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Barriers to effective treatment in the UK

In the pathway leading to effective treatment in the UK, the bar is raised at several sequential points, leaving very many patients unable to access help.

1. The background understanding of many doctors is flawed, with these misunderstandings commonplace.
 - a. Lyme is perceived as rare in some areas (geographical and rural/suburban/urban) and rare in the UK. UK surveillance uses the same constraints as US surveillance which has been known for some time to have under-estimated by a factor of at least 10. Consideration of Lyme is dismissed on the basis of rarity. (Even RCGP recently quoted as recommending doctors in *rural* areas should do Lyme course.)
 - b. Lyme is “self-resolving”. It is not, and persistent disease is serious. Patients often have the possibility of Lyme dismissed if possible infection happened years ago.
 - c. Lyme can only be considered when there is a known tick bite. Tick bites are easily unnoticed and Lyme should be considered when exposure is possible.
2. Our medical system means that patients are quickly referred away from generalists to specialists, who only consider one part or system. Patients are regularly seeing several different consultants for symptoms in several body systems. We have few doctors capable or willing to look for the characteristic, unusual pattern of otherwise common symptoms seen in Lyme. We do not have the equivalent of the US internist; very significant in considering a multi-system, largely subjective-symptom disease like Lyme.
3. The testing regime is flawed

- a. The screening and confirmatory tests used look only for antibodies which are often absent or undetectable.
- b. The reliability of the tests is not good enough to bear the importance of the outcome.
- c. The tests themselves are designed to minimise false positives, in spite of the consequent increase in the risk of false negatives. This puts fear of statistical inaccuracy above patient welfare.
- d. Use of other tests, which might support diagnosis, is not recommended or recognised. Pattern recognition, essential to Lyme diagnosis, is not used. (microscopy, Lymphocyte Transformation Tests, such as Elispot, Lymespot revised, iSpot Lyme, Melisa, PCR on urine with application of ultrasound, other new technologies)
- e. There is little interest or demand for research to establish the reliability of other testing technologies, even though the current testing regime is known to be flawed.
- f. A particular cause for concern is the screening-out of patients on the ELISA when it is known that some patients show a positive Western Blot but negative ELISA. It is recommended that a Western Blot should be requested at the same time as ELISA in cases of strong clinical suspicion but in our experience doctors sometimes have these requests turned down.

4. The testing regime is misapplied in practice

- a. Doctors do not always know that an EM rash should be treated without testing.
- b. Doctors do not know how to recognise the variety of EM rashes, especially if not target shaped.
- c. Doctors do not know that an EM rash is often absent (~1/3) and do not sufficiently recognise “summer-flu” symptoms.
- d. Doctors often dismiss signs on the basis that “Lyme is rare”.
- e. Doctors often test too early before immune response can develop.
- f. Doctors often test after antibiotic treatment, not recognising that treatment affects the response.
- g. Doctors often specifically use post-treatment testing to confirm “cure”, ignoring continuing symptoms.

- h. Doctors do not always understand how the 2 tier system works and the statistically demonstrated limitations of each stage.
- i. RIPL's notes on test reports makes it seem as though serology rules out Lyme whereas the Virastripe test information makes clear that it does not. "A negative result does not exclude... presence of the disease."
- j. Seronegative disease not usually accepted, although there is much evidence for this and Lyme is an immune-evading and immune-suppressing disease.
- k. There is constant referral by RIPL to cross-reactions with EBV. Given the high prevalence of EBV in the population and the fact that some of these people have negative EBV tests, this is a specific cause for concern.
- l. Tests including IgM positives are frequently ruled out on the basis that IgM is not found in chronic infection. This is not true in Lyme and even the Virastripe test kit says this. The immune response in Lyme is variable and IgM can be present long-term, while IgG does not develop. RIPL states in these cases "if late disease is suspected no further action is required".
- m. Doctors, GPs and Consultants rule out Lyme on the basis of negative serology despite the presence of strong clinical indicators.
- n. The need to make a clinical diagnosis is not widely understood and/or accepted.

5. The treatment regime is flawed

- a. Treatment protocols severely under-estimate the flexibility and persistence of the pathogen. They fall very short of ILADS recommendations and ignore what is known about the organism. Eg slow replication time (2x per day), long "life-cycle" and many strategies for avoidance and persistence.
- b. Persistence of the pathogen beyond short courses of antibiotics is not recognised. Continuing symptoms are ascribed solely to long-term effects of the disease on the body, at a stage when bacterial infection is still part of the equation.
- c. The vital initial courses are too short and too weak. This is the stage when double the time on double the dose would make a life-time's difference to the outcome.
- d. Recommendations for late and chronic Lyme do not assert the possible need for aggressive or prolonged therapy. Chronic Lyme is completely rejected by many doctors and is given "speech mark" status by NHS Choices website.

- e. Guidance does not support continuing treatment until symptoms are gone, but sticking to a pre-determined standardised timetable
- f. Testing procedures during treatment which can give indications of how recovery is progressing are not recommended or recognised.

6. Treatment regimes are misapplied

- a. Doctors often give the recommended lowest level of therapy, then cease regardless of continuing symptoms. Patients are regarded as “cured”.
- b. IV antibiotics indicated for disseminated Lyme are rarely given.
- c. Doctors rarely treat right up to the limit of guidance, despite continuing symptoms.
- d. They rarely repeat antibiotic courses in the light of continuing symptoms.
- e. Doctors do not understand the phenomenon of the Herxheimer reaction in Lyme, similar to syphilis but possible throughout treatment, and we have heard of antibiotics being withdrawn from patients as a result of this misunderstanding.