

Mead, Paul (CDC/OID/NCEZID)

From: Edward McSweegan (b)(6)
Sent: Thursday, February 22, 2007 8:00 PM
To: Susan O'Connell
Subject: RE: Lyme vaccine article - thanks for a very useful letter.

Dr. O'Connell:

Thank you for your note.

I sent a copy of it to Dr. Steve Barrett who built and manages the Quackwatch website. I have urged him to consider updating the section on Lyme disease, but I believe he has been somewhat distracted by other matters in recent years. Still, it may be possible to update the Lyme material by copying it to another site with HTML links back to the Quackwatch index page. I'm looking into this possibility. I have already drafted some updated material just in case. If you and your colleagues would like to suggest needed changes, new data, and references please send them to me.

If outer space is the military's ultimate "high ground," then cyberspace is the high ground in an information war. And what we have here is a war. Actually, a disinformation war. An insurgency against evidence-based medicine. It's time to start shooting back.

I'm vaguely familiar with your informal group to counteract misinformation. Durland Fish mentioned it to me. Sounds like a good start. Certainly, we have to do a better job of quickly responding to the accusations and antics of activists. We also have to do a better job of educating members of Congress and, in your case, Parliament. And we have to do a better job of keeping in touch with science and medical writers in the press and providing them with the necessary facts, references, quotes and sound bites.

Personally, I had been thinking that it might be useful to have a limited access website containing material to facilitate quick responses to reporters' questions and to facilitate the drafting of letters to legislators and editors. Such an online repository might contain copies of published articles on treatment trials and appropriate diagnostic methods, published commentaries on chronic Lyme disease, previously published letters to the editor, and examples of letters to send to local and national legislators. I suspect many physicians and scientists would like nothing more than to dash off a response to a newspaper or congressman, but lack the time to look up the references, dig out the quotes, and hone their message down to 300 or 400 words. This kind of repository would help.

I already have my own little repository, which I rely on for drafting letters to the editor (of Nature, Epi & Inf, The Hartford Courant, The Washington Post, and others), letters to congressmen (Phil Baker and I both responded to a Dec. 2006 ILADS-inspired congressional letter to the CDC), book reviews, and columns I write for a local Maryland paper. It's a lot easier to load and shoot if the ammunition is handy.

Anyway, it's one idea. Another might be to start a visible organization of researchers and ID docs with clearly stated goals and concerns similar to SEA: Scientists and Engineers for America (<http://www.sefora.org/> <<http://www.sefora.org/>>). It could provide a convenient focal point for communication and strategy.

Whatever course we choose, it's going to be a long struggle. The Lymeas and their parasitic LLMDs have been at this for a long time. Their tireless legislative and letter-writing efforts are, to me, reminiscent of the tactics of Intelligent Design proponents: question evidence-based conclusions without providing compelling alternative data, and then cite one's own beliefs and arguments as evidence of controversy and confusion within the scientific and