

[BLINK 12/27/2004] IF YOU ARE NEW TO LYME.....

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...the very first thing you must learn is that the diagnosis and treatment of Lyme Disease (as well as several other related vector-borne illnesses) is an extremely controversial and politically charged subject. One result is that an unmoderated newsgroup such as this finds itself under constant attack from anonymous individuals with questionable motivations, who utilize a combination of subterfuge (e.g., posting as other well-known users with slightly mis-spelled user names), intimidation, and well-timed inflammatory posts to maintain a perpetual flame-war within the newsgroup. Thus, while there are occasional nuggets of valuable information found here, this simply may not be the best location for the uninitiated to find basic information.

So where else should you look?

For the mainstream CONSERVATIVE view on diagnosis and treatment, visit these sites (HOWEVER READ FURTHER BELOW):

<http://www.aldf.com>

<http://www.journals.uchicago.edu/CID/journal/issues/v31nS1/000342/000342.html>

You should be aware that not everyone is in agreement with the above "mainstream" guidelines and opinions. For starters, a significant number of successfully diagnosed Lyme patients have found the mainstream minimal treatment regimen as recommended above to be insufficient, leaving them with ongoing and sometimes serious illness. Further, an unknown (and possibly large) number of persons who are newly infected may be going undiagnosed based on widespread acceptance and reliance on the controversial two-tier testing (ELISA, THEN perhaps Western Blot) currently recommended by the mainstream/conservative camp. Be aware that if you see a local doctor, these conservative guidelines and opinions are those with which (s)he will most likely be familiar.

While not as widely accepted at this time, more progressive guidelines for diagnosis and treatment exist. If you suspect you have Lyme or one of the

associated diseases (even if you have previously tested negative), or if you have been diagnosed and received the mainstream course of treatment but have not improved, it's time to make yourself aware of the more progressive views on these illnesses, as well as the political forces that may be hindering an honest and open dialog regarding the many problems surrounding these illnesses.

What political forces? Those active in the grassroots Lyme community have been warning for years that Lyme (and several associated illnesses) are more widespread, and much more persistent and serious than is currently acknowledged. How much more widespread and serious no one can say exactly but some suspect the epidemic is quite extensive, with many people remaining undiagnosed, or misdiagnosed with other problems that are difficult to differentiate from Lyme and/or associated infections. Combine this with the fact that, even for an apparently significant percentage of those who are "lucky" enough to be correctly diagnosed, cost-effective and reliable treatment remains elusive. Again no one can HONESTLY say with confidence how many cases have not responded to standard courses of treatment, but grassroot progressives suspect the number of treatment failures is much higher than claimed by conservative estimates. Part of the problem is the extended length of time it can take (sometimes years) for late-stage illness to manifest itself.

So if the progressives are correct, there is a potentially large population of persons infected with one or more persistent organisms, whose only known semi-reliable treatment (usually months to years of antibiotics) is potentially expensive, especially if administered via IV. Most importantly, the expense of such extended, open-ended treatment is nearly impossible to predict, even on a patient by patient basis, never mind over an entire patient population. From a business perspective (for example, from the point of view of an insurance actuary) this could only be perceived as a nightmare scenario for the managed healthcare industry.

This is a likely explanation for the relentless stream of well-publicized conservative studies and opinions in the large media and mainstream journals, attempting to demonstrate that

- (1) Only a small percentage of the population is infected (with the subtle implication that current testing methods are adequate to determine this is true, which they most certainly are NOT),
- (2) Of the small group actually infected, the vast majority are cured with a short, cost-effective "standard" course of oral antibiotics (a conclusion based at least partly on studies which rely on those same questionable blood tests), and finally
- (3) the "very small number" of people who remain ill after the "standard" course of antibiotics must be suffering from some "post-Lyme syndrome" whose cause, while not well understood, cannot possibly come from persistent infection since the standard treatment has been "proven" to be so effective.

Many grassroots Lyme activists and patients are concerned that at least some well-known conservative experts have acknowledged (or worse, unacknowledged) associations with (and thus might be unduly influenced by) large business interests

like the managed healthcare industry. Grassroots groups' concerns and suspicions are further fed by the fact that so many Lyme sufferers' everyday experiences (as well as a sizeable body of inexplicably ignored studies and reports) seriously contradict the conservative findings.

Incidentally, the problems discussed here are not peculiar to the realm of Lyme Disease but are representative of systematic (albeit subtle) managed healthcare manipulation of the perception of various diseases across the board, in the ongoing effort by the insurance industry to influence and control the behavior of practicing physicians, thus controlling healthcare cost. Most everyone knows today's healthcare system is broken — the reason is that MBAs, not doctors, now define standards of medical care.

In response, patients and advocates have set up their own web sites to provide the public with an alternative view with regard to Lyme and associated illnesses. Here are a couple of those sites:

<http://www.lymediseaseassociation.org>

<http://www.lymenet.org> (a moderated support group is available here)

A growing group of physicians and researchers acknowledge the problems and limitations of the mainstream interpretation of Lyme Disease and related infections:

<http://www.ilads.org>

Here are two well-known books that describe in detail the many problems and challenges facing Lyme patients (try your local library before buying!)

<http://www.amazon.com/exec/obidos/tg/detail/-/0805075631/103-1882334-3516605?v=glance>

http://www.medicine-book.com/Everything_You_Need_to_Know_About_Lyme_Disease_and_Other_TickBorne_Dis

The above links are only meant as starting places! There are many other helpful progressive resources as well — too many to list here.

Many find the difference in opinion between the conservative and progressive camps (as well as the level of hostility often associated with those differences) to be stunning, especially at first. Each individual must ultimately decide which of the two starkly differing interpretations of these diseases best fits their own experience and proceed accordingly.

Good luck!