

# Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

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- *From:* "a\_weisman@xxxxxxxx" <a\_weisman@xxxxxxxx>
  - *Date:* 5 Apr 2005 12:54:13 -0700
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eugeneshapiroisapig wrote:

- > why is it that docs with their own infusion clinics are looked upon
- > with suspicion?

It is a conflict of interest. Medicare makes it illegal for a doctor to have an ownership interest in such a clinic (not saying that is the case in the clinic you describe). But even the appearance of being co located tends to create suspicion. That's why.

- > I agree with your comments about doctors rejecting patient information.
- > I do feel, however, that intelligent patients can be a part of advocacy
- > groups which work to inform doctors outside of patient visits in the
- > clinic where rejection is the most likely reaction.

Yes though doctors tend not to want to participate in such forums. It is hard to get "face time" with a doctor whether you're a patient, a pharmaceutical rep bearing gifts or whatever. As to their CME credits, most tend to get them either in the vacation setting OR in a very focused setting—at a professional seminar or conference as conveniently as possible.

- > I feel that the number one sin that most doctors commit is failing to
- > listen to patients.

Studies show that when a doctor asks a patient a

This involves failure in history taking as well a question, that they listen for an average of 8 seconds or fifteen seconds before cutting them off.

You know what is really obnoxious? That question "what are your top three symptoms" and they won't listen to the rest. Which is absurd—the same doctor who doesn't trust a patient (as Dr House says 'patients lie') now is trusting them to know what is the most important symptom for diagnosis. But what if the most important symptom is fourth or

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fifth? Another thing I hate, you go to the doctor as a Lyme patient, you've made a list of things to discuss since you're cognitively challenged, the doctor sees the list and says "I don't have time to go into all that." Well whose problem is it that they deliberately overbook? Whose fault is it that they haven't left enough time for all their patients? See I never mind waiting to see a doctor who doesn't give me short shrift because I figure they're giving other patients the time and they'll give me the time too. But after waiting I don't intend to get cut off.

And these jerks think they shouldn't be sued?

And Lyme "patient advocates" are all for legislation which would protect them.

- > failure to take into consideration patient views on disease. I may be
- > an unusual case but more than once I have had a doctor tell me that I
- > know more about the disease in question (not lyme) than did they.

Me too. Which is a sad commentary on THEM. At least they admit to the depths of their profound ignorance though.

>If

- > you can reach this point by being intelligent and rational (and
- > efficient with time) and citing scientific and medical journals, you
- > may be able to sway a physician.

MAYBE. In your case. I think it is rare to change their minds generally. Particularly when they deal with it a lot. I was able to make inroads most easily with the interventional radiologist who inserted my PICC lines. He already thought the ID doc at his hospital was a moron (and the ID colleagues too). So by the time of my third PICC line it was me he was asking questions. Me who he called for a referral when his kid got bit.

- > I recommend writing a letter, which
- > saves everyone time and effort and gives the doctor the opportunity to
- > digest information without being placed in an embarrassing situation
- > where they have to admit a lack of understanding directly in front of a
- > patient during a clinic visit.

I don't know that they read them. I've written a few. At this point HIPAA gives you the right to correct factual errors in medical records which is an opening. However, that applies more to the doctor reporting something wrong in your history—his report says you had a high normal body temperature normally, but you said that your normal was 96 and now you're running 99 or 100 chronically rather than "correcting" their medical opinion that you don't have Lyme. But it is still an opening.

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- > Of course I have an advantage which many people do not which is
- > direct access to most major medical and scientific journals and an
- > ability to discuss some scientific subjects with a physician at least
- > on their level if not above.

Several of us have similar access.

- > As far as Steere goes, I can only comment on his pervasive
- > influence in medical journal articles and then his writings in
- medical
- > textbooks, his employment of PR firms, and his involvement with the
- > ALDF which all testify to his pernicious obstinate and aggressive
- > seeking behavior to ensure that medical professionals are exposed
- only
- > to his side of the story.

Yes. But still the marketplace of ideas says that if his ideas are bad they shouldn't sell. However, I don't think doctors are very smart consumers of medical information, they tend not to read thoroughly or critically as we've discussed.

- > Steere has been directly involved in (1) ALDF (2) dearborn conference
- > and IDSA Lyme panel (3) he wrote the horrible 1993 paper which he
- > continues to cite to this day (4) he oversaw laboratory testing,
- whose
- > results look very suspicious, for the Klempner project (these two
- > papers, which he repeatedly refers to and treats as gospel, are the
- > mainstays of the Steere repression)
- > (5) Lyme vaccine development, worked like a dog for SmithKline
- > (6) has stated numerous times in media interviews his belief that
- most
- > post Lyme patients are hysterical, hypochondriac, etc.

I don't know that he "worked like a dog for SKB now Glaxo. He was "principal investigator" but I think it was somewhat of a ceremonial position and that Dennis Parenti was much more hands on. In fact, Steere published a paper on LFA-1 as a possible cause of OspA linked "autoimmunity" just as the vaccine came out which troubled SKB quite a bit.

Yes he does tend to cite himself quite a bit. I've noticed that about him and Sigal, they are very self referential (and self reverential). Much of what they write is NOT original research or new studies but a bunch of opinion pieces masquerading as studies.

Sometimes they just reinvent numbers out of nowhere. For example, the frequency of rash was stated as 40–60% in most studies early on. Recently they cite a figure of 80 or even 90% (saying that if you don't have it it probably isn't Lyme). But what study was the new figure based on? If you track it back, I believe the origin was from studies that used the rash as a major entrance criteria which artificially

inflated the number. Outrageous but true. Otherwise they just reinvented it out of nowhere.

- > however I must agree that there has been a major failure in the lyme
- > advocacy community to effectively transmit information. My guess is
- > that most everyday doctors have never heard of the numerous papers
- > which establish persistent infection as a cause for post lyme. Steere
- > and others very rarely mention these papers and I have never seen a
- > mention of some of the more provocative such as the staubinger study
- in
- > dogs, or even sven bergstrom's paper on migrating birds reactivating.

And though I tend to agree with most of that work still the sheer VOLUME of work on the other side outweighs (literally) that work. Not in quality but quantity. Since doctors don't tend to read critically I don't think they sort the wheat from the chaff. I don't think they tend to think of the limitations of things like the Klempner study which deliberately extrapolates its results far beyond what is fair. And klempner has done nothing to caveat his work, he KNOWS how it is being used and KNEW how it would be used. That study was NOT intended to be the beginning of many questions but the END of all.

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• *Follow-Ups:*

- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**  
◇ From: a\_weisman@xxxxxxxxxx

• *References:*

- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**  
◇ From: a\_weisman@xxxxxxxxxx
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**  
◇ From: derdrittemann2003
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◇ From: Rita Stanley
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**  
◇ From: pmerv
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**  
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- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**  
◇ From: Rita Stanley
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**  
◇ From: eugeneshapiroisapig
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