

## LYME TREATMENT FREEDOM PETITION

For over 15 years individuals with Lyme disease have had to struggle to find a physician who would take their illness seriously. The vast majority of physicians have been following a philosophy, which propounds that Lyme disease is a short-lived, inconsequential disease. The physicians who have proposed and continue to support this theory are sought out by Insurance companies as “Lyme experts”.

We, as patients with Lyme disease, know what a horrific disease this is, and have suffered through many years of pain and suffering. We have been required to go out of our states to find physicians who are not only knowledgeable about this disease, but are also willing to oppose the paradigm adopted by the insurance industry. Our treatment has frequently not been covered by our insurance plans, and we have had enormous out of pocket expenses. This would occur during times when our level of functioning was so severely compromised that we either could not work at all, or had to make dramatic changes in our work status. The financial stress associated with this disease has destroyed our careers, families and security.

The few doctors courageous to treat us, knowing they were opposing a powerful enemy, have been subjected to attacks and threats. Most of them have been forced to defend their medical licenses because they refused to trivialize what they knew was an extremely complicated and chronically debilitating disease. They have been accused of “over diagnosis” and “over treatment” by other physicians whose conflicts of interest should be transparent since they uniformly are hired by Insurance companies as “experts”, thus making their testimony suspect.

We have been unable to “fight back” with concrete definite disproof of this theory until now. We now have scientifically proven, incontrovertible evidence that our disease is chronically persistent without known biological endpoint.

Dr. Brian Fallon has completed the first randomized controlled crossover study designed to analyze the response to intravenous antibiotics in patients with chronic neurological Lyme disease, who have already received extensive antibiotic treatment in the past. His results have demonstrated that

despite 2-3 months of intravenous antibiotics and 7-8 months of oral antibiotics, those of us with chronic Lyme disease demonstrate significant abnormalities on brain PET scans, cognitive testing and pain testing. ***Those of us who received another 10 weeks of antibiotics intravenously responded to this therapy with improvement of all objective parameters. Those of us receiving the placebo did not.***

***By the end of 12 weeks off treatment there was evidence of relapse.***

These results must be used to dispel the following insulting and destructive illusions:

1. that anyone with Lyme disease who does not respond to 2-4 weeks of antibiotics has a psychiatric illness and needs psychotherapy.
2. that “it is impossible” for us to still be infected after “excessive courses of antibiotics.”
3. that the physicians who treat us for chronic Lyme disease are “heretics” and “mavericks” who deserve to have their licenses summarily removed before they do more harm to unsuspecting, defenseless patients.

***We object to the above attacks and we call for an immediate change in the prevailing attitude. We demand the following:***

1. That the physicians who attend regular conferences on Lyme disease, and are treating their patients appropriately for chronic Lyme disease, be sheltered and protected from the harassment they have been facing.
2. That the physicians who have refused to treat, and continue to refuse to treat, patients with persisting symptoms of Lyme disease beyond 2-4 weeks should be subjected to the same scrutiny by their peers as they have subjected on our physicians, and should be removed as “experts” in Lyme disease. There are only two possible theories for their refusal to accept the facts:
  - a. they are ignorant
  - b. they have a financial motivation to follow that dictum

Neither of the above reasons are acceptable to us and the time has come to remove these doctors from the list of “Lyme expert” until they accept the strong scientific evidence contradicting their approach.

3. That Insurance companies may not use a physician as a “Lyme expert” if that physician has a financial incentive to refuse coverage for treatment. All physicians who are to function as independent experts should be chosen from a pool of practicing physicians with no know ties to insurance companies who have proven expertise in the clinical management of Lyme disease.

***IF YOU AGREE WITH THESE PETITON CONCERNS,  
PLEASE WRITE, “I AGREE WITH THE ABOVE.”***

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Sincerely,

Signature \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Date \_\_\_\_\_

**Please Fax to: Lesley Ann Fein M.D., M.P.H. at (973) 575-9340. Your petition will be used to inform legislatures and medical state boards about patient desires for treatment options in Lyme.**

The idea is to use this when asking legislators to write letters to the Board of medical Examiners objecting to this witch hunt.

What would be great would be for patients to get the petition and download it. They can then write their name and state at the bottom with a comment "I agree with the above" and send it back to you or me. That way I can add their names to the list. Other ways would be to get people to sign at the bottom and fax it to me at:

(973) 575-9340