

Re: In Praise of Lyme Activists

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pmerv@direcway.com wrote:

- > *Just for the record: Several years ago, after the resignation of*
- > *previous president Kerry Fordyce, members of the Lyme Disease*
- > *Association of New Jersey begged Pat Smith to accept a leadership*
- > *position in LDANJ because of her experience, track record of*
- > *achievements, and ability to work with others. Subsequently, LDANJ*
- > *decided to become national in focus, becoming LDA. This decision was*
- > *welcomed by many active groups in the Lyme community since we felt a*
- > *need for an umbrella group we could support and work with. Since then*
- > *many groups have joined LDA as affiliates and chapters. LDA has*
- > *already*
- > *funded dozens of research projects and with its affiliates has raised*
- > *over \$3.5 million to fight Lyme disease. Their motto is "Find A*
- > *Cure."*
- > *To find out more about LDA, visit their website*
- > *www.lymediseaseassociation.org.*
- >
- > *From personal experience, Pat Smith is a straight-shooting,*
- > *hard-working, no-nonsense, skilled and dedicated patient advocate and*
- > *it is my honor to work with her and with other LDA affiliates.*
- > --
- > *Phyllis Mervine, President*
- > *California Lyme Disease Association*
- > *Affiliate of the Lyme Disease Association, Inc.*
- > *PO Box 1423*
- > *Ukiah, CA 95482*
- >
- >
- > *Check our websites*
- > *calda.intranets.com*
- > *www.lymedisease.org*
- > *www.lymetimes.org*

And "just for the record" Phyllis, you are completely full of shit.

So you have your "record" and I have mine.

FYI Yours has nothing to do with reality.

And a question. IF Pat Smith was SO FREAKING WONDERFUL why did it take your group (which so far as I can tell consists of YOU and you alone) so long to join up with her evil Lyme empire?

And, greg, that's a BIG part of the problem. National Capital Lyme Assn consists of a husband and wife and pretty much nothing and nobody else. Their greatest "accomplishment" was the "wonderful" nightline segment. Thanks! The kansas city Lyme group, well that's a big whoop consisting of ed olsen (a big player in Lymeland for sure) and less than half a dozen others who are members of the BOD.

So people can set themselves up as WHATEVER LYME DISEASE ORGANIZATION and name themselves "leader" and that doesn't make them "official" in any sense of the word as it is ordinarily used, nor does it give them "power" much less "true power" much less legitimacy.

And the utter unmitigated gall of them to claim to speak for anyone other than themselves and anyone who has authorised them to do so!

Really, unmitigated gall!

Chutzpah!

And it doesn't matter if Phyllis has been around since the days of Methusalah. Or that she has "worked hard" all that time. Or that she means well. It doesn't matter about any of them.

What really gets me is that IF Phyllis were named a Lyme patient representative to an NIH advisory group today she'd almost certainly sign off on the same thing with no objections, help them recruit and when the results came out be as silent as a church mouse!
Again the first part of the solution is to FIRE THEM ALL!