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General concerns about the situation for Lyme disease patients in the UK

- A. Although this is a uniquely complex illness, surrounded by controversy, and there are undoubtedly some people who will always suffer badly, it seems to us that an enormous amount of damage is done to a large number of people by GPs and consultants not being aware of, or not applying, knowledge which is well known. We **regularly see mistakes** being made, contradicting NHS guidance and RCGP recommendations, resulting in ineffective treatment.
- B. The level and quality of **communication** between all involved parties with respect to Lyme disease is deeply troubling. There appears to be a combination of factual inaccuracy, incomplete/ineffective communication, lack of identification, lack of trust, abrogation of responsibility and that dangerous combination of arrogance and ignorance, present in the interactions between government, PHE, NHS management, consultants, BIA, GPs, RCGP, scientists and patients. From the patient perspective, when met with a doctor who shows lack of knowledge about the illness and the bacteria, but who also does not trust the patient to describe symptoms, who dismisses patient's reports, who shows no empathy, who writes off "the internet" in one sweep, and who has complete power over the patient, is it surprising that patients have no trust in their doctors.
- Where patients meet good, open-minded and considerate doctors, these are usually completely handicapped by the context in which they have to operate. It has been known for some to tell patients to go abroad, knowing they cannot treat the patient properly.
- C. A particularly acute example of the communication and misunderstanding problem is seen in the **perception that patients "want" a Lyme disease diagnosis**. Patients dealing with life-limiting symptoms given no satisfactory explanation will often research and

realise Lyme is a possible cause. They discover that it is a sophisticated, persistent, bacterium with a genome which is considerably more complex and larger than that of the Syphilis bacterium, and yet their doctors seem to know little about it or its prevalence. This is why patients turn to support groups and the internet, and persist in their questions to doctors.

- D. Another example of the poor communication is that although doctors are generally under-informed about Lyme disease, and frequently (through our experience) diagnosing and treating patients incorrectly, there seems to be **no vehicle to improve this**. Although the LDA and RCGP together produced an online course about Lyme, take-up has been very poor, and there seems to be no other effort to ensure doctor adherence to guidance.
- E. As a result patients are very **isolated**. Not only do the medical profession reject their experience but because of this patients suffer lack of empathy and practical consideration from employers, friends, wider family, schools, universities. Close family, partners, children, parents, suffer from the practical impact and from not being able to help their loved one. The benefits system is not designed to cope with invisible chronic illness and patients often find that online patient groups like ours are their only support option.
- F. In order to do a simple thing like check their own test results, patients often have to make strenuous efforts to ask for print-outs from consultants and GPs. Occasionally patients even have to make a **subject access request** to RIPL just to view their own test results.
- G. Generally doctors seem to be trying to minimise antibiotic use in Lyme, by **prescribing close to the minimum** suggested by current guidance. Courses of only 10 days 100mg bd doxycycline are not uncommon. We have even seen 100mg per day for a week. We understand that limiting antibiotic use is appropriate in a system-wide context but it is misapplied when it comes to Lyme. We do not limit antibiotic use when treating Syphilis or TB, and neither should we for Lyme. The general principle with antibiotic use is that you either don't treat or you treat effectively; half-measures are the damaging action. This is happening all the time in cases of acute Lyme.

- H. There is almost total **ignorance of co-infections** in the UK. Babesia is often regarded as being not present in the UK whereas we know of many UK-infected patients being treated for it by US and other doctors. Doctors are usually completely ignorant about diseases such as Bartonella, Anaplasma/Ehrlichia etc . Aside from the need to identify and treat these co-infections, their presence can often lend support to the Lyme diagnosis because they indicate that a tick-bite has occurred.

- I. The provision of **awareness-raising** in the general public is left almost entirely to patient organisations, charities and commercial enterprises. Every surgery in the country warns about the dangers of Malaria, only caught outside this country. Almost no surgeries warn about Lyme disease and ticks, although this can be a life-changing disease and endemic throughout the country. PHE's public information campaign consists of a few pages about Lyme hidden deep in an esoteric website. We would have recommendations to make about routine prevention tactics such as inclusion in school risk awareness procedures, training of pharmacy, surgery and A&E staff in tick removal, warning signs in places where the public might be at particular risk, provision of public awareness materials through schools, rambling clubs, children's groups.

- J. In situations where infection is difficult to identify, there is one route which is not being exploited nor investigated. It is possible to **PCR the tick** when this has been kept. Theoretically in this situation a good patient scenario is to treat prophylactically, whilst testing the tick. Treatment can be withdrawn if the tick proves to be negative, or continued if positive with the advantage that treatment was started very early. If no treatment is given, it still means that an asymptomatic patient can receive an almost definite answer within 10 days or so, and not have to wait for weeks for the appearance of hard-to-identify symptoms. Why is this option not being pursued?

- K. Patients who go to specialist Lyme doctors are often **subjected to criticism** and the doctors described as charlatans and quacks, trying to make money out of gullible patients. Although there are irresponsible practitioners in every field, most Lyme doctors are reputable professionals making no more money than private consultants in the UK. When Lyme patients report such things as treatment for biofilms or co-infections, which doctors haven't heard of, their reaction is often to see the Lyme specialist as a quack. They need to have better advice readily available to them. Lyme patients cannot be treated by the NHS, but their doctors disapprove of their attempts to find private treatment and do not understand or support it. Patients feel abandoned.

- L. In almost every aspect of Lyme disease there is a difference between **theory and practice**. Authorities defend the status quo on the basis of theory but what patients experience is the practice, which is often inferior.