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10 October 2006

BADA-UK Statement, Ho-Yen Lyme Disease Article

One Click Introduction

It gives The One Click Group great pleasure today to publish the statement from the UK charity BADA-UK (Borreliosis and Associated Diseases Awareness) that thoroughly rebuts, debunks and puts into context the recent article entitled Lyme Disease - let's dispel the myths written by Dr Darrel Ho-Yen, head of Microbiology at the Raigmore Hospital, Inverness, Scotland.

It will come as absolutely no surprise to our readers to learn that this article was published in the failing Myalgic 'Encephalopathy' Association charity magazine, ME Essential.

Why is this MEA charity run as the personal fiefdom and income generator platform for its Medical Adviser, the abusive and physically violent Dr Charles Shepherd, so worried about the evidenced links between Lyme Disease/Borreliosis and ME/CFS that are now constantly being published in papers, in the media, on websites and in Support Groups et al around the world?

In February 1999, Shepherd was given a substantial file on the links between Lyme Disease/Borreliosis and ME/CFS by one of his very own MEA charity Co-Trustees. He buried it.

In 2002, Shepherd went further and announced during the compilation of the Chief Medical Officer's Working Group Report on CFS/ME that all in-depth tests and investigations for ME/CFS labelled patients, the wastepaper basket diagnosis, should be denied. Charity rep Shepherd's endeavours to protect and promote his personal income stream derived on the backs of sick people are globally notorious.

The links between ME/CFS and Lyme Disease/Borreliosis have caused these UK ME/CFS charities more concern than any other issue in recent times because they make a comprehensive nonsense of their offerings; hence their furious scrabbling attempts to cast doubt on these evidenced links.

Since Dr Ho-Yen has studied microbiology, he will know that ticks may carry up to half a dozen disease-causing micro-organisms. As stated by BADA-UK on their website: "In the UK and most of Europe the most commonly found species of Borrelia include Borrelia burgdorferi, B garinii, B afzelii and B valaisiana. Of these species hundreds of subtypes of differing strains are known to exist. This is why many physicians prefer to use the term 'Borreliosis' and not 'Lyme disease' until such times as the causative bacteria can be identified as Borrelia burgdorferi sensu stricto, and not Borrelia burgdorferi senso lato. It is also possible for some to be infected with multiple strains, to have both Lyme disease and Borreliosis."

It has been noted with considerable amusement by scientists that nowhere does Ho-Yen even **mention** the word Borreliosis in his article, thus obviating the entire credibility of its content in toto.

On review of Ho-Yen's article, as published in the ME Essential magazine, October 2006, it has one common trait to that of the majority of publications in relation to the possible cause of ME/CFS. That common trait is the over-bearing willingness of so called specialists to discount a possible, if not probable, physical cause for an ever growing percentage of those diagnosed as having ME/CFS. Instead, placing the

sole onus of recovery on to the mental and emotional status of the patient and this 'sticking to the guidelines' over which doctors cannot reach any form of consensus.

Dr Ho-Yen, an experienced microbiologist, is accepting of the likely bacterial/viral cause of ME/CFS. Yet instead of involving himself in the design, implementation and publication of a proper controlled trial, he seems more concerned over the publication and promotion of his book 'Better Recovery from Viral Illnesses'.

This shameless self-promoting article offers nothing more than anecdotal hearsay as to the likely involvement of Lyme Disease, a bacterial infection found most commonly in America, in UK patients diagnosed as having ME/CFS.

To add further insult and possibly injury to those patients willing to take responsibility for their chronic and debilitating ill health, he promotes his book discussing the role of viral infections in ME/CFS.

Q. Given that Borrelia Burgdorferi, the pathogen at the centre of this article, is a bacterial infection, for whose benefit was this article really written?

A. The failing UK ME/CFS charities who are desperately trying to convince the sick that all in-depth tests and investigations of ME/CFS labelled patients should be denied to protect their vested interests and for the benefit of Dr Ho-Yen to be able to use a public platform to plug his book.

The next time that Dr Ho-Yen elects to go into print on behalf of one of the discredited ME/CFS UK charities on the issue of his book and Lyme Disease whilst failing to mention Borreliosis, he should perhaps consider this: That the consequences of such self-promotion have a very nasty habit of the facts of the matter turning around and biting the author crunchingly in the bum - the tender part where so many egos of self-styled 'experts' reside.

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BADA-UK
Borreliosis & Associated Diseases Awareness
Registered Charity 1113329
www.bada-uk.org

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STATEMENT FROM BADA-UK

Providing the facts in relation to the Dr Darren Ho-Yen article entitled Lyme Disease – let's dispel the myths, published by the UK ME/CFS Myalgic 'Encephalopathy' Association charity magazine, ME Essential.

Whilst Dr Ho-Yen is quite correct in his assertion that Lyme disease accounts for only a small percentage of those misdiagnosed as having ME/CFS, this in itself does not discount the possibility of one, or several, tick-borne diseases being the cause of a patient's ill health. For as indicated by Dr Ho-Yen, ME could be caused by quite literally hundreds of different viruses and bacteria, and it need not only be one infection to blame. Yet without more detailed and comprehensive medical studies, taking into account the exact nature of all bacterial/viral infections present in those diagnosed as having ME/CFS, the role of Lyme disease as a contributing factor cannot be excluded.

Lyme disease, in the strict sense, is predominantly an American infection, brought about by a spirochaetal infection known as Borrelia Burgdorferi sensu stricto (Bb.ss). In the UK, and throughout Europe, Borrelia Burgdorferi senso lato (Bb.sl) is more prevalent such as Borrelia garinii, Borrelia afzelii and Borrelia valaisiana to name but a few.

To complicate diagnosis further, it is also accepted that for each recognised strain of Borrelia, there are quite literally hundreds of sub-species of strain still to be investigated to any degree by modern science.

What is also recognised by the scientific establishment is the many ways in which Borrelia is able to evade or suppress the human immune system. One method for example is Borrelia's ability to change its physical form from the worm like spirochaete, to small cyst like structures able to situate themselves within selected and sequestered sites throughout the human anatomy. Borrelia is also known to hide within the immune system cells themselves using the cell membrane as a cloaking device, thus enabling it to evade the production of antibodies. However, the standard form of testing carried out in the UK involves the need for antibodies to be present in blood samples drawn, yet as indicated above, Borrelia need not necessarily be found in the blood of a patient, but can still be present within their system.

Furthermore, in the published paper 'Audit of the laboratory diagnosis of Lyme disease in Scotland' by Dr. Ho-Yen et al, it was noted 'When the revised scoring system was applied retrospectively (April 2003 to March 2004), 39 (33 %) of the 116 serum samples previously negative or equivocal became weak positive or stronger.' Therefore, surely it would be incumbent upon Dr. Ho-Yen to review all 500 patients over the past 10 years using this revised scoring system, to more accurately reflect those for whom Lyme disease could be a contributing factor?

The current 'two-tier' blood testing procedure, as designed and patented by the American Centres for Disease Control and Prevention (CDC), was never intended for use as a diagnostic technique in individuals. Its intended purpose was for the epidemiological study of the infection amongst the American population. As such,

the qualifying biomedical requirements were set artificially high, to exclude other medical conditions. With the highly advanced abilities of Borrelia to evade detection by the human immune system, along with the restrictive nature of the current two-tier blood testing procedure used as a diagnostic test in the UK and throughout Europe, it is not possible to conclusively exclude the role of Borrelia in a patient's ill-health. And indeed, in America, Public Law 107-116 was signed by President Bush in 2002, in an attempt to cease the misuse of what was intended as surveillance case definition being used as a diagnostic tool.
(See http://www.lyme.org/legislative/publaw107116.html for full details of Public Law 107-116)

Currently in the UK and Europe positive serological evidence of infection is still required to confirm the 'clinical' diagnosis of Lyme disease. Yet according to EUCALB (European Union Concerted Action on Lyme Borreliosis) 'A minimum standard of at least 90% specificity for the screening tests and 95% specificity for the immunoblot should be established in the population where the assay is to be used.' Without positive serology following an initial screening test, no further immunoblot testing will be undertaken, yet neither provide 100% reliable results.

The recognition by Dr. Ho-Yen of Borrelia to be misdiagnosed as ME/CFS in 5% of his patients should be heeded very carefully by the ME/CFS community as a whole, for 5% of the estimated 240,000 patients diagnosed as having ME/CFS equals 12,000 possibly misdiagnosed Borreliosis patients. It also justifies the perceived link between those currently diagnosed as having ME/CFS, yet questioning Lyme disease, along with all other tick-borne infections, as an alternative diagnosis.

Further justification is also demonstrated by those who have gone on to improve and recover their health following a misdiagnosis of ME/CFS, having experienced no benefits from the psychological intervention offered by means of Graded Exercise Therapy and Cognitive Behavioural Therapy (GET/CBT), which have in themselves proven to be harmful to some diagnosed as having ME/CFS. It has also been demonstrated that the more prolonged intervening period between infection to commencement of treatment, correlates directly to the duration of treatment required to eradicate a chronic, late stage infection. To discount the effectiveness of any antibiotic treatment regime, purely on the basis that an extended course of treatment is required, is contrary to all that is known about the treatment of Tuberculosis, for example, or a chronic infection of Syphilis, which is another spirochaetal infection.

Whilst it is true that the Highlands is by far more heavily populated by ticks, in comparison to those living in more urban areas, infected ticks have been found in areas such as Richmond and Bushy Park in London. Additionally, infected ticks have been found in other areas throughout the UK such as Exmoor, the New Forest, the South Downs, parts of Wiltshire and Berkshire, Thetford Forest, the Lake District and the Yorkshire moors. How many patients, that have been diagnosed with ME/CFS, have visited the countryside, or even a city centre park for a picnic, have been involved in outdoor sports or had close contact with animals and wildlife in general, and been bitten unknowingly by an infected tick? Contrary to the majority of published medical guidance on the diagnosis of Lyme disease, which state that a patient will experience a 'characteristic rash', it is well documented that as few as 40% of people, positively diagnosed, recall any visible rash. It is also known that there are specific strains of Borrelia infection which are less likely to produce any Erythema migrans (EM) rash.

Ticks within the UK are also known to be capable of passing on more than one bacterial infection following a single bite. Bartonella, Babesiosis and Ehrlichiosis are co-infections found within UK ticks. Yet testing for co-infections is not undertaken as a matter of course for any patient attending their GP's surgery following a known tick bite, and not discussed in the original article written by Dr. Ho-Yen.

A great many patients have taken responsibility for their own health concerns, whilst the global medical establishment argues over whose guidelines and criteria are most appropriate. The various published ME/CFS diagnostic criteria currently require that any bacterial/viral infections are excluded as a possible cause of a patient's ill-health, before a diagnosis of ME/CFS can be given. Sadly, to date, there is no conclusive testing procedure available to doctors that can conclusively rule out the role of Borrelia, or co-infections, in a patient experiencing symptoms of ME/CFS. As such, many patients have been required to take it upon themselves to fund private treatment in order to exclude the possible role of a bacterial/viral infection being to blame for their chronic ill-health, and as a result, many have regained their health following treatment for infection. If only this same approach were to be taken by those charged with improving patient's health. Yet it is the case that once diagnosed as having ME/CFS any further physical examinations are deemed as unwarranted, according to the guidelines Dr. Ho-Yen believes should be adhered to by those diagnosed as having ME/CFS.

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To learn more about Lyme Disease/Borreliosis, please visit BADA-UK
Registered Charity No. 1113329

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For further information on the links between Lyme Disease/Borreliosis and ME/CFS, click here