

Re: In Praise of Lyme Activists

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From: Rita Stanley (rlstanleyNOSPAM_at_comcast.net)

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Iraq in pictures

<http://fallujapictures.blogspot.com/>

<a_weisman@yahoo.com> wrote in message

news:1104429765.415454.79700@z14g2000cwz.googlegroups.com...

GregGerber@hotmail.com wrote:

> derdrittemann2003@yahoo.com wrote:

> > Why antagonize people with this sort of thing?

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>

>

>Where and when? At the risk of "Cluttering the newsgroup" show us.

>Because if I had heard of her doing it, I wouldn't have said that she didn't.

>I would simply have said that she signed off on it in the first place

>and that it was obvious with foresight not just hindsight that the

>study SUCKED and was DESIGNED to screw us. But that is one thing and

>believe me it isn't just with hindsight that I criticize the study.

>MANY of us criticized it at the time.

>Rita Stanley talked about that in a recent post, how our criticisms

>Lyme "leaders" and the fact that they don't accept input suggestions

>critique or criticism, they act unilaterally but purportedly on behalf

>of us all and anyone who disagrees is shunned and attacked and

>dismissed and silenced.

Yes. The Klempner study was criticised by a number of us before the study.

Some of us even wrote to some higher government officials - this was done

behind the scenes. Not any of your "lyme leaders". Just some folks who

actually knew higher ups in the Clinton administration.

But the overriding element at the time was to shut up, and let the "experts"

do their thing because "something good" MIGHT (note the faith element) come

of it. The "professionals" sat silent. The presentation by Klempner at the

LDF symposium was met with basically NO questioning (one patient made a

statement). It was butt-kissing at its worst. There were groans from some

patients in the audience. That's it. And the patients were told that if they

interfered it might harm those poor souls who were getting an extra month

of antibiotics. What crap. No 'professionals' asked any questions or gave

any critiques. These 'professionals' were sheep.

And when all was said and done-- the study was done--, ONLY then, did you

hear outcry. And then it was as if people were amazed at how they were lead

down the merry path! Why it was a surprise that the study design was biased

to get the outcome it did! Wow!

Self-censoring, refusal to question, keeping others from "rocking the

Lymeland boat"--what rot. Look at the mess Lymeland is in. Where is

reasonableness? Stand back and look at what non-IDSAs actually looks like:

fringe and flaky; salt cures, and sputniks, 5 anti-microbials rotated

willy-nilly, and cat's claw, heparin and quinolones and questran and etc

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etc. And don't say anything against any of this! Let the patients figure it out after they are damaged physically and financially. You are only adding more credibility to IDSA. You do it to yourselves. While a support group leader (I have retired after 10 years), I heard so much terrible doctoring, I couldn't decide whether to scream or cry. The IDSA failures become non-IDSA failures.

>Except here where there is no censor!

>But I would NOT have criticized her for not speaking out later if I knew that she had.

I never saw it. Makes a good story afterwards. Of course, then after the results were shoved in everyone's faces, it was deemed suitable to do so and everyone acted betrayed--after the horse was out of the barn and far away, then it was fine to say something. 'llmids' even came out of their holes when they felt safe. Hey, do you think the Klempner people were laughing at the stupidity or not? They used every trick they knew to keep people in line so that they could do what they wanted. Anyone who understood simple basics about study design, knew the study was biased and flawed, and knew what the outcome basically be. Biased studies are so commonplace, that any real professional knows to look for the biases. Any real professional will look and will let out a holler, not sit back and take it.

Believe what you want Lymeland. It's all yours.

Enjoy,

Rita