

## Re: In Praise of Lyme Activists

**Source:** <http://sci.tech-archive.net/Archive/sci.med.diseases.lyme/2004-12/0999.html>

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GregGerber@hotmail.com wrote:

> *I will make my answer to these posts relatively brief. I consider Pat  
> Smith, president of LDA, to have an official leadership position and  
> true power.*

Well "official" but essentially self proclaimed. And perhaps "official" but perhaps NOT "legitimate" in that there has never been a vote, a referendum, or, more gallingly, any effort to seek the input or welcoming of the input of those she claims to lead.

As to "true power" well that's a funny one.

"true power" LOL

Sure thing greg.

ROTFL LMAO

"True power" "the pat" is ruler of the land of the cripples and on one has the strength to resist her.

But "true power" gimme a break!

She ain't nothing. Most of the "opposition" has never even heard of her. (though they have heard of karen and the ldf although they may not have heard good things).

"True power" doesn't mean that politicians give you an audience and a photo op. That is more for them than for you. "True power" means you can get things you want done, done. And NO ONE on the Lyme patient advocacy side of things has anything remotely like "true power."

And if you think so, you really need to do a serious reality check.

Another thing. If I start (or take over) an organization and declare myself or somehow become "the leader" I don't see that as being "officially" anything.

Perhaps you are confusing being OFFICIOUS with being "official"?

I could agree that "The pat" is OFFICIOUS, pushy and a battleaxe.

But "official" well that's something I would quibble with. Other than in the context of self authenticating officiality, which is all that this is, and what does that mean, because ANYONE could rise to the same level of "officialdom" in an entirely self referential fashion.

*>I have never heard her say that everyone who gets Lyme  
> disease gets desperately sick, but she has addressed the issue of the  
> treatment failures many times in many official speeches and  
statements.*

Well show us what "the pat" DID say greg. Let me see how "the pat" addressed the topic of the frequency of treatment failures.

But I find it hard to agree that "the pat" is the ONLY "OFFICIAL" source in Lymeland. Sure she wants it that way and would have it that way, but that doesn't make it true.

If it turns out that "the pat" is the only "survivor" well what an accomplishment for "the pat" having eliminated the competition in Lyme Survivor.

But seriously this is like becoming king of the land of the cripples. What kind of accomplishment is that? When "the pat" is one of the only ones who isn't sick with Lyme! And having scorched the earth to become the only Lyme survivor, well the kingdom is in shambles, there's little or nothing left, Lyme patient advocacy has been made irrelevant, an afterthought, and "the pat" had a big role in that. For YEARS "the pat" and "the karen" fought like children over everything while the cause suffered. Their egos were clearly much more important to them than the cause they claimed to be trying to serve. And that ain't "leadership" whether or not it is "official."

*> If you are saying she said something YOU need to prove it --you need  
to  
> prove the positive, don't ask me to prove the negative, it doesn't  
> exist.*

Why not show us what you say "the pat" DID say then. I don't even think "the pat" is particularly knowledgable about the real subtle issues which ARE the real issues when it comes to all of this, and that is a HUGE problem. "The pat" doesn't even understand what the real issues are to be advocating for.

The holy grail to "the pat" is a "reliable diagnostic test" and as much as that is DEMANDED (without consideration for the notion that the answer is going to be the C6 test or the two step ELISA WB) it is NOT the answer at all, it isn't even the issue that really is affecting

most chronic patients.

The issues that are affecting them are whether or not long term antibiotics helps. If not and at the point that it doesn't, what will help? If there is nothing, we need to begin the search for something that does. And the attitudes of most doctors make it impossible to get treatment appropriately even with positive testing., And reliable testing not officially approved is simply rejected without any real basis or reason (PCR testing which is generally accepted in almost every other field but Infectious Disease doctors and rheumatologists and neurologists reject in lyme citing "false positives" (with no explanation) or "contamination" with no evidence or reason).

And the issue is changing these attitudes, really educating doctors, not by yelling at them or legislating at them, not by insulting them or harassing them but by convincing them, persuading them, showing them the evidence and the \$\$\$ which would attract credible researchers and produce credible science which would ultimately convince and persuade, even if it takes time, even if it takes a new generation of doctors.

But "the pat" and the others are demagogues, NOT "leaders" they offer demagogic simplistic "legislative" "answers" not real solutions. Legislate that there MUST be a reliable test and voila, mother nature will respond (and so will the medical and scientific communities). Legislate that doctors MUST do as Burrascano does and that Burrascano should be immune from consequences for his actions, let's give him total immunity!

"Real power" LOL

> *am not gonna clutter this newsgroup with statements and  
> speeches lacking the claims you say are made --that would be all of  
> them.*

Well at the risk of "cluttering this newsgroup" show us a couple greg.

It is not as if this newsgroup is otherise "uncluttered."

>*No I do not consider Lisa or Kathleen to be leaders or people  
> with any official role. I do not want to continue with this argument,  
I  
> consider it ridiculous.*

See I don't consider it ridiculous. What about tincup (that freaking moron)? What about Ellen Lubarsky? What about cheryl o? What about Jill Auerbach? What about karen and tom? What about Phyllis?

Please explain the distinctions. Please explain who died and made "the pat" the ONLY "official" spokesperson for us all. Tell me how it came about.

And how do we impeach "the pat" How do we say to ALL OF THEM: "YOU'RE FIRED!"

Seriously.

By the way it is childish to engage in a discussion but say "Well I don't want to talk about THAT" and even worse "My final pronouncement is THE FINAL PRONOUNCEMENT." and insulting to say that it is "ridiculous."

Peronally I consider it ridiculous that you are saying what you're saying and that you're declaring "the pat" the ONLY "official" spokesperson and even more ridiculous, in fact ABSURD that you're saying that "the pat" has "real power."

Seriously gimme a break.

> *Finally, you are not understanding what I am saying about the clones*  
> *--the fact is that a significant percent of strains are proven never*  
> *to*  
> *disseminate in the human host, ever, meaning they cannot, by their*  
> *nature, cause anything but the rash.*

No greg. I DO understand that. What did I say that indicated that I didn't understand that?

What I didn't understand was your use of the word "clone"

I asked if you meant to use the word "clone" interchangeably with the word "strain"

Which I think would be incorrect and inaccurate and certainly unclear in that "strains" are not "clones" in the ordinary sense of the word or even the scientific sense, microbiologic sense.

> *When you count these people in a*  
> *Lyme study (and say that treatment worked for them) and do not*  
> *quantify*  
> *their number or differentiate between them and patients infected by*  
> *the*  
> *true disseminating strains, you have a study rendered meaningless by*  
> *noise, not a study that "has meaning for those in it."*

Well I disagree. First ARE YOU USING THE WORDS "CLONE" and "STRAIN" INTERCHANGEABLY?

I don't think it is correct to do so and that is ALL I was asking.

And, second, how does the study NOT have meaning for those in it and I might add, those similarly situated?

Of course it does!

The problem is that the results cannot fairly be extrapolated beyond that.

It is amazing to me that you would argue otherwise.

And I certainly only said what I said AGAIN not what you seem to be saying or responding to!

*>Instead, you*

*> have a study without any real meaning for how a particular individual*

*> with a known, particular strain will respond to treatment in the*

*> future. The study is telling patients that their treatment efficacy*

*> amounts to the toss of a coin, and not any biological reality. It is*

*> as if I tested those with either Lyme disease or a freckles and*

*failed*

*> to distinguish between then two groups but counted all of them as*

*> having potentially disseminating Lyme disease and said the treatment*

*> was great because those with the freckles did not develop late stage*

*> Lyme disease. The study becomes statistically ludicrous and cannot*

*tell*

*> us what is going on.*

Yes very nice. But again an argument responding to what? Not any argument I made.

*> I am happy to explain this in more detail --but the response you gave*

*> was in many parts irrelevant to this and not understanding of what I*

*> meant.*

*>*

*> GG*

No your response is irrelevant greg.

Please read what I wrote. Not what you think I wrote but never did.