

I just wanted to thank you for covering Lyme Disease in woman's hour yesterday.

I have had ME/CFS for 18 years and last year tested positive for Lyme Disease using a German laboratory. I got tested because my sister in law who was on a visit to the UK from Australia suggested I get tested for Lyme Disease as she had seen a programme on it in Australia. Prior to this I knew nothing about Lyme Disease despite owning dogs for the last 28 years and having regularly removed ticks from my dogs. I have since tested negative on NHS tests. The NHS tests rely on the creation of antibodies unlike the German tests which are a direct test. My GP recently agreed to refer me to an NHS Infectious Disease Consultant but I never got to see him as he rejected the referral and said my symptoms were ME/CFS. I have developed sensitivities to perfumes, chemicals, exhaust fumes etc and can no longer go anywhere in public. I have to wear a face mask for medical appointments and ensure that staff will not be wearing perfume etc. I no longer see family or friends. My life is a living hell. I have also lost 2 stone 9 lbs in weight in the last 18 months with no explanation from the NHS. Recently I have seen numerous specialists immunologist, neurologist, endocrinologist and I am going to be referred to a gastroenterologist. Why do the NHS refuse to accept the Lyme Elispot test in the UK when the Elispot is the gold standard of testing for TB in this country? If only the NHS would wake up to the incidence of acute and in particular chronic Lyme Disease. The NHS and NICE need to act to improve the recognition, diagnosis and treatment of Lyme Disease. Because of my sensitivities I am unable to travel abroad to see a Lyme literate doctor who follows the International Lyme and Associated Diseases Society guidelines. For me personally this equates to no hope.

Sarah

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