

# Lost in the Woods: treatment uncertainties and ethical issues affecting patients with Lyme disease

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**Background:** Lyme disease is the most important vector-borne infection in Europe and North America (Steere 2001). It is most commonly acquired from the bite of an infected tick, while walking or undertaking recreational activity in wooded areas. Incidence of Lyme disease has risen dramatically during the past three decades, with more than 100,000 cases now being reported world-wide each year (Steere *et al.* 2004, Lindgren and Jaenson 2006). From a clinical perspective, Lyme disease is a potentially complex illness (Steere 2001, Davidson *et al.* 2003). If treated early with antibiotics there are usually few complications and most patients make a complete recovery. However, where diagnosis and treatment are delayed, the infection can progress to more serious or life-threatening conditions involving the skin, nervous system, heart and joints (Steere 2001). Lyme disease is a Notifiable Disease in a growing number of jurisdictions and an increasingly high-profile public health issue (Feder *et al.* 2007, Tonks 2007, Ogden *et al.* 2008).

**The Ethical Issue:** There are currently two approaches to the treatment of Lyme disease. The Infectious Diseases Society of America (IDSA) has developed evidence-based guidelines that promote short-term treatment with antibiotics. These guidelines have been adapted for use in Britain. In contrast, guidelines developed by the International Lyme and Associated Disease Society (ILADS) promote long-term antibiotic therapy and other treatments in the belief that Lyme disease is insidious, and potentially a chronic condition. This has created a significant amount of conflict and controversy among practitioners (Tonks 2007; Auwaerter *et al.*, 2011) and resulted in significant confusion for patients, especially where the infection is thought to be persistent. A number of ethico-legal issues are relevant and include (1) evidence of conflict of interest in planning and conducting research; (2) Increased confusion and uncertainty to patients who are affected by the disease and who think they are affected by the disease; (3) poor professional conduct amongst the scientific and clinical community; (4) misrepresentation of scientific evidence (5) treatment uncertainties that leave many patients desperate and confused.

**The presentation:** The presentation will illustrate some of these ethical issues using a patient narrative recorded using a story developed, based on current evidence of the issues raised above. The format will be a mixture of consultation and narration.

**The Objectives of the presentations are to:** (1) Illustrate the importance of patient narrative in understanding multitudinal view points and hence in providing patient centred care; (2) Demonstrate why medical humanities are key to and sometimes the only ethical way to illustrate complex issues which are essential to providing ethical and effective patient centred care

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