

CO-FOUNDERS' OF LYME DISEASE UK
STATEMENT FOR PARLIAMENTARY FORUM ON LYME DISEASE 19TH
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Our names are Natasha Metcalf and Louise Dean and we co-founded and run the online patient support network, Lyme Disease UK. We have been running for less than 2 years and our membership is already over 1300 people. The extent of the suffering goes beyond a few minor disruptions to daily life and trivial complaints. The majority of our members' lives have been completely shut down with sufferers being unable to work, drive or socialise. People are struggling to keep up with the demands of family life and relationships are being severely compromised.

We witness harrowing stories being shared in our group on almost an hourly basis. Despite the denial of the existence of chronic Lyme disease, we have noticed that those in our group who do seem to be steadily regaining their health tend to be under the care of private, often overseas doctors who do believe in persistent infection. These practitioners use the extensive knowledge and experience they have gained over the years to tailor make treatment plans for individuals that take into consideration not only Lyme disease itself, but co-infections as well. Additionally, endocrine imbalances, heavy metal and mould toxicity, gut dysbiosis and many other factors that can cause chronic illness are also investigated. To get these people well, the spotlight needs to be shone on all the components of their illness in order for recovery to be achieved.

We feel that this is the direction the NHS needs to go in - we need doctors who can join the dots from multiple disciplines and treat patients with this highly complex illness in a holistic and individualised way.

The general impression gained from our support network is that if you don't have funds to get private help, you don't stand a chance of recovering in this country from

this extremely debilitating illness. Many of our group members have been previously diagnosed with conditions such as ME and fibromyalgia, yet often the recommended treatment hasn't helped them.

Whilst the debate about the existence of chronic Lyme disease drags on, thousands of us are subjected to a life of misery caught in the crossfire of this monumental medical disagreement. It is shocking that in a country where healthcare should be available to all, many find that the only chance they have of recovering is if they step away from the mainstream and pay for treatment privately when the NHS draws a blank.

As patients, we want real, tangible change. We're fed up of being told categorically that chronic Lyme disease doesn't exist when the James Lind Alliance findings revealed that there are still so many uncertainties surrounding this disease. There are studies out there that suggest the bacteria can persist beyond short courses of antibiotics, yet it seems as though this research is being ignored. There is also the issue of those of us who were never diagnosed and treated in the initial stages of the illness.

Patients are mystified by the apparent prevailing attitude amongst the medical profession that this is a 'fashionable' disease for which people would pay anything for a positive test result. Our experience from running the support group does not reflect this belief. It is clear that patients do not want to be lumbered with such a complex, debilitating and misunderstood disease which often proves to be extremely expensive in terms of private treatment costs and loss of income due to poor health. We find that the majority of people in our group had busy lives full of ambitions and plans before this illness struck - it's not something people sought out or desired.

We want open minded doctors in the UK to meet with and listen to the Lyme literate doctors who actually get people like us *better*. This is what it should be about... not the politics or the arguments over semantics or the 'Lyme wars'...but simply about *getting patients better*.