

Re: In Praise of Lyme Activists

Source: <http://sci.tech-archive.net/Archive/sci.med.diseases.lyme/2004-12/1006.html>

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GregGerber@hotmail.com wrote:

- > *LDA is considered by most the major Lyme disease patient advocacy*
- > *organization, and Pat Smith is its President. There is a board of*
- > *directors that oversees the organization.*

HOWEVER the BOD is NOT truly independent nor is it in any way accountable. They are all hand picked by "the pat" and are all yes people. None of them has EVER DARED to question "the pat" much less say "NO" to anything she asked of them.

Unlike many BODs they truly play a very limited role and serve at her pleasure rather than the other way around.

In other words, this is totally and utterly meaningless in this instance.

- >*As to what happens inside*
- > *that board, I have no knowledge whatsoever. I don't think these*
- > *positions are, in general, voted on by everyone with a given disease*
- in*
- > *other disease organizations, are they? If so, I am sure you will*
- > *enlighten me. GG*

No perhaps not. However, "the pat" and other Lyme "leaders" are singularly unaccountable and refuse to be held accountable FOR ANYTHING.

Not only that, and this is the real rub, they do not encourage or welcome input of any sort. All ideas not their own are seen as "threats to their turf" rather than possible constructive ideas that might help advance the cause.

Kathleen was right about one thing, and pretty much one thing only. "The pat" has hurt the cause MUCH MORE than she has ever helped it.

Taking credit for EVERYTHING doesn't mean it is deserved. Taking credit and eschewing all blame is simply galling and that is the style of

"leadership" that we're talking about. What really gets me beyond that is the element of "dishonesty" or you might call it "spin" that goes on. Clear defeats are termed successes. Credit is sought and claimed but no blame is accepted--the answer to defeat and blame other than saying it is something other than that is the refrain about good intentions and hard work (reminescent of George W Bush in Debate 2 and all his "good people working hard" nonsense. Well I guess it worked for him too!

But it is bullshit.

What is unique about what passes for "leadership" in Lymeland is that it has no legitimacy and seeks none but still purports to speak for all. It is the classic leadership mistake of a cult of personality which elevates the personality of the "leader" above the interests of those that he or she or it claim to lead.

And time after time the petty turf wars of "the pat" vs "the karen" and the two of them vs anyone else have hurt the Lyme community. All the attendant nonsense is damaging too.

They surely do NOT speak for me or most people that I know.

And I really am sick of the old refrain about their hard work and good intentions. LOTS of people have worked hard and had good intentions in this cause and have been attacked nonetheless. And at some point results do matter not just hard work and good intentions. The point at which I don't find the old hard work good intentions refrain meaningful is when mistakes are repeatedly ad infinitum and outside help and ideas are eschewed simply for the sake of the leaders' ego and that is the case and has been time after time after time, at least in my observation and in my opinion and MANY share those observations and opinions.