

## Parliamentary Lyme Meeting

On 19<sup>th</sup> January 2015 a large group of patients and families converged on Meeting Room 14 in the Palace of Westminster for a meeting with PHE and Department of Health representatives and our own panel of experts, facilitated by Simon Hughes MP and chaired by The Countess of Mar. The meeting was brought about by the incredible energy and determination of Demetrios Loukas and Denise Longman.

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, Department of Health Public Health Directorate

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

**The Countess of Mar** opened with a speech that showed how clearly she understands and sympathises with the issues of Lyme Disease. She talked about scientific method, referring to the history of Galileo, and the need always to reconstruct theories in the light of evidence. Microscopy was where the science started and microscopy and culture are the way forward now. She told of the attitudes to Lyme now, the discounting of it as “fashionable”, the way sero-negative patients are always denied diagnosis, and the lack of credibility of the low UK Lyme figures compared to the much higher, and climbing, figures elsewhere in the world.

**Armin Schwarzbach MD PhD** (specialist for laboratory medicine and infectious diseases from Augsburg, Germany) pointed out the great age of the *Borrelia* bacterium, believed to be 15 million years. Now it is known to exist in many subspecies around the world and pleomorphic forms and biofilms have been cultured *in vitro*. (See his latest paper at <http://mic.sgmjournals.org/content/early/2015/01/05/mic.0.000027.short> )

Dr Schwarzbach then discussed the early and later responses of the body to Lyme infection, sharing information well-accepted by Lyme doctors and patients. A discussion of some of the testing difficulties and inter-test disagreements followed – negative ELISAs giving positive immunoblots, low test sensitivity, the problem of false negatives, the difficulties of the persistent IgM response which confuses non-experts, and the difficulty of finding Lyme in the CSF (cerebrospinal fluid).

More generally, but still important, he noted that although Lyme symptoms can appear unspecific, the combination or pattern of symptoms is very diagnostic. However this takes time (at least an hour) to draw out of a consultation. Tests on the cellular immune response, eg LTT and Elispot, are better than looking for antibodies, but NO illness can be ruled out solely by lab tests. He talked about the involvement of *Borrelia* in the wide variety of damaging and economically important diseases with which we are familiar, Alzheimer’s, where the plaques can be *Borrelia* biofilms, Autism, MS etc, emphasized that treatment must always be continued until symptoms are controlled, and then compared in detail the contrasting attitudes of the CDC and “other” clinicians and scientists to Lyme Disease and its treatment.

He left us with a list of proposals that in his view are necessary before the UK treatment of Lyme will be adequate. Briefly this included improved testing, antibiotic use, studies of pleomorphy, new antibiotics, training of new and established doctors, and education of the public.

**Dr Mark Ashworth**, Demetrios' GP, spoke next in a brief but impassioned plea to his profession to be the sort of doctors that patients need – open-minded, listening, not arrogant either individually or as a profession about what they know, or think they know, and prepared to be a true advocate for the patient. He has learnt an enormous amount with and from Demetrios as he has accompanied him on his disease journey.

**Chris Moore** is the MD of Nordic Laboratories, an outfit set up to provide an alternative to the predominantly serological testing available in standard labs. He confirmed what we know – that many patients are experts in their own disease and expect support from their doctors. He demonstrated by means of a show of hands that many present did not get that support or help from the NHS and even those tested positive by the NHS have to pay for private treatment abroad. He looked back to the history of the link between H. pylori and stomach ulcers to show how resistant the medical profession has always been to change of the status quo. He spent some time demonstrating clearly what a huge economic cost, as well as the human suffering, comes from late and inadequate diagnosis of Lyme, involving higher health service costs in the long-term, loss of economic activity and contribution and instead the need to be dependent on State Benefits. Finally he challenged how it was possible that with established research telling us that tick numbers, activity and exposure are all on the increase, the UK figures for Lyme diagnosis were so low, and insisted that doctors should 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 and by NICE guidelines which prevent him giving IV antibiotics. Doctors should be able to treat difficult diseases off guidelines, including using complementary medicine and supportive therapies such as CoQ10, probiotics, multivitamins, Vit Bs, Magnesium, transfer Factor etc.

**Dr Chris Newton** is a biochemist who is Research Director of the CIMMBER foundation. His presentation ranged widely. He discussed the immune response to infection and how Borrelia can evade it and how delayed or inadequate treatment, because of poor testing and no confidence from GPs, just allows the infection to spread and become harder to treat. He presented a lot of detail on the factors that can get in the way of a good recovery, such as genetic factors, stress, diet, disruption of hormones, and gut dysbiosis. He can see vulnerabilities in Borrelia's metabolic needs which could serve as a focus for new drug treatments. He described, and gave a possible mode of action for, PMFT (pulsed magnetic field therapy – "rifing"). Lastly Dr Newton presented some data from Dr Alan MacDonald (who kindly also sent a video presentation to the conference which may be accessed here <http://vimeo.com/117122902>) showing his work on Fluorescent In-Situ Hybridisation (FISH) which is able to identify Borrelia DNA within patients. Dr Newton's presentation was very detailed and his own summary is available elsewhere.

**Dr Beryl Beynon**, who is the director and founder of Well-One clinic in Beverley, explained and described how the clinic was set up and the work they do with those the NHS doesn't help. Her work has increasingly included Lyme and people come from up to 200 miles away. She treats adults and children, using antibiotics and rife treatment and aims to get people into remission and back to work. She has also worked with ME patients and considers that rifing may help people with MND and Alzheimer's. She is very concerned about the way that NICE guidelines and fear of disciplining is leading doctors to be reluctant to diagnose and treat patients appropriately according to their experience and clinical observations.

**Peter Kemp** gave a fascinating presentation of slides showing Borrelia bacteria in various stages, under dark field microscopy, in samples taken from patients who had had chronic Lyme for many years. With the aid of these visually stunning videos and stills, Kemp demonstrated that

- Spirochetes are intracellular parasites which can be seen emerging from red blood cells in the “string of pearls” form.
- They are too thick to be mistaken for cell walls, as claimed by PHE
- They are not collagen fibrils, else they would be immediately present in the drawn samples
- Spirochetes can be found in the blood of (CFS) patients with negative NHS Lyme tests.
- Spirochetes in the classical form can be cultured from chronic Lyme patients
- In one case, these spirochetes, cultured from someone with a negative NHS test, reacted with a FISH probe 100% specific for *B burgdorferi*.

Kemp concluded that PHE’s disparaging of microscopy was unscientific and illogical.

His own (longer) summary and the video presentation are well worth looking at.

**Denise Longman**, a retired research scientist, covered a huge range of concerns on behalf of the 12000 signatories she now has on the UK Lyme Petition. It’s impossible to do justice to her presentation briefly – it described all the areas that concern Lyme patients, both for themselves and the wider public, and did so in a way that was both fact-filled and passionate. She has produced her own summary of her presentation and the slides are also available for viewing. So, giving only an outline of Denise’s content, she challenged PHE with the issues of:

- Congenital transmission, for which there is documented evidence, and experience that it can be controlled with antibiotics
- Alzheimer’s Disease: with 850 000 sufferers and a cost of £26 billion, it is scandalous that the possibility of halting or reversing the degeneration is not being explored and she challenged PHE to screen and treat with antibiotics.
- The persistence of Lyme infection beyond “standard” antibiotic treatment – 273 studies
- ME/CFS and Fibromyalgia: Lyme so often implicated (~80%+ of CFS according to experienced doctors) so why is Lyme not investigated as part of the differential diagnosis?
- True infection statistics: UK figures are completely unbelievable when compared to rest of Europe and with existing knowledge of tick and host behaviour and infection.
- Time-scale of awareness: knowledge seems to have retreated since early 1990s.
- Antibiotic stewardship: are the concerns about over-use preventing legitimate treatment?
- Misinformation from PHE and treatment of patients: Attitudes that this is “fashionable” and over-diagnosed abound and Dr M Dryden’s complete reliance on testing are a great concern
- Sero-negativity and blood-testing: reliance on anti-body tests means that Lyme is under-reported and patients are under-diagnosed and under-treated. Validation of tests questionable.
- DNA tests should be used, looking for the organism itself, not the reaction to the organism by a damaged immune system.
- Blood and tissue banks: denial of the true nature of Lyme puts the safety of the blood supply at serious risk of contamination.

Denise Longman concluded by referring to Demetrios’ case and calling for change for those who know they have the disease and cannot be treated, and for those struggling with undiagnosed disease who could be helped.

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 dissent 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 a general feeling of frustration and some interruptions from the floor. Countess Mar called the meeting to order so that she could close at the designated time of 4pm. It had been unclear that the meeting would need to close exactly at 4pm and the lack of opportunity to question the government panel was deeply disappointing. She attempted to acknowledge the work Tim Brooks has done at Porton but there was an unwillingness to accept that he has brought any improvement to the pre-existing bad situation. 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.