LDA Comment on the Lyme disease meeting at Westminster on January 19th 2015

Introduction

This meeting in a seminar room at the House of Commons was organised by a patient, Demetrios Loukas, through his MP Simon Hughes. This followed his failure to get a diagnosis of Lyme disease through the NHS and subsequent receipt of positive test results from the German laboratory Infectolab.

LDA were asked by the organisers not to attend the meeting, though reasons were not given for this exclusion. The following account is derived from information received from people who were present and from publicly available news items and blogs on the internet, links to which are provided below.

Published Programme

Chair: The Countess of Mar
1. Dr Armin Schwarzbach (until recently of Infectolab and the BCA clinic in Augsburg and now Arminlabs both in Augsberg, Germany) and Chris Moore (Nordic labs, Denmark)
2. Dr. Beryl Beynon (the Well One Clinic, Beverley, Yorks) and Dr. Chris Newton (Cytogenex and adviser to the Well One clinic)
3. Peter Kemp and Denise Longman (Organiser and fellow patient)
4. Dr. Mark Ashworth (Demetrios' GP) and Dr. Michael Wetzler
5. Demetrios Loukas
6. Q&A

The programme seems not to have quite followed this order. Many of the speakers overran their allotted slot and no time was left for questions and answers**.**

What happened

The room, with a capacity of 170 was fairly full. We don't know whether many MPs were present; one report says 2 or 3 attended but only stayed a short while. The Parliamentary Under Secretary of State for Public Health, Jane Ellison MP, was represented by four people, two from the Department of Health and two from Public Health England.

From questions that were asked by Chris Moore, and responded to by a show of hands, it seems that many patients had had a negative NHS test for Lyme disease, many had been diagnosed with Lyme disease using overseas tests and many had been treated at overseas clinics.

Simon Hughes MP introduced the speakers and Departmental representatives and then left. The Countess of Mar chaired the meeting. All the talks were by people who had been involved in the organiser's case.

Armin Schwarzbach said he had no financial interest. He talked about Lyme disease history, symptoms and laboratory tests. He said there were problems of sensitivity with the ELISA and western blot. He discussed other tests - LTT and ELISPOT - which he said are better than the western blot. He mentioned pleomorphic forms of Borrelia and biofilms both of which he believes should be taken into account in treatment.

Demetrios' GP Dr Ashworth, spoke for only 3 mins. He said he didn't know anything about LB before Demetrios' case and advised fellow GPs to keep an open mind.

Chris Moore (Nordic Labs) spoke about the failures of current tests and the economic impact of late diagnosis.

Michael Wetzler discussed what he could and could not do as a GP and mentioned alternative and complementary therapies.

Chris Newton said that the western blot should not be used, although the line blot was OK, though he seems not to have explained why he has come to this view. He said the NHS should be using PCR. He referred to Alan Macdonald's work and showed some slides of his work. He said there was great concern that no new antibiotics had been developed for several years, but mentioned teixobactin. He also talked about pulsed magnetic field therapy.

Dr Beynon described how she became involved in Lyme disease by chance when she found Lyme disease patients attending her clinic. She doesn't claim to have a cure but says she can put patients into remission. She uses a short course of antibiotics followed by Rife machine therapy. 82% of her patients are female and she wondered whether hormones were involved in some way; many have cats, and most are >50 years of age. She said GPs are being monitored for antibiotic use therefore GPs won't prescribe without good reason.

Peter Kemp said microscopy is still used for syphilis & showed slides, talking for quite a long time about this disease. He showed photographs and videos of what he said were Borrelia he has grown on microscope slides. This presentation has been made available, with added comments to counter remarks made at the time of the meeting.

Lady Mar as chair said they had to vacate the room by 4pm and time was getting short. She proposed missing out Denise Longman, the last speaker. However, Demetrios said that she had come a long way and should have her say. He took the microphone from Lady Mar and handed it to Denise.

Denise Longman suggested the NHS should screen all patients with Alzheimer's disease or ME for Borrelia and raised concerns about transplacental transmission. She said the UK figures for incidence came nowhere near the true figure and questioned how Germany could have so many more than the UK. She said that in Germany twice as many women as men are affected. She said birds are very important hosts. This presentation has been made available.

Lady Mar invited Tim Brooks, Public Health England, to speak. He spoke about awareness raising in public places warning of ticks and Lyme disease but he was heckled by people who had not seen a notice in their particular area. He started talking about incidence of Lyme disease, saying that all RIPL can comment on is cases coming though the laboratory and that he believed that there are many others diagnosed on clinical grounds. People started shouting their disagreement - "my GP wouldn't diagnose me on clinical grounds" etc. Lady Mar tried to quieten them but she was also shouted down.

Tim Brooks said he thought that it was possible that what was shown on Peter Kemp's' slides were collagen fibrils, not spirochaetes, and he invited Peter to bring samples and controls to Porton where they could examine them together and RIPL could perform PCR on them.

Addendum: In this last paragraph Demetrios' name had been used in error instead of Peter's. Tim Brooks has contacted us to say that Peter Kemp claimed PHE said the fibrils were collagen but Tim did not recognise that remark. He thinks the fibrils are fibrin.

Reactions on the day

Many patients were uplifted by the day, feeling that their grievances had been put forward. Some were disappointed that there was no time for the planned question and answer session. Some parliamentary officials were shocked by the aggressive nature of the response to Tim Brooks. Some patients voiced concern via social media that LDA had been asked not to attend this meeting.

Accounts written later

The following accounts were written by people who were there, and these are included for completeness sake so that readers can draw their own conclusions.

From Lyme disease UK, a support website run by two patients who also manage a private Facebook group for people with an interest in Lyme disease. Also a further document produced on 6th February with a bit more detail.

From a patient who writes a blog on Lyme disease

From Alliance for Natural Health International, a news item By Meleni Aldridge.

From the Academy of Nutritional Medicine

LDA's comment

It is understandable that many people may feel angry and frustrated at the apparent slow pace of change and limited progress in improving NHS care and treatment of Lyme disease. The organisers had asked for ministerial attendance, and it is unfortunate that Tim Brooks, acting as the Minister's representative, was shouted down. As it is, the Departmental officials present are aware of the history of Lyme disease in the UK together with deeply entrenched problems with regard to medical training and practice, and are able to put their report in context.

It is important to say that some of these presentations, and some of the on-line accounts, do not have all their facts straight and in ways were as biased as some presentations which have been given by NHS consultants on Lyme disease. Exactly as in those, the danger is that audiences will have believed what they were told. LDA has a responsibility to question and challenge where we think doctors and patients may have been misled at the meeting and in reading the various accounts that have been posted on-line.

Public Health England
The attack launched on PHE at the meeting and again in Peter Kemp's updated presentation, is not justified. Many should be able to recall the attitude of the HPA up to April 2012 when the reference laboratory moved from Southampton to PHE at Porton. A look at the slides presented by Tim Brooks at LDA's conference in July 2014 demonstrates that the situation has improved. Credit should be given where credit is due.

The ACDP report, referenced by Peter Kemp, was produced at the beginning of RIPL's involvement and was based on information passed on by the HPA. Following intervention by LDA, an update was issued to the October 2013 ACDP meeting with a different outlook and explaining that PHE were by then working with patient groups. This has been publicly confirmed in a recent parliamentary written answer.

Testing
The NHS tests for Lyme disease are no worse than any other Lyme serology tests; they detect antibodies if they are there to be detected. There are several reasons why people with definite Lyme disease may have negative EIA/ELISA and immunoblot tests for Lyme disease. We discussed some of these in our recent January 2015 newsletter. There is no "better" test for Lyme disease at the moment. The culture method introduced by Advanced Laboratory Services takes at least 6 days and more often 8 to 16 weeks to produce an answer, and depends on Borrelia present in the blood sample. Borrelia migrate from the bloodstream to tissues early in infection.

Immunoblots from different manufacturers vary in the antigens they use and may produce different results. They are essentially using what researchers have found to be the main antigens expressed in early disease and in later disease which are reasonably specific to Lyme

disease. RIPL have exchanged samples with Raigmore hospital, the national Scottish reference laboratory for Lyme disease, which uses a different immunoblot, in order to see if there are differences. We hope to be told shortly the results of this exchange.

The fault in the NHS and PHE is not in choice of test, but in a failure to widely publicise that negative serology can occur. LDA's help desk is documenting a great many people not receiving treatment because of negative serology probably caused by early antibiotics. In the absence of better tests, it is vital to acknowledge the limitations of current ones. Whilst ever patients are told "Your test is negative so you don't have Lyme disease" those same patients will search for a positive test and they will go to private overseas clinics to find one.

It is not correct to say, as one speaker said at the meeting, that PCR is the only test available to detect *B. miyamotoi* infections. In a Russian study(Platonov et al. 2011) 48/51 patents with PCR confirmed *B. miyamotoi* infections cross-reacted to the antigens in the EUROIMMUN ELSIA used. We do not know, however, how the other UK tests would react, though as they contain many of the same antigens, it is likely they would detect some cases.

Infectolab in Germany have diagnosed many people using the LTT and CD57 tests. However, LTT tests are not accepted as useful in most countries (Müller et al. 2012; Baehr et al. 2010) and a low CD57 count is not specific to Lyme disease. Studies have found that not only do normal, healthy people often have a low CD57, but that this level fluctuates.

Infectolab used to add a comment following a CD57 test which if the result was low said

> "*The CD57-cell-count is an indication for a chronic immune-suppressive situation caused by Borrelia burgdorferi."*

This comment was changed shortly before August 2014 to-

> *"The CD57-cell-count indicate a chronic immune-suppressive situation which may be caused by Borrelia burgdorferi."*

Anyone given test results by Infectolab prior to August 2014 with a low CD57 will have been led to believe that they definitely had Lyme disease.

It is not fair to mislead patients in this way. The bulk of the public will not spend hours reading technical papers to check whether what they are told by a laboratory is true. They believe the results just as NHS consultants believe in negative immunoblot results. One group of patients pays for expensive treatment they may not need and another group is denied the treatment that they do need.

Education and awareness is badly needed in the NHS or patients will continue flocking to overseas laboratories where the test results and diagnoses may not be accepted by the NHS and PHE.

This reinforces the view that Lyme disease is a difficult and controversial illness and in turn has a negative effect on doctors' attitudes and adds to the stigma experienced by Lyme disease patients. This problem is shared by other countries in Europe.

The use of microscopy

While syphilis and relapsing fever spirochaetes may be found in blood smears, it is widely acknowledged that Borrelia spirochaetes very quickly migrate to tissues and there are very few in the blood stream after early infection. This is why PCR on blood is not sensitive enough to be used as a diagnostic test and also why microscopy is likely to fail as a diagnostic tool for Lyme disease.

Microscopy, even at low magnification is difficult. The act of taking something out of its living environment introduces changes which continue as material interacts with a new environment. It takes considerable experience to distinguish these changes and to be able to tell what would be present in the natural environment and what has been created in the artificial environment

of a microscope slide. This becomes much harder with the high magnifications required, at the limit of optical microscopy, to visualise spirochaetes.

B burgdorferi is an obligate parasite: it cannot reproduce outside its host as it does not have the means of manufacturing the compounds that are required for growth. (Brisson et al. 2012) This is why culture is so difficult and requires special media. Advanced Laboratory Services use special techniques to distinguish between collagen fibrils and spirochaetes as it is known to be difficult.(Wood et al. 2015) LDA was not present at the meeting, so does not know what techniques Peter Kemp uses.

If Peter has discovered a way of growing *B.burgdorferi* on a microscope slide, then it would clearly be very useful. LDA hopes that he will take up PHE's offer so this question can be resolved. Continuing uncertainty in this area does not benefit patients and only serves to create further mistrust.

Incidence of Lyme disease in the UK

It is widely acknowledged, by Public Health England and by doctors, that there are many more cases of Lyme disease than just the laboratory confirmed cases. LDA believes there are considerably more than the 2000 the HPA has guessed in the past, and other doctors suspect this too.(Evans et al. 2014) At present we have no way of knowing.

More than one person implied in their presentation that incidence in the UK should be approaching that of Germany. However, cases of Lyme disease have been reported on for more than a century in mainland Europe, but not until the second half of the last century in the UK. A higher percentage of ticks in mainland Europe carry *B burgdorferi* sl than do ticks in the UK.(James et al. 2014) It seems possible that Lyme disease has arrived in the UK relatively recently and is still spreading. Because this country is an island there are still some zoonoses which affect mainland Europe which have not yet reached Britain, and the same applies to Ireland.

The quoted figure of "over 60 % of animals, birds and ticks" from sites in the UK infected with *Borrelia burgdorferi* may be a misapprehension and is not confirmed by more recent surveys.(Bettridge et al. 2013; Hansford et al. 2014) The Carey study in 1992 did not distinguish between the genospecies of *B burgdorferi* sl, so this figure will have included more than the known pathogenic strains of *B burgdorferi*. In addition, it does not state what proportion of the ticks were nymphs, the stage most likely to attach to humans. It is as important not to overstate the risks as it is not to understate them.

German statistics do not show that twice as many women as men are infected. The paper linked to in the last presentation is a paper which looked at diagnoses in people registered with a health insurance company. 62% of the group were women, 48% men, so one would expect higher numbers of women contracting Lyme disease. In the two years studied 0.47% of the men contracted Lyme disease and 0.55% of the women. In a different two years, the figures may have been different.

ME/CFS and fibromyalgia

Some patients diagnosed with these conditions have been misdiagnosed (Devasahayam et al. 2012). There are also anecdotal reports of patients with an ME diagnosis receiving a confirmed diagnosis of Lyme disease but there are no published reports on numbers.

No reference was given for the "80 to 90% according to 3 prestigious ME doctors" so whether this is hearsay, informed guesswork or the result of research using recognised reputable tests for Lyme disease, is impossible to judge.

What happens now

This is the third Lyme disease meeting held at Westminster. The first was in November 2008, and the second was BADA's awareness exhibition in November 2010. These events are useful in raising the profile of Lyme disease.

Following this meeting, Department of Health officials have reported back to the Minister and have made some suggestions for ways forward on

- Communication & awareness
- Research
- Surveillance.

Initiatives for raising awareness amongst the public and amongst doctors will carry on as already planned and PHE will hold another Open Day in April at which they will be able to describe their existing projects and their plans.

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