximately 500% between 1998 and 2006.

2.6.4 *“Areas where infection is acquired [sic] include Exmoor, the New Forest, the South Downs, parts of Wiltshire and Berkshire, Thetford Forest, the Lake District, the Yorkshire moors and the Scottish Highlands.”* These areas may have higher than average numbers of cases, but cases have been recorded all over the UK[17], including in suburban environments. For example, Lyme disease is known to be present in Richmond park, London [18] (see also paragraph 1.4.1).

## 2.7 What are ticks?

2.7.1 LDA broadly agrees with this paragraph. However, ticks may be found in urban and suburban environments as well as woodland and heathland areas. It is stated here that “*early removal of the tick greatly lowers the risk of transmitting infection*”. There is evidence to support this, but there is research that implies that it does not eliminate the risk entirely, contrary to the statement on the General Information page (see paragraph 1.5.1).

## 2.8 Are all ticks infected?

2.8.1 We welcome the statement “*As a precautionary measure, any ixodid tick should be regarded as potentially carrying infection*”. There is little doubt that infection rates vary across local tick populations, but research in this area is patchy and not generalisable. The HPA’s own Tick Recording Scheme does not test collected ticks for their pathogens (see paragraph 10.1).

## 2.9 How can Lyme borreliosis be prevented?

2.9.1 This information is not disputed. LDA welcomes its addition to the HPA website.

## 3 Prevention of Lyme borreliosis

3.1 Most of this information is not disputed. However, the statement “*The infection cannot be passed person-to person, nor from other animals.*” is not entirely true (see paragraph 2.1.1).

3.2 Nevertheless, tick bites remain by far the most common source of infection. The precautions mentioned, and the method of removing ticks, are good advice.

## 4 Guidelines for Health Professionals

### 4.1 **Treatment of nervous system Lyme disease**

4.1.1 These guidelines were written by largely the same group of people responsible for the IDSA guidelines, and should, therefore, not be considered as corroboratory. These guidelines are critical of published work that does not support the authors’ views, yet controversial studies are accepted without question (see section 11.2).

### 4.2 **IDSA guidelines** (see also paragraph 5.4.1)

4.2.1 These guidelines have been widely criticised by medical professionals and patient groups[19], and are currently under investigation by the Attorney General of Connecticut. Criticisms include the selective use of evidence, the use of poor quality evidence, statements that are directly contradicted by published research, conflicts of interest declared by the authors, and the authors lack of clinical experience.

### 4.3 **Tick management handbook**

4.3.1 This document was published by the Connecticut Agricultural Experiment Station, and funded partly by the US Centres for Disease Control (CDC). It is exclusively American in scope, and, therefore, may not be entirely applicable to the UK.

4.3.2 Criticisms can be made of certain details. For example, the statement that Erythema Migrans rash occurs in 70-90% of patients is not supported by the majority of peer-reviewed literature. However, this document offers much good quality information on tick biology, potential infections, and effective prevention of bites.

4.3.3 Worthy of note are statements such as,

*“In the absence of an EM rash, Lyme disease can be difficult to diagnose because its symptoms and signs vary among individuals and can be similar to those of many other diseases.”*,

and,

*“These tests are not reliable enough to be used as the sole criterion for a diagnosis, however, especially during the early stages of the disease.”*

The diverse range of non-specific symptoms is also made clear. These statements tend to support the views of LDA, other patients' groups, and many medical professionals, and to contradict the dictum that current tests are completely reliable.

#### **4.4 A report on unorthodox and unvalidated laboratory tests** (see also section 8)

4.4.1 This report also makes clear the diverse range of concurrent symptoms present in many cases of Lyme disease.

4.4.2 LDA supports the overall conclusion that unvalidated tests should not form the basis of diagnosis of Lyme disease. However, we do not know of any independent practitioners who make diagnoses solely on the basis of any test.

4.4.3 The report states,

*“There is currently no scientific evidence to support longer term therapy in the absence of objective evidence for continuing active infection.”*

This is misleading as there is peer-reviewed literature indicating both benefit from longer term treatment[11,12,13,14], and the ability of *Borrelia spp* to survive conventional antibiotic protocols[10]. Objective evidence of infection may be lacking in many genuine cases, given the well-documented lack of reliability of all current test methods.

4.4.4 The report perpetuates the partial truth that Lyme is most likely to be acquired in certain forested areas of the UK, but omits to mention that the disease is found in ticks from nearly all parts of the UK (see paragraph 2.6.4).

4.4.5 The report emphasises the potential side effects of antibiotics, chiefly the risk of diarrhoea. LDA does not dispute the existence of these side effects, and agrees that antibiotics should be used with prudence. However, to use this to deny treatment to people who already have a very poor quality of life is unjustifiable.

## **5 Diagnosis**

### **5.1 Summary**

5.1.1 This section is expanded in subsequent paragraphs, and is commented on in detail below.

### **5.2 Laboratory investigations**

5.2.1 Testing is certainly useful, but the confidence in its performance is misplaced. The two stage serology test is an indirect method of testing for *Borrelia* infection, and the interpretive criteria for a positive result as defined by the US Centre for Disease Control (CDC) et al have been widely criticised as being too strict [1], and many patients with a strong clinical case, or

positive testing by other methods such as PCR, test negative by this method [15]. European reviews have questioned the quality of the serological screening tests[20].

5.2.2 In practice, it is likely that people with the other conditions mentioned as causing false positives would have other tests done before Lyme would be considered, so these conditions would be picked up or eliminated first. It seems likely that most sufferers are never tested at all, and many only have tests after years of misdiagnosis. It is also possible that many of the 'false positives' attributed to other conditions are really genuine positives. Given the wide range of known symptoms it would be easy to misdiagnose Lyme as a viral or autoimmune condition.

5.2.3 It is stated that the tests are fully validated. However, there is no independent gold standard test with which the results of the two stage test can be compared, so assessment of the test's reliability must be open to question. Validation is the process of demonstrating that a medical product fulfils its stated Indications for Use. A validation process sufficient to attain a Notified Body CE mark does not guarantee the reliability of the test. Carefully and restrictively worded Indications for Use could lead to successful validation of a relatively poorly performing product.

5.2.4 It is illogical to warn only of the dangers of false positives. Any test may have false positives and false negatives. In the case of Lyme disease the risk from a false positive is giving unnecessary treatment. Serious complications associated with antibiotic treatment are rare and the more common but less serious complications can be minimised if basic precautions are taken. A false negative leading to a refusal of treatment can potentially lead to lifelong disability with extremely unpleasant and unpredictable illness. A false negative, therefore, risks a far worse outcome than a false positive.

5.2.5 Worthy of note is the sentence,

*“The significance of any result, negative or positive, should be interpreted carefully by clinicians in the light of the patient’s clinical presentation and tick exposure risk history.”*

LDA agrees with this statement. However, the majority of clinicians lack experience or training in recognising Lyme disease, so may over-rely on the results of the tests.

5.2.6 There are at least three genospecies of *Borrelia* currently known to cause disease in the UK, usually referred to collectively as *Borrelia burgdorferi* s.l. (sensu lato, “in the broad sense”). Within each genospecies there are many known strains with considerable genetic variation[21,22]. Given the lack of research and the fact that the causative organism is relatively new to science, there is a relatively high probability that there are genospecies and strains yet to be discovered. The current test looks for antibodies that match a limited number of laboratory-cultured strains and may, therefore, be insensitive to the majority of antibodies. *B. burgdorferi* s.l. is difficult to culture in the laboratory and it has been reported that cultured forms show changes in their plasmids and surface proteins which could further reduce the sensitivity of the test to wild strains[23].

5.2.7 It is known that *B. burgdorferi* can exist in a cell wall deficient form which is

undetectable by the immune system[24,25].

5.2.8 It is widely accepted that short duration or low dose antibiotic treatment before a test may abrogate a normal immune response and prevent the formation of antibodies[26]. This is also acknowledged on the HPA website. Many sufferers may have had short courses of antibiotics before being tested for Lyme Disease, and would be, therefore, more likely to falsely test negative. *B. burgdorferi* s.l. are by far the most genetically complex bacteria known[27,28], and they have evolved to avoid detection by the immune system[29,30].

### **5.3 Clinical discussions**

5.3.1 *“The LDU has a range of tests that can be applied in cases of diagnostic uncertainty.”* There is no test that is completely reliable in confirming or ruling out Lyme borreliosis. Lyme borreliosis is a diagnosis of probability based on the whole clinical picture exhibited by the patient. In cases of diagnostic uncertainty, physicians must be trained to make a clinical diagnosis and not rely on testing alone.

5.3.2 LDA has heard many accounts from patients of inaccurate information being provided by General Practitioners, Infectious Disease Specialists, Neurologists and others.

### **5.4 Treatment**

5.4.1 Many medical professionals and Lyme charities feel that the IDSA guidelines are not fully representative of clinical experience and published research and contain major flaws (see also paragraph 4.2.1). Indeed there have been calls for these guidelines to be withdrawn[19]. Criticisms include the selective use of evidence, the use of poor quality evidence, statements that are directly contradicted by published research, and the lack of clinical experience of the authors.

5.4.2 There is much published research that shows that *B. burgdorferi* s.l. can survive short courses of antibiotics [10], and very many sufferers find in practice that long courses of antibiotics are necessary.

5.4.3 The dangers of long term courses of antibiotics in this context have been exaggerated. A great number of sufferers are successfully treated with long term antibiotics, with little or no adverse effect. The single documented case of death associated with antibiotic treatment for Lyme borreliosis was due not to the antibiotic, but to complications arising from a broken catheter tip[31]. Large numbers of these catheters are routinely used around the world for intravenous drug delivery. The occasional very rare complication should not be used as a reason to deny treatment. This type of occasional mishap is not specific to Lyme disease treatment, but can happen in any intravenous treatment.

5.4.4 It should also be noted that other drugs used for long term treatment of individual symptoms have their own risks, yet are used routinely with little question. We hear from many patients who are, for example, prescribed steroidal anti-inflammatories or psychoactive drugs, which, whilst they may have a place in treatment, have arguably greater risk than antibiotics.

### **5.5 Epidemiological functions**

5.5.1 See paragraphs 5.6.1 and 6.2.1.

## **5.6 Enhanced surveillance**

5.6.1 Any additional information is welcome in order to increase our knowledge of this poorly understood disease. However, as most practitioners are not trained to recognise Lyme borreliosis it is likely that the majority of cases go undiagnosed and unrecorded. It should be noted that Enhanced Surveillance only collects data on cases previously confirmed by testing.

## **5.7 International liaison**

5.7.1 This paragraph gives a false sense of international consensus on the diagnosis and treatment of Lyme disease. In fact it is highly controversial, with some learned medical bodies taking a very different view of Lyme disease than is presented by the HPA[32]. The picture of Lyme disease that is currently most widely promoted originates from a relatively small group, is not a consensus view, and is open to valid criticism from other learned schools of thought, especially as regards the scientific reasoning involved.

## **5.8 Vaccine**

5.8.1 This paragraph is not disputed. The US vaccine was withdrawn partly due to concerns that it caused many cases of illness, possibly due to reactivation of latent infection.

## **5.9 Co-infections**

5.9.1 No evidence is quoted for the assertion that coinfections are rare. Testing is not routinely carried out for the presence of organisms other than *B. burgdorferi*, so it would be more accurate to say that the true incidence of co-infections is not known in the UK. Some reported pathogens are thought to be immune system suppressive, from work in animal models[33], so may increase the possibility of a false negative serology test.

# 6 Epidemiology

## **6.1 Background**

6.1.1 This paragraph correctly identifies small mammals and birds as the reservoir hosts for Lyme disease.

6.1.2 "*Several pathogenic genospecies of *Borrelia burgdorferi* have been identified in Europe, and there is some evidence for variation in types of clinical presentations caused by these different genospecies.*" This is true, and for this reason there is also variation in clinical presentation between Europe and the United States[2], yet it is stated elsewhere that US diagnostic guidelines and reference papers are applicable in the UK.

## **6.2 Surveillance**

6.2.1 The enhanced surveillance collects additional data only on cases already confirmed by testing. Therefore, clinically diagnosed cases are not included. In addition, an unknown but potentially large proportion of Lyme borreliosis cases test negative, so vital information on these cases is not being collected.

## **6.3 Results**

6.3.1 (See paragraph 2.6.2.) The old estimate of 1000-2000 cases per year is

repeated here despite the large increase in confirmed cases in recent years, and despite the increased estimate of up to 3000 cases per year quoted elsewhere on the HPA website.

#### **6.4 Annual totals and rates**

6.4.1 it should be noted that this paragraph calculates incidence rates based on laboratory confirmed cases only. The increase in cases cannot be attributed in any part to the enhanced surveillance, as this only gathers additional information on cases already confirmed by testing.

#### **6.5 Age and sex**

6.5.1 This paragraph is not disputed.

#### **6.6 Occupationally acquired cases**

6.6.1 At present, occupationally acquired Lyme disease is reportable to the HSE, but other cases are not recorded in this way. This raises the issue that all cases should be subject to some form of mandatory recording.

#### **6.7 Seasonality**

6.7.1 This paragraph is factual. It should also be noted that, although less common, tick feeding has been observed during the winter[34], so it is possible to be infected at any time of year.

#### **6.8 Geographical distributions**

6.8.1 See sections 2.6 and 2.8.

#### **6.9 Clinical presentations**

6.9.1 It may not be true that the erythema migrans rash is the most common symptom (see paragraphs 1.3.1 and 7.1.1). The rest of the paragraph is not disputed, but the list of known symptoms is very much longer than the brief examples given, and does not help patients or clinicians to recognise them.

### **7 Lyme borreliosis in England and Wales: 2006**

#### **7.1 Symptoms**

7.1.1 From the quoted figures, 37% of patients were reported with erythema migrans (EM), therefore, if the figures are correct, the majority (63%) of patients do not manifest EM. Other, less visible, symptoms are frequently reported in Lyme disease, making it hard to assert that EM is the most common symptom.

7.1.2 It is also stated that no clinical details other than EM were available for 326 (42%) of the 768 patients. This casts doubt on other figures, for example, that neuroborreliosis was identified in 8% of patients. If they have no clinical information on 42% of cases, then the incidence of neuroborreliosis would be, more correctly, 62 out of 442 cases, or 14%. It is not stated how neuroborreliosis was identified in these cases. Relying only on clear signs such as facial palsy may underestimate the true incidence.

#### **7.2 Seasonality**

7.2.1 This paragraph is not disputed (see also paragraph 6.7.1).

### **7.3 Location of exposure**

7.3.1 Specific areas in the UK are mentioned as being endemic for Lyme borreliosis. It should be noted that there have been laboratory-confirmed cases in most counties[3,17]. The whole of the UK should be regarded as endemic (see also paragraph 2.6.4).

### **7.4 Travel**

7.4.1 This paragraph is not disputed.

## **8 Unorthodox clinical and laboratory practices related to Lyme borreliosis**

### **8.1 Background**

8.1.1 The practitioners referred to are, in general, experienced doctors who make diagnoses, not on the basis of alternative tests but by primarily considering the patient's clinical presentation. This is as recommended by the US CDC, *“Lyme disease is diagnosed based on symptoms, physical findings (e.g., rash), and the possibility of exposure to infected ticks; laboratory testing is helpful in the later stages of disease.”*

8.1.2 We are concerned that the assessment of the risk of tick exposure is not weighted enough in favour of realising that any person can be bitten by a tick anywhere in the UK, including urban and suburban environments, and that the majority of tick bites may go unnoticed. The assessment of ‘tick-bite risk’ is likely to be carried out by a patient’s GP. However, many GPs are relatively uninformed about tick distribution and biology and this too is a cause for concern.

8.1.3 No evidence has been provided that Lyme borreliosis is over diagnosed. An experienced practitioner will make a diagnosis that best matches the patient's presentation. Except in patients with contra-indications such as allergy, the dangers of long term courses of antibiotics have been exaggerated.

### **8.2 Unorthodox testing**

8.2.1 *“There are a number of unorthodox tests available in certain commercial laboratories that have been proven in independent studies not to be of value.”* The reason alternative tests are being developed is the unreliability of conventional tests. There is no gold standard test for the presence of *B. burgdorferi* s.l. against which different testing methods can be compared, therefore assessment of the reliability of any test is open to question. Sensitivity and specificity vary amongst all types of test, so test results should only be used by trained Lyme clinicians to support the clinical diagnosis, not to supplant it. This highlights the need for research into improving testing methods.

### **8.3 Seronegative Lyme borreliosis**

8.3.1 This paragraph implies that seronegative Lyme borreliosis should be a diagnosis of last resort. LDA knows of many sufferers who have clinical presentations strongly consistent with Lyme borreliosis, often including history of tick bites and erythema migrans rashes, and yet have negative tests.

8.3.2 “...it is very uncommon for patients with late stage Lyme borreliosis to be seronegative, unless they received early inappropriate treatment, that did not eradicate the infection but could have abrogated an antibody response.” There is a great deal of peer-reviewed research that shows that serology tests can have high false negative rates[15]. Many sufferers may have had short courses of antibiotics before being tested for Lyme Disease, and are, therefore, more likely to falsely test negative.

#### **8.4 Post Lyme syndrome (see also section 2.3)**

8.4.1 There is no direct evidence for the existence of Post Lyme Syndrome, defined as the persistence of symptoms after “adequate treatment”, yet it is presented as fact. This hypothesis is based on the assumption that a short course of antibiotics will remove the infection, so any ongoing symptoms must be a separate, aseptic condition with an assumed autoimmune or psychological cause. This is illogical. With any other condition, if a patient is treated, but symptoms are slow to respond and return when treatment ceases, you would conclude that the treatment was ineffective or insufficient. Why not with Lyme?

8.4.2 The dangers of long term courses of antibiotics in this context have been exaggerated (see paragraph 5.4.3). Medications used for symptomatic treatment can have greater risks than antibiotics, yet their use is not questioned.

8.4.3 Comparison with other spirochaetal infections may not be valid when discussing treatment. *B. burgdorferi* s.l. is the most genetically complex bacterium known, with approximately three times the number of functioning genes of its nearest rival, also a spirochaete. The overwhelming balance of scientific evidence shows that *B. burgdorferi* s.l. can survive even after months of antibiotic treatment[10].

#### **8.5 Chronic Lyme disease**

8.5.1 The practitioners we know of do not make diagnoses on the basis of 'unorthodox tests', rather they consider the entire clinical picture. This will include test results, but will not rely on them exclusively. Many of the practitioners referred to broadly follow the principles embodied in the ILADS guidelines which according to the HPA website have been “*shown to contain inaccurate information*”. This has not been substantiated. The paper used to support this claim is an opinion piece only (see paragraph 11.3). How best to diagnose and treat Lyme disease is still very much a matter of debate. Under these circumstances practitioners are allowed to use their clinical judgement in any individual case provided differential diagnosis has been fully performed. Where guidelines are produced by more than one professional medical body, practitioners can make their own decision which to follow [35].

8.5.2 The majority of GPs and even Infectious Disease specialists have little experience of Lyme disease, so they will almost certainly accept the information provided by the HPA. This does not address the fact that many areas of the science surrounding Lyme disease are still the subject of debate and are not as rigidly delineated as the HPA website tends to indicate (see paragraphs 5.3.2 and 5.7.1).

#### **8.6 Information on the Internet**

8.6.1 There is poor quality information on the internet, but the HPA dismiss at a stroke all information that does not follow their view, regardless of evidence. Papers used to justify this are highly selected (see section 11).

## 9 Tick Awareness leaflet

9.1 This links to a leaflet published by the New Forest District Council. The leaflet is concerned primarily with prevention of tick bites and correct removal of feeding ticks, and good advice is given in both respects. There are detail criticisms - for example, the statement that infected ticks are only found in a few named parts of the country.

## 10 Tick Recording Scheme

10.1 It is stated here, "*This will improve our understanding of the public health risk posed by ticks and tickborne infections.*", yet the following sentence reads, "*At the current time, the tick recording scheme does not test ticks for any pathogens they may carry.*" It is difficult to see how a scheme that does not test for tick borne pathogens could improve our understanding of the risk of such infections.

## 11 Reference papers

11.1 Some of the papers referenced by the authors can themselves be criticised. The following is non-exhaustive.

11.2 Klempner et al "Two Controlled Trials of Antibiotic Treatment in Patients with Persistent Symptoms and a History of Lyme Disease." *N Engl J Med* 2001;345:85–92 NOTE: this is the correct reference, the HPA website reference is incorrect.

11.2.1 This study claims to investigate the effectiveness of long term antibiotic treatment. It has been widely criticised as being poorly designed and as reaching unjustified conclusions. Detailed criticisms can be found at [www.ilads.org/position2.html](http://www.ilads.org/position2.html) and <http://www.verimresearch.com/Verim%20Research%20Klempner%20Lyme%20Treatment%20Analysis.pdf>.

11.2.2 In summary: average length of illness in the study group was 4.7 years. Patients were treated with intravenous ceftriaxone for four weeks, followed by oral doxycycline for eight weeks. The dose of doxycycline used is considered inadequate by many practitioners, and was likely to have resulted in insufficient concentration in the cerebrospinal fluid[36].

11.2.3 It is widely accepted that the longer someone has Lyme Borreliosis the more difficult it is to treat. In effect this study was of short term treatment of patients with a long duration of illness, and was therefore almost guaranteed to show poor results.

11.2.4 The authors make the unjustifiable assumption that any course of antibiotics longer than four weeks will achieve similarly negative results.

11.3 Cooper JD, Feder HM. "Inaccurate information about Lyme disease on the Internet." *Pediatr Infect Dis J* 2004;**23**(12):1105-8.

11.3.1 The authors assume that the IDSA guidelines are correct, and that any published information that is contrary to these guidelines is wrong. This paper is the personal opinion of the authors and provides no evidence other than the

widely criticised IDSA guidelines. This paper has no value as a scientific reference.

## References

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