

Denise Longman's Presentation to accompany slides Parliamentary meeting January 2015

Slide 1 Informed Lyme Patients – Presenting our Concerns about Lyme Borreliosis

Ladies and Gentlemen:

I'm speaking today because it's my duty to the 12,000 plus signatories to the UK Lyme Petition, which demands more public awareness, reliable diagnoses and adequate treatment for Lyme disease. And also to explain why patients are dissatisfied with PHE's management of borreliosis in England.

Slide 2 Grave Concerns

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

Patients denigrated

Slide 3 Congenital transmission

We have families in this room and on our Facebook group who have found that their children are infected, most probably from birth.

There is documented evidence for placental transmission, which first dates back to 1985, and now amounts to 28 peer reviewed papers and 88 Medline links showing that this occurs. In summary, if antibiotics are used during pregnancy the outcome is favourable; but if not, 67% of pregnancies will have a bad outcome.

Borreliosis is damaging not just the generation who are infected now, but the next generation as well.

Slide 4 Alzheimer's disease and Lyme dementia

The Alzheimer's Society estimates that there will soon be 850,000 people in Britain living with dementia, the majority of whom are wholly or partly due to Alzheimer's disease. The economic costs of this will rise to over £26 billion.

Borreliosis infections have been documented to produce states of dementia, and **French researchers this year recommend screening for Borrelia in all dementia patients**, as well as in the Alzheimer's type of neuro-degenerative cases.

They had found “ over a ten-fold increased occurrence of Alzheimer's Disease when there is detectable evidence of spirochaetal infection”

For more information on this topic and the DNA evidence from Dr MacDonald's work, see the Spirochaetal Alzheimer's Association web site.

<http://www.spirochaetalalzheimersassociation.org/index.html>

Imagine if antibiotic therapy could halt or partially reverse the disease! The benefit to suffering humanity would go hand in hand with a huge benefit to the Exchequer. Will the Department of Health act on this information and screen Alzheimer's patients for borrelia?

Slide 5 Chronic Disease and persistent infections denied.

Over the decades the Department of Health have not informed the public that borreliosis is easy to catch, hard to cure, and can become a persistent infection. Yet there are 273 peer-reviewed publications showing persistence of borreliosis in animals and humans after the standard or even extended antibiotic therapy.

Very sick patients, with the same symptoms as they had before treatment, are being told they have a post Lyme syndrome – which is a term that refers to no defined pathology.

Slide 6 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. Yet NHS doctors rarely consider Lyme disease as a differential diagnosis in suspected ME/CFS 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?

Slide 7 What is the true incidence in the UK?

Lyme patients are bewildered by figures from the Dept of Health which state that the disease is at a low rate in the UK, only 1.7 per 100,000 of the population, and they are dismayed to receive letters from the Health Minister which seem to suggest there is “no Lyme problem” in our country.

Slide 8 Graph of incidence rate in northern Europe

In Germany the incidence is about a quarter of a million NEW cases each year. These statistics also show that twice as many women as men are infected.

<http://www.hindawi.com/journals/jir/2012/595427/>

It isn't logical that the UK has the lowest incidence in northern Europe, and only 1/80th of the incidence of our nearest neighbours, not given our role as the Heathrow Airport of the bird world. Thus patients have no confidence whatsoever in the PHE figures.

Slide 9 Birds are spreading infected ticks around the world

The WHO stated in a 1993 workshop in Slovakia that birds are important vectors of borreliosis

http://whqlibdoc.who.int/hq/1993/WHO_CDS_VPH_93.132.pdf

Our own tick expert the late Professor Klaus Kurtenbach stated that pheasants and game birds all over the UK are harbouring the infection. Also, we have hundreds of millions if not billions of migratory birds entering and leaving Britain.

Slide 10 The WHO map

The UK was well aware of the emerging incidence of Lyme during the 1980s. By 1989, the data that UK researchers gave to the WHO shows that they found cases of Erythema Borreliosis Migrans all over Britain.

(<http://www.ciesin.org/docs/001-613/map25.gif>)

Slide 11 A serious problem, recognised as long ago as 1993

For example, in England, in 1993, NATO held an Advanced Workshop on Lyme disease in London with many European and US doctors and scientists attending.

Oxford tick scientist Dot Carey reported that over 60% of animals, birds and ticks collected from many UK sites were infected with borrelia burgdorferi, and the results were confirmed by DNA polymerase chain reaction tests.

<http://ard.bmj.com/content/52/5/387.full.pdf>

1993 should have been the year when the whole of the British public was educated about the danger of tick-borne diseases. But they were not warned.

Slide 12 Too many antibiotics?

Some patients believe we are being deprived of antibiotics for reasons of antibiotic stewardship being put before our medical needs.

However, the amount of antibiotics that are used in farming and for pets totals at least the amount used for humans, and might be actually ten times more depending on the unrecorded illicit use in agribusiness.

Perhaps this needs addressing first before worrying about giving patients long-term antibiotics.

Slide 13 A Government warning is needed

We have asked repeatedly for PHE and the D of H to act with the greatest speed to

- a) Warn the public,
- b) Educate doctors
- c) Provide accurate diagnoses
- d) Give adequate treatment

One government advert on TV could begin the awareness in Britain that would soon save thousands of lives from being ruined.

It is not the job of charities and patient groups to make leaflets and distribute them to raise awareness in doctors and the public – this is the responsibility of PHE and the Department of Health.

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?

Slide 14 We are not "disaffected patients."

We are struggling to regain our health while our public servants seem to have washed their hands of us.

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, 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 quote: “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.

Slide 15 DNA will lead the way

Expert patients are aware of the seronegativity issue and we all know about borrelia’s ability to evade the immune system. This is a major reason we cannot have any faith in the antibody tests used by PHE.

Also, how can we rely on tests that have only been verified by the manufacturers in 54 patients, and then, only in a highly selective cohort, and in comparison to other kits relying on exactly the same methods? This is not validation by any scientific norm. The test kits used by the NHS have never been assessed for their ability to detect an infection in hard to diagnose cases, and those cases are the ones who may turn out to be the most ill due to an inadequate immune response.

PHE have acknowledged that they cannot detect borrelia miyamotoi, yet that strain is confirmed to occur in Britain.

We need to use methods such as those perfected by Eva Sapi and Advanced Laboratory Services in Pennsylvania, or the method 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.

DNA PCR/sequencing technology is the only test available at the moment to detect the newly identified B. Miyamotoi pathogenic borrelia species. PHE antibody screening tests for Lyme disease will not identify this pathogen. What if it were found to be the major cause of Lyme-like diseases in the UK?

Slide 16

We have seen how one particular patient, Demetrios Loukas, has run the gauntlet of a system that is not working. Through serendipity, his own persistence and the sheer good luck of finding knowledgeable doctors and scientists, not forgetting the support from his MP the Minister of Justice, he is on the road to recovery. 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.

Health Ministers and Public Health scientists, we call on you to give the British public a fighting chance to beat this epidemic. If necessary, use the expertise already available in European and American commercial labs and collaborate with as many of the knowledgeable scientists as you possibly can.

Slide 17

“The controversy in Lyme disease research is a shameful affair. And I say that because the whole thing is politically tainted. Money goes to people who have, for the past 30 years, produced the same thing—nothing.”

“Serology has to be started from scratch with people who don’t know beforehand the results of their research. There are lots of physicians around who wouldn’t touch a Lyme disease patient. They tell the nurse, “You tell the guy to get out of here. I don’t want to see him.” That is shameful. So [this] shame includes physicians who don’t even have the courage to tell a patient, “You have Lyme disease and I don’t know anything about it.””

Willy Burgdorfer 2007