

Patient-led Parliamentary Lyme Forum

19th May 2015, 1-4pm – Committee Room 14, Palace of Westminster.

On the government panel were:

- Tim Brooks, Head of Rare and Imported Pathogens Laboratory, PHE
- Amanda Semper, Scientific Program Manager, Rare and Imported Pathogens Laboratory, PHE
- Ailsa Wight, Deputy Director Infectious Diseases and Blood Policy Branch, Public Health Directorate (we believe)

Microphones were not easy to use and had the effect of blurring speech. Only speakers who used the microphones properly, kept their heads forward and spoke clearly were consistently audible.

Simon Hughes introduced the meeting and then handed over to the **Countess of Mar** to chair.

The Countess of Mar

Lady Mar offered thanks to Simon Hughes and all those who had made the meeting happen. She talked about the scientific method of creating hypotheses tested by evidence and the need to reject hypotheses when evidence arises which disproves them. She gave the example of Galileo and the reaction he received when he challenged the scientific status quo. She mentioned that the cultivation of bacteria in early microbiology had been important, and should be so still, and then gave an overview of the development of the understanding and awareness of Lyme in recent history.

She described the current situation in the UK where Lyme is regarded as a “fashionable” disease and the reality is that patients are told they don’t have Lyme if serology is negative. She pointed to the recent 10 fold upward revision in numbers of people contracting Lyme by the CDC, the fact that Germany is reporting an increase in cases and that even Scotland, which also has very tight diagnosis criteria, is reporting higher numbers and asked why the numbers aren’t increasing dramatically in England. She commented that Lyme had perhaps suffered in treatment options from the “mad dash to reduce antibiotic use”

Armin Schwarzbach MD PhD (specialist for laboratory medicine and infectious diseases from Augsburg, Germany, member of the German Borreliosis Society)

After declaring no financial interests and his attendance as a private individual, Dr Schwarzbach started by pointing out the great age of *Borrelia*, believed to be 15million years. The first Lyme sufferer was perhaps the iceman “Otzi” in whose preserved body *Borrelia* bacteria were found. It’s believed that the tattoos on the backs of his knees were attempts to treat his joint pain. Skip to 2012, and there are many subspecies prevalent around the world. Pleomorphic forms and biofilms have been cultured in vitro. See his latest paper <http://mic.sgmjournals.org/content/early/2015/01/05/mic.0.000027.short>

Schwarzbach discussed the early and later responses to Lyme infection

- Recent infection can produce an EM rash from 5 days to 10 weeks after the bite, the short mild illness is often known as a summer flu and yet few doctors know enough to question about possible tick exposure.
- Only 30-40% develop an EM rash which must always be treated
- Only 30-40% chronic Lyme patients remember a tick bite
- EMs can be multifocal and can recur later.

- Bell's Palsy, which indicates cerebral spinal fluid infection.
- Another classic sign of the chronic disease is the arthritis in the knees (or elsewhere) in the absence of any other arthritic illness.
- Acrodermatitis chronica atrophicans – a skin infection.

He gave an example of patients with negative ELISA but positive immunoblot and pointed to the evidence of a large amount of inter-test disagreement. In 1993 average test sensitivity was 43% in one study, indicating an issue with false negatives. There is also evidence of a positive IgM response persisting for many months, which is a peculiar feature of Lyme which causes inexperienced doctors to be confused: IgM usually indicates recent not chronic illness. But Chronic Lyme can exist with +ve IgM. He also pointed out how difficult it can be to demonstrate Lyme in neurologic patients – in one study out of 27 patients only one had +ve antibodies in the CSF (cerebrospinal fluid).

The symptoms of chronic disease are individually not specific to Lyme but the combination of these symptoms is diagnostic especially when combined with a history of tick bite. Clinical diagnosis is time-consuming and will take an hour or more to do properly. From Radboud University he quoted Leo Joosten as saying that LTT and Elispot, which are tests for cellular immune reaction, are to be preferred to tests for the antibody response, ELISA and Western Blot. The Elispot is 80% sensitive and has 94% specificity which is very good in a context where 100% reliability is not possible and they can be repeated during treatment for monitoring purposes. He pointed out that there is no illness which can be ruled out solely on the basis of lab tests.

He ran through a series of indications that Borrelia is implicated in a wide variety of illnesses, such as Alzheimers, Autism, MS etc. Hence its nickname of the Great Imitator.

Treatment should be continued until the symptoms are controlled, determined by constant monitoring, not according to some pre-set protocol. Worldwide guidelines rely on Klempner study in 2001 which has many shortcomings. Other studies by Cameron and Fallon support need for longer courses of antibiotics.

Schwarzbach then ran through a long list of attitudes and beliefs about Lyme contrasting the CDC view with that of others – similar to many such lists. His last point in this section was that the CDC view is that therapeutic success is a reduction of major symptoms, with remaining minor symptoms acceptably dealt with symptomatically, whereas others would avoid purely symptomatic relief for minor symptoms but would aim to treat both major and minor symptoms as part of therapeutic success.

Schwarzbach's proposals of what needs to be done were:

- Good studies on reliability of immunoblot and ELISA, and test standardization
- Studies on short-term and long-term antibiotics in Chronic Lyme
- In vivo (cf in vitro) studies about pleomorphy and biofilms
- Development and search for new antibiotics
- Teaching about Lyme (standardized medical histories, diagnosis and treatment) at university medical schools.
- Training for current GPs about Lyme (and other TBDs) diagnosis and treatment.
- Prevention and awareness training for the general public, by government agencies.

Dr Mark Ashworth

Dr Ashworth is Demetrios' doctor and gave a very short but passionate presentation about the role and attitudes of a GP. He said that he has learnt a tremendous amount over the past few years by accompanying Deme through his disease and treatment. It is so important for GPs to keep open minds and listening ears. Doctors generally must not believe that they have a monopoly on knowledge but should accept where they either individually or corporately do not know the full story. They must be prepared to act as a patient advocate, representing and working for the patient. He ended with a plea to his profession to keep listening and to keep an open mind.

Chris Moore (Managing Director of Nordic Laboratories)

Chris posed the question "Borrelia – should we be screening for this infection differently?" In his experience patients do know a lot about this disease and rightfully expect support and active discussion with their doctors. They see many private doctors, perhaps because they have more time to spend on difficult cases.

He demonstrated the need for better testing by a series of questions to the audience answered via a show of hands – it was clearly shown that patients here are obliged to get diagnosis and treatment abroad. He pointed out that all professional labs will claim to be the best but patients and doctors need to be critical and be more critical of tests than just taking negative or positive answer. He saw the need for tests that were not based on serology.

Citing the WHO 2010 report, he said that Lyme is the most common vector-borne disease today, and that a number of factors (climate change, ticks living longer, people coming into contact with ticks more often) are leading to ever increasing rates of infection. He used the story of *H. pylori* to illustrate that resistance to change has been a characteristic of the medical world for many years. Chris Moore spent some time demonstrating the personal and economic cost, (including lost work years, lost tax, increased benefits and NHS spend) to the country of slow, late diagnosis, compared to quick, early diagnosis and the inevitable reduction in treatment success.

So in conclusion we have a situation of known increase in tick numbers and in tick exposure, but NHS reporting no similar huge change in numbers which is linked to test which incline to false negatives. Doctors must be encouraged to use antibiotics based on clinical symptoms.

Dr Michael Wetzler

Dr Wetzler is a GP who is keen to help patients with Lyme Disease, but is restricted by the attitude of the NHS. He is not in a position to comment on different tests but does point out that NICE guidelines mean that he cannot give IV antibiotics to patients who would benefit from them. He spoke about the recent Cuomo Law passed in New York State which now protects doctors treating patients away from the official guidelines from investigation. He has been involved with complementary medicine, mentioned ILADS as a source of information and gave a list of useful support therapies for Lyme – CoQ10, probiotics, multivitamins, Vit Bs, Magnesium, transfer Factor etc.

Dr Chris Newton

Dr Newton is a biochemist who is Research director at The CIMMBER Foundation. He initially commented that the Western Blot should only be used for research purposes and that clinical diagnosis should use all the available tests, since none is 100% reliable, particularly recommending a line-blot serology test with PCR assay.

Dr Newton started his presentation by describing and explaining the normal sequence of immune events when a tick deposits a cargo of pathogens into the skin. He also indicated the ways that this process can be faulty or avoided by *Borrelia* such that the bacteria are able to spread infection around the body.

He went on to describe how poor testing and lack of clinical confidence could delay or prevent timely treatment, such that bacteria further disseminate into the tissues, making subsequent treatment more problematic. During treatment, the severity of symptoms and success of outcome is further influenced by genetic factors, such as HLA and methylation cycle genes, and by environmental factors such as stress, diet (notably carbohydrate-loading), disruption of the HPA adrenal axis and gut dysbiosis. These were discussed in some detail.

The subject then turned briefly to peculiarities of *Borrelia*'s metabolic requirements and the possible opportunities these give for targets for new drugs. A therapy available when antibiotics fail is Pulsed Magnetic Field Therapy (PMFT) which Dr Newton investigates with the help of Well-One clinic, and he described a potential mechanism of action involving increasing the immune reactivity of the innate immune system.

Dr Newton also presented data provided by Dr Alan MacDonald (who was unable to attend), regarding his work on Fluorescent In-situ Hybridization (FISH) using Molecular Beacons - highly template-specific fluorescent DNA and RNA probes. These showed the presence of borrelial material within Lyme patients.

Dr Newton's more detailed summary is below and his presentation slides are also available.

Summary of talk on Lyme disease presented by Dr Chris Newton at the Houses of Parliament, 19th January 2015

*An opening slide addressed the first stage of infection where the tick deposited a cargo of infectious agents into the lower epidermis/upper dermis of the skin. Within the dermis, cells of the innate immune system and the complement cascade (Cc) should react, however some species of *Borrelia* fail to activate the Cc, and tissue neutrophil numbers are not only low, but their oxidative burst appears to be inhibited by the expression of surface antigens, such as *OspB*. Critical to the subsequent immune response to *Borrelia*, Dr Newton discussed the role of the local inflammatory response and extent to which dendritic cells are able to phagocytose *Borrelia* and transport displayed antigens to lymph nodes where they can instruct the development of T-helper (Th) lymphocytes (CD4) and cytotoxic T lymphocytes (CD8). If this response is not robust, then insufficient numbers of antigen-specific CD4 and CD8 cells will return to the site of infection to prevent further spread of the organism around the body.*

In addition to a discussion of the early skin events post infection, several GP scenarios were presented where the least favourable was that the symptoms of Lyme disease could go undiagnosed due to clinical uncertainty and poor diagnostic testing systems. The outcome of this failure to provide timely therapy would be the dissemination of the microorganisms to sites distant from the initial tick bite, making subsequent treatments, when and if eventually provided, much less effective than when provide earlier.

*The influence of chronic long term stress, changes in the HPA-adrenal axis, gut dysbiosis and interaction with dietary factors such as the carbohydrate load was then discussed from the point of view of immune system reactivity to a chronic infection with *Borrelia*. Whilst *Borrelia* infection is the primary factor driving the manifestation of symptoms of Lyme disease, the degree to which these symptoms are apparent may be modulated by 'environmental factors' in the catholic sense, as indicated in a slide that discussed the 'hierarchy of influence on health'. Genetic factors, such as the presence of particular HLA markers, the expression of certain microRNAs (that modulate*

inflammatory pathways) and also the degree to which methylation cycles are compromised, were also discussed within this hierarchy of influence.

A small discussion was then presented on the need for new antibiotics, possibly targeting the uptake of essential nutrients by Borrelia. In particular, these organisms are unable to synthesis purines (components of the DNA molecule) and they need to transport these molecules across their membranes, making this transporter system a legitimate drug/antibiotic target. Borrelia as a genus is also rather unusual in that their membranes only contain the phospholipids, phosphatidylglycerol and phosphatidylcholine and to synthesise the latter, they have to 'steal' choline from our cells and tissues. Choline is combined with diacylglycerol by a special form of phosphatidylcholine synthase, making this enzyme another useful drug/antibiotic target.

Whilst little antibiotic development has occurred over the past 25 years, a new agent has just appeared in the literature named Teixobactin. It remains to be seen whether this will be effective against Borrelia and co-infecting agents.

When antibiotics fail, as they do for many individuals with chronic Lyme disease, Pulsed Magnetic Field Therapy (PMFT) would appear to be beneficial for some individuals and this was discussed in terms of a potential mechanism of action. Studies have indicated that within the control region of several genes there exists an electromagnetic responsive region or element. One such set of genes codes for heat shock proteins (Hsps) such as Hsp70. These proteins act as molecular chaperones to protect other proteins in times of cellular stress. Hsps have been suggested to act as Damage Associated Molecular Pattern (DAMP) that can activate the Toll-like receptors of innate immune cells. In this way PMFT may increase the immune reactivity of the innate immune system and this may have a beneficial effect to reduce the bacterial load of Lyme disease organisms.

Dr Newton also presented data provide by Dr Alan MacDonald (who was unable to attend), regarding his work on Fluorescent In-situ Hybridization (FISH) using Molecular Beacons - highly template-specific fluorescent DNA and RNA probes. These data clearly demonstrated the presence of fluorescent signals within clinical material obtained from individuals suspected of having Lyme disease.

Dr Beryl Beynon (Director of Well-One clinic in Beverley)

Dr Beynon explained the origins of the Well-One clinic, as an enterprise designed to serve those whom the NHS wouldn't treat whilst raising funds for her charitable medical work in Eastern Europe and beyond. Early on she found herself treating Lyme patients, Dr Chris Newton had become involved on the diagnostics side and she acquired a Rife machine.

She explained that lack of choice drove patients to come to her from as far as 200 miles, and she described how the aim of Well-One is to treat as well as possible, getting patients into remission and back to work. She has treated children successfully, and she has worked with people with ME, people who have needed counselling and considers that rife treatment may well help people with MND and Alzheimer's. She noted that about 80% of her patients are women but is unsure whether this is biological or whether societal differences lead to women being more exposed in dress and behaviour. She considers cats even more of a liability than dogs, with regard to exposing their owners to ticks.

She stated how concerned she is that NICE guidelines and fear of contravention is leading doctors to be reluctant to treat with antibiotics when appropriate. Doctors are no longer "free" to make their own responsible clinical decisions. She doubts whether she will be licensed again and although personally, because of her age, this is not a problem, she doesn't know who will take over her clinic and patients.

Peter Kemp

Peter has kindly provided his own summary of his talk.

Kemp demonstrated how spirochaetes have been observable with darkfield microscopy for over 100 years and how this type of microscopy is still used to diagnose syphilis, another spirochaete infection. Illustrated the 'string of pearls' morphology in which a spirochaete changes into a chain of coccoid bodies called 'propagules'. The morphology was shown in Lyme borreliosis spirochaetes in a micrograph by Mysterud and Laane published in 2013.

Kemp's video microscopy showed spirochaetes of varied sizes and stages of 'string of pearls' morphology. Video clips were from an experiment observing 11 donor's blood with the microscope. 9 of the 11 had been diagnosed with M.E. or Chronic Fatigue Syndrome (CFS). 10 had negative NHS tests for borreliosis, one not tested. 9 had private tests which were positive. The 11 donors represented a total of 235 years of illness and 170 years of lost productivity.

*Kemp explained that the absence of the organisms on freshly made slides contradicts Public Health England's assertion that these organisms could be collagen fibrils. Further videos showed the effect of Sodium Chlorite on the spirochaetes. The bactericidal chemical made the spirochaetes lose their flexibility and become rigid. The next video showed that a common antibiotic had a similar effect. Next were shown videos of intracellular spirochaetes. Public Health England claim that spirochaetes cannot be seen emerging from blood cells because they are 'extracellular'. The videos showed motile spirochaetes inside red blood cells that had become transparent. The spirochaetes were at varied stages of the 'string of pearls' morphology. Kemp pointed out that sometimes it was possible to get an impression of where the cell membrane of the transparent cells was; but as the membrane itself is only 7.5 nanometres thick, it cannot be seen with visible light microscopy. This contradicts Public Health England's claim that the 'spirochaetes' could be fragments of membranes from dead cells. Micrographs showed 'classic' helical (corkscrew shaped) spirochaetes grown in long-term culture from 5 donors. These were followed by a set of pictures from one culture that reacted with a Molecular Beacon fluorescent DNA probe, 100% specific for *Borrelia burgdorferi*. The donor was NHS negative for Lyme borreliosis.*

Kemp concluded that Public Health England's disparaging of microscopy was unscientific and illogical.

<http://www.counsellingme.com/microscopy/MeetingMicroscopy.html>

Denise Longman (retired research scientist)

Denise has also summarised her presentation for us.

Ms Longman explained that she represented over 12,000 signatories of the UK Lyme Petition, and that she would show why so many are dissatisfied with the way that PHE are handling borreliosis in England.

Patients had grave concerns about:

Congenital transmission,

Alzheimer's disease and other Dementias

Sudden deaths from stroke and heart disease

Blood and tissue banks contaminated

Public and doctors not aware of the true incidence

Chronic disease denied - therefore prevalence not monitored

Denigration of patients

Congenital transmission: a lot of evidence now in the literature, dating back to 1985, showing placental infection of the foetus, with adverse outcomes in 67% of cases if the mother's Lyme infection was not treated with antibiotics, but successful outcomes if antibiotics were used.

Alzheimer's Disease costs to rise soon to £26 billion with 850,000 cases in the UK. Research beginning with Dr Alan MacDonald in 1985 and now confirmed by several other scientists, with absolute proof by DNA evidence, that borreliosis is implicated in Alzheimer's disease, with the latest paper by French scientists recommending screening of all dementia patients for neuroborreliosis. Postulated that antibiotics could halt or even reverse the progress of the neurodegeneration in patients, with massive benefits to the Exchequer as well as alleviation of human suffering. Directed people to see more evidence at the web site Spirochaetal Alzheimer's Association web site. <http://www.spirochaetalalzheimersassociation.org/index.html>
Asked if PHE would begin to screen patients with neurodegenerative diseases for borreliosis.

Persistent infection: the health authorities have failed to alert the public that Lyme borreliosis is easy to catch, hard to cure and difficult to treat in many cases. Stated that there are 273 peer-reviewed publications showing persistence of infection after the standard or even extended antibiotic therapy.

ME, CFS and Fibromyalgia Large numbers of ME/CFS or Fibromyalgia patients have been discovering that they have Lyme disease after private tests, the figures are 80 to 90% according to 3 prestigious ME doctors. NHS doctors rarely consider Lyme disease as a differential diagnosis in ME/CFS/FM cases, despite a directive to do so in the NICE guidelines. But who can blame them, when PHE maintains that Lyme is such a rare disease, and if the tests miss so many cases?

True numbers of new infections showed graph of incidence figures for countries in northern Europe and questioned why England and Wales had only 1 eightieth of the incidence rate of our nearest neighbours, despite similar climate and terrain. Germany had a quarter of a million new cases each year, with twice as many women as men being infected. Distribution of infected ticks was well known to be carried out by migratory birds, as detailed in the WHO symposium in 1993, and the British Isles were a haven for hundreds of millions of these birds. The late Klaus Kurtenbach had warned via the BBC in 2007 that pheasants were harbouring the infection in Britain.

Time scale of knowledge by 1989, the WHO was aware that borreliosis had been reported from all over Britain, and by 1993, after the NATO advanced workshop in London, the Department of Health should have taken action to warn and protect the general public. Instead, even our doctors and specialists seem to be still unaware that borreliosis could be caught anywhere in the UK.

Antibiotic stewardship questioned whether the problem over-use of antibiotics had any bearing on not giving patients long-term treatment.

Duty of the Department of Health it was not the responsibility of charities and patients to make leaflets and warn about Lyme borreliosis, the onus lies on the Dept of Health to do so. Why wait for the situation to get worse? Why not act now? In Eastern Europe victims of tick bites go immediately to their doctor and receive antibiotics whether they have had a rash or not. Why keep our UK citizens in the dark?

Abuse of patients and misinformation from PHE In a report on Lyme borreliosis submitted to the Health and Safety Executive, in 2012, PHE refer to us as "disaffected patients". Their policy is to "manage us". They propose to train our doctors in "disengagement" strategies' – in other words, learn how to get rid of us. PHE's Professor Dryden recently addressed infectious disease doctors at a conference, calling Lyme a "fashionable disease" and portraying patients as living in a "parallel universe".

Furthermore the same doctor has also lectured that the ELISA tests are "too sensitive" and are likely to give false positives, with no mention of the possibility of them missing 50% of cases by being falsely negative. Most worrying of all he continues to write to GPs that if the ELISA test is negative then the patient does not have Lyme disease. This is dangerous.

Seronegativity, and inaccurate blood tests patients were aware of the phenomenon of not making antibodies, because they had learned of how borreliosis has effects on the immune system. The present tests, which look for antibodies, are thus missing many cases due to that reason alone. Also, the manufacturers of the test kits had not validated their accuracy in the hard-to-diagnose patients, and had only used a small cohort of obvious cases. PHE have acknowledged that they cannot detect *Borrelia miyamotoi*, yet that strain is confirmed to occur in Britain. What if it were found to be the major cause of Lyme-like disease in the UK?

DNA tests should be used methods such as those perfected by Eva Sapi and Advanced Laboratory Services in Pennsylvania, or using Molecular Beacons as described by Dr MacDonald, or the FDA approved test of Dr Sin Lee in Connecticut.

We should not rely on the detection of antibodies alone, but rather on the detection of the organism itself.

Summary Demetrios Loukas has run the gauntlet of a system that is not working. He has spent all of his savings on treatment prescribed in Germany. He is not alone, as many other patients have been forced to go abroad for successful private diagnosis and treatment. Pity those, who know that they are infected but cannot access private treatment. Pity even more, those who struggle with their incurable “syndromes” not knowing that they are infected and possibly infecting their children! This situation is shameful.

<http://counsellingme.com/DenPresentation/DenPresentation.html>

At this point, with time running out, the audience began to cheer Denise and become restive. It was clear that opportunities for questioning were disappearing, and Lady Mar called on Tim Brooks to respond. It has to be said that the body language of Dr Brooks throughout the afternoon had not suggested that he was interested or attentive and only one of the panel, Amanda Semper, had looked engaged and had seemed to be taking any notes.

Tim Brooks made a number of statements at this point which were greeted with heckling and general dissatisfaction; in retrospect this was probably not the best strategy but people were very frustrated to have lost the opportunity to question properly and so to hear the same old statements yet again was more than people’s patience could bear. It became difficult to follow the discussion. Statements, which all elicited negative reactions were

- Incidence has been rising but PHE only reports lab-identified cases, the others are just treated by GPs
- PHE was making efforts to educate the public and there was now information available in National Parks
- The UK is an island which explained the lower numbers of Lyme cases
- He offered Peter Kemp the opportunity to visit Porton and compare tests, making some reference to the large number of spirochetes in Peter’s samples, indicating a lack of understanding of Peter’s methods
- He had a responsibility to patients to make sure they were diagnosed with the right illness, the implication being that Lyme was often not the right answer, just the desired answer.
- PHE offers an extended spectrum of tests which could be requested by a GP – exactly what this is, other than more antibody tests for some co-infections, was not clear.

By this stage there was considerable frustration being expressed from the floor with some interruptions. Lady Mar called the meeting to order so that she could close at the designated time of 4pm. She attempted to acknowledge the work Tim Brooks has done at Porton but there was little willingness to accept this. However when she said something about having tried to chair the meeting, she was rewarded by a spontaneous and generous round of applause from everyone – it

was clear that her efforts had been appreciated and no-one wanted her to think any of the ill feeling was directed her way. The meeting broke up rather abruptly.

Dr Alan MacDonald, leading Lyme researcher and pathologist kindly contributed a video presentation which can be found in two parts here:

Part 1 <http://vimeo.com/117122902>

Part 2: <http://vimeo.com/117201634>

Links to the slide presentations from Dr Armin Shwarzbach, Dr Chris Newton and Dr Beryl Beynon can be found, with another account of the meeting, on the blog of **Joanne Drayson** at

<http://lookingatlyme.blogspot.co.uk/2015/01/lyme-disease-parliamentary-meeting.html>

Two young sufferers' stories were covered by radio and TV, linked to the meeting, and these can be found at

<http://www.bbc.co.uk/programmes/b04ykk52> and

<https://www.facebook.com/video.php?v=776236982466894> (the latter had had over 80 000 views less than two weeks after broadcast)