

Dear Colleague;

There has recently been a remarkable increase in news items about Lyme disease in New Jersey and the New York metropolitan area, as well as around the United States. Unfortunately, much of this is sensationalist and inaccurate. In speaking to other Lyme disease researchers and clinicians, I sense increasing frustration with the media attention which has served only to fan the flames of Lyme hysteria.

Reports of a conference in Nebraska were published in a number of newspapers, trumpeting the value of malaria therapy for chronic Lyme disease. Physicians spoke of the value of this modality. Two patients claimed near total cure. The articles claimed that this was a new innovative form of therapy, full of promise, with no rebuttal of these claims.

An unfortunate 12 year old girl died of progressive neurologic dysfunction recently. She had been evaluated by infectious disease, immunology, rheumatology, and neurology specialists at three hospitals, all of whom stated that there was no evidence of infection with Borrelia burgdorferi. Nonetheless, her physician states categorically that she died of Lyme disease (no autopsy was done). They have used her demise to berate the Lyme disease academics as not taking Lyme disease seriously, unaware of the many manifestations of Lyme disease and poorly responsive to the needs of the public; the true believers have the only real insights into the disease, which requires prolonged therapy and may be incurable.

One of my colleagues gave an important and well received talk at the Stockholm meetings, in which he stated that Lyme disease was being over-diagnosed and over-treated in his hospital. A few months later a letter questioning the research and his ethics was sent by the President of the Lyme Borreliosis Foundation to two officials of this hospital. The letter went on to state that the audience was shocked and upset with the presentation; neither is the case. The letter stated that the audience disagreed with the conclusions; in fact, the audience applauded the findings, which confirmed another study. The letter went on to make a thinly veiled threat: if this is the sort of person you allow to represent your hospital, we of the Foundation will no longer be able to refer our members to your institution for evaluation and therapy.

It has become apparent that we, the scientific and medical community must do a better job of educating the public. We have absented our responsibility in this area and this vacuum has been filled by other organizations, less rigorous in their examination of "facts". Unsupported speculation has been presented as truth, apprehension has replaced appropriate concern in endemic communities. The hysteria and medical malpractice associated with Lyme disease is actually obscuring the true severity of the public health problem. It is time that the scientists, physicians, and educators who work with Lyme Disease organize to respond to these problems.

This long letter is my first attempt to organize us into an effective counterforce to the various purveyors of misinformation and hysteria. Once we have organized and given ourselves a proper name, we will find Federal, private, and corporate funding and begin the long task of making ourselves known. We will contact every magazine, newspaper, radio and television station, and Health Department in areas endemic for Lyme disease, so that we can deliver the opposing, rational, view on malaria therapy, never-ending antibiotic therapy, and other unproven remedies for Lyme disease. We will continue to develop educational materials for the lay public and health care providers which express our consensus views. It is our responsibility to respond to ignorance, quackery, and personal attack in a responsible fashion. By organizing and making ourselves available we can diminish the pathologic influences which are currently the sole source of public and media information on Lyme disease. We have not been active in this arena thus far in the history of the Lyme disease public health problem. Events are accelerating so that a response by a united front is needed now. I very much hope that you will join me in this effort.

Sincerely,



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Please complete the attached form and send it back as soon as possible. If there are others you think should be included in this effort, please make a copy of this form and have your colleagues join us. If I omitted someone from this initial mailing, it was an inadvertent error.