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LETTER TO THE EDITOR

Lyme disease – the challenge for patients

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Dear Editor,

'The challenge of Lyme disease: tired of Lyme wars' by Kullberg *et al.*[1] came as a welcome relief for patients with Lyme disease. The dilemma of the treating physician and patient confronted with a limited evidence base is the central theme. The uncertainties which threaten to undermine the doctor-patient relationship are acknowledged with the emphasis on further research, proper care and resolution rather than conflict.

In contrast, the editorial 'Lyme borreliosis: the challenge of accuracy' by Klempner *et al.*[2] portrays the Kullberg editorial as a 'plea' and the language of conflict is resurrected with references to 'the field' and to 'standards' with patient support groups redefined as 'activists'.

The Klempner editorial attempts to defend the Klempner trials[3] against the criticism of Kullberg, stating 'Klempner *et al.* did not find any evidence, based on over 700 samples from 129 patients that were examined by culture and polymerase chain reaction (PCR) assays, for persistence of *B. burgdorferi* sensu stricto infection in patients with persistent treatment for Lyme borreliosis.'

Despite low sensitivity, an exclusion criterion for the original study was a positive PCR result for *B. burgdorferi* DNA in plasma or cerebrospinal fluid. It is predictable that 129 baseline blood samples and 128 cerebrospinal fluid samples tested negative for *B. burgdorferi* DNA and that 458 blood samples during treatment continued to test negative, giving a total of 715 negative PCR results. This degree of selection bias with absent data on blood cultures cannot be accepted as 'lack of evidence of persistence'. Eight patients (6.25%) did show evidence of intrathecal antibody production.

Since the Klempner editorial was published, a further European study has corroborated Kullberg's view that the performance of serological assays is suboptimal.[4]

Patients are disheartened by doctors apparently trying to score points off one another instead of directing their expertise towards resolving undeniable uncertainties. The challenge for patients struggling with Lyme disease is not academic. Uncertainty, fear, pain and hardship can seem endless. How do patients understand that although the Infectious Diseases Society of America (IDSA) recommends further treatment for continuing objective arthritis, subjective pain does not count? Or that because fatigue is non-specific a trial demonstrating significant improvement[5] is considered a failure?

Lack of good quality evidence concerning diagnosis and treatment disempowers doctors and all too often disenfranchises and alienates patients. Unfortunately the recent editorial by Klempner *et al.*, by foreclosing valid questions, can only perpetuate this state of affairs.

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