

Michael A. Schwartz, MD  
and Allen Steere

**Subject:** [Fwd: mmi Steere story]

**Date:** Tue, 25 Apr 2000 09:54:13 -0400

**From:** Kathleen <kathleen.dickson@snet.net>

**Organization:** SeCT Lyme Support Group

**To:** thomas.ryan@po.state.ct.us

Richard Brand, M.D. wrote:

>  
 > Friends and colleagues, The following is a post I received today from my  
 > friend and learned psychiatrist Michael Schwartz, MD, concerning his  
 > experience with Alan Steere. Please advise if you have any thoughts  
 > concerning the utility of his story in the Massachusetts investigation, or  
 > any other matter, and I will forward them to Dr. Schwartz. Regards, Rick  
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>  
 > Rick:

> Here is my story with Dr. Steere: It was the mid-1970's and Lyme Disease  
 > was not a household word. Joan and I rented a summer cottage on Shelter  
 > Island, on the Eastern End of Long Island. An idyllic place. It was  
 > strange to note that several of the locals had facial palsy - nice people  
 > all, but it was a great summer. There was a pond, many deer.....

> One day, I happened to notice that I had a bright red mark on my forearm.  
 > A VERY bright red mark. It was a little hot, otherwise unremarkable, but  
 > odd because of its brightness. I ignored it. The next day it was still  
 > there. A day later, it was bigger. Over subsequent days, the "mark" became  
 > a coin shaped lesion, then bigger but oblong, and bigger and bigger and  
 > bigger. At some point I went to a local gp in New York who -- like me --  
 > had no idea what was wrong -- "let's watch it, he said." The rash kept  
 > growing. It became larger than a silver dollar. And hot. Along with  
 > this, I was now really ill! I had fatigue, restlessness, malaise, and  
 > flu-like symptoms. Something was clearly wrong but I had no idea what!

> That weekend, I was back on Shelter Island, on my wonderful porch, reading  
 > the local freebie paper. A tiny article caught my attention about a "new  
 > disease" discovered on Shelter Island. It was tic borne. The first sign  
 > was a bright red rash. But there had been no tic bite. THEN I REMEMBERED.  
 > The time, before the rash, back in New York City after a weekend on Shelter  
 > Island, when I awoke in the middle of the night with a stinging pain in my  
 > arm, and went into the bathroom, not clear what was wrong. There was  
 > nothing, no something small. A magnifying lens did the trick -- a small  
 > tick!! Ugghh!! I removed it with Vaseline and tweezers, went back to bed,  
 > and promptly forgot the whole incident. But the red spot came precisely  
 > where the tic had bitten me.

> So I went back to Cornell (my old medical school) and visited my old (real  
 > old -- now Professor Emeritus) parasitology teacher -- the distinguished  
 > Dr. Ben Keen. Is this a lyme tic bite? I will never forget his wizened  
 > smile as he raised his arm in triumph and pride!! "Congratulations, young  
 > man," he said -- "You have made the correct diagnosis." What to do?  
 > Without hesitation, he told me that THE place to go to was Yale, where  
 > there was a doctor Steere who was THE expert in this emerging illness. He  
 > would help me as much as anyone could. Yale was the place to go.

> But first I went the library and read everything I could about Lyme. I  
 > did not like what I read. The facial palsy association, for example, was  
 > already there, but little about treatment or prognosis. No one knew!!  
 > However, it was known the causative organism was a spirochete -- like, I  
 > thought, syphilis. This upset me because I knew how hard syphilis was to  
 > treat -- you thought you eliminated it and you didn't -- it could come  
 > back, much worse, years later. And worse, come back not as the rash, or

> initial lesion, but come back anywhere -- as brain disease, joint disease,  
> and more and more and more. "Well", I thought, "like syphilis", so there  
> ARE medications that treat syphilis -- these must be the same medications  
> to take -- "but I'll bet you gotta blast it, like syphilis", "and your  
> first shot is your best shot, like syphilis -- you gotta blast it to  
> smithereens so it doesn't come back and 'blast' you."  
>  
> Off I went to Dr. Steere. He agreed to see me quickly, he was  
> professional, busy, not particularly friendly. But he exuded all of the  
> airs that one might expect from an international authority from Yale. The  
> diagnosis was easily made. But he told me that there was no treatment.  
> It looked like syphilis but the antibiotics that I wanted to take were  
> ineffective. They would not work. He would not give them to me, despite my  
> requests. They were completely useless -- he had studied this, had all the  
> data, all the reports, and nothing good ever came from antibiotics in the  
> case of Lyme. Even though there was this "family resemblance" to syphilis  
> -- even though a spirochete was causing the problem, this particular  
> spirochete did not respond to medication. The only thing to do was to join  
> his clinic as a patient and have him follow me. They were studying Lyme,  
> they would eventually have a treatment. There were some tantalizing leads  
> concerning immunity and some possible things to do in that way. He could  
> treat me with what they developed as they developed it. I was to see him  
> from time to time and in time..... For the present, nothing. Dr. Steere  
> was adamant that this was the ONLY way to go. No treatment for now. I was  
> stunned. But I trusted Dr. Steere, and Yale, and the powerful expertise  
> regarding Lyme that he had assembled.  
>  
> I had been EAGER to treat this "bug" with a "bug" medicine. But I was a  
> doctor and I had learned to be a "good patient." You do what your doctor  
> tells you. And he was the best in the world!! So quite miserably, but  
> confident that I was doing all that I could, I got on the train and went  
> home.  
>  
> And I got sicker and sicker and sicker. Days passed, and more and more.  
> The rash got larger and larger and larger. Finally it circled completely  
> around my arm like a band-bracelet with one end overlapping the other. And  
> I was incapacitated. Calls to Steere were unhelpful -- just wait it out,  
> he said, we are studying this.  
>  
> So finally, I did what I had never thought that I would do -- I got some  
> antibiotics and treated myself. I really blasted myself. I felt very bad  
> about doing this (and very fortunate that as a doctor, I could actually get  
> antibiotics). VERY, VERY quickly -- very soon after I took these pills --  
> the rash started to break up!! It got blotchy and weaker. It stopped  
> growing. the next day blotchier still. Like a miracle!! And I started to  
> feel better, for the first time since this started. Much better.  
>  
> Gleefully, I called Dr. Steere. Antibiotics helped after all!! I wanted  
> to rush over to his clinic, show him the improvement in progress, have him  
> follow this, have him test me, and have him offer this to others. I will  
> never forget our phone conversation. First of all, he was obviously  
> irritated that I had done this. His voice was strained and very, very  
> cold. I had messed things up by doing this! He told me that the strong  
> temporal association between my taking antibiotics and my dramatic  
> improvement could have been a coincidence!! (There is no doubt that there  
> was a VERY tight temporal relationship and remarkably rapidity of relief  
> following medication -- after weeks -- more than a month -- of unrelenting  
> misery.) He had heard of other such stories and such "cures", but he would  
> not accept them -- the placebo response, suggestibility, it was going away  
> anyway, etc., etc. So I asked him why he had not told me earlier on that  
> he "had heard of such cures". I had plainly, and repeatedly asked him  
> about antibiotics and the very antibiotic class that I had taken -- the one  
> for spirochetes. And he had simply told me -- with clear finality -- that

> they just did not work. I asked him for medication and he told me it NEVER  
> worked. He didn't tell me about these other cases. And now, he was quite  
> clear -- what happened to me -- and what happened to others like me -- had  
> nothing to do with medical science. Only data from clinical trials with  
> placebo controls prove anything, and he was saving me for such a trial. In  
> fact, what I did merely undermined his science!! My personal experience  
> had no scientific value or clinical value. In fact, it was a bad thing. I  
> should stop doing what I was doing immediately.

>  
> I was stunned. There was something very wrong with what this man was  
> doing. He wouldn't even see me. He wouldn't even look at my arm or my  
> blood as a natural work-in-progress. Further calls to him and his group  
> clarified what he was doing and where he was coming from. He was a  
> "scientist". He wanted me, and the other "clinical material" to be pure  
> for his "clinical experiments." The hell with patients as people --  
> clinical reality and people's lives in the here and now. He was studying  
> immunity in Lyme -- (or some such thing) -- the crusade was the thing --  
> the science, and not his present patient's daily needs. I accused him of  
> this and he (I suppose naturally) got colder and more distant. There was  
> nothing left to say. So I "fired" him. He had felt that he was doing the  
> correct thing, even the withholding of other successes -- he was doing  
> clinical science. He wouldn't even see me as a "work in progress."  
> Clearly there was room here -- with disclosure about limitations -- for an  
> "open labeled clinical-trial" (give some other people like me the same  
> antibiotic that I and others had taken, and study what was happening). But  
> he was saving us for bigger, more impressive studies. He didn't tell me  
> what he knew, even in response to my direct questioning, and he was doing  
> the same to his other patients (his other 'clinical material'). Our being  
> sacrificed for others would be worth it -- in his mind -- our own needs and  
> beliefs be damned. Talk about arrogance and playing God!!

>  
> "Alan", I had said (of course I am paraphrasing -- over 20 years have  
> passed -- but like the Kennedy assassination, these horrible moments are  
> burned into your brain with remarkable accuracy seemingly forever) . "This  
> antibiotic saved me from great misery and from God knows what horror in the  
> future." The response to the medication was totally dramatic -- the  
> temporal sequence of what happened before my trial and afterwards -- cure  
> locked in step with treatment. I CERTAINLY WAS A BELIEVER IN WHAT  
> HAPPENED TO ME. I, WHO LIVED THIS, WAS CONVINCED!!! So why not at least  
> present some patients with my syndrome with an open labeled trial of  
> medication..... But I was clearly wasting my time.

>  
> And within a few day, it was all gone. The rash and all the symptoms. And  
> I felt fine for the first time since this all started. I FELT FINE!! Were  
> there sequelae? Clinically, I don't think so. But with an insidious  
> spirochete you never know. Is this aging or Lyme. This I live with but  
> this is life. Years after the incident with Steere, the medication that I  
> had taken was the standard treatment. At doses even higher than the ones  
> I gave myself, so I got a titer, had high levels, and took a (then)  
> standard treatment. And so it goes.

>  
> I think I became a better doctor. I think that I listen to patients more  
> than I might have. I understand why the classic healers of Greek  
> mythology -- Aesclepius and Chiron -- were ill themselves. Also, I have  
> published an uncontrolled clinical trial myself, and I strongly endorse  
> them. I have written about the value of the "single-case study." So much  
> in medical science has come from single case studies but there is a bias  
> against this and in favor of large, double-blind placebo controlled  
> studies. Of course they have their place, but they have drastic limits also  
> (there are numerous papers in the scientific literature that describe the  
> limits of these types of studies -- but many, many academic leaders have  
> blinders here and treat the "double blind placebo controlled study --  
> rather mindlessly, like a sort of 'Holy Grail.') I try to fight this

> mindlessness -- that is part of why I founded AAPP. However, fighting the  
> establishment on these issues in kind of like fighting the wind....  
>  
> After all these years -- and the fact that I avoided major tragedy by  
> taking action myself -- I still despise Alan Steere. For years I was sure  
> that I would punch the guy in the face if I ran into him, even in a public  
> place like a medical convention. He lied to me -- he held back information  
> -- that antibiotics had helped others - information that HE didn't think  
> was important enough but to me, the patient, what could be more important!!  
> The bastard was playing GOD with my life, and he was treating me like a  
> child -- I did not have the judgment to make up my own mind -- he would do  
> it for me. Also, he was deceiving himself -- he thought that he was doing  
> it correctly. He was saving me -- in an untreated state -- for his studies.  
> The studies took priority over the "material" (human beings) who were being  
> studied. I suppose that he felt that this was justified because knowledge  
> gained could help much larger numbers of human beings. But if he felt this  
> was justified -- and I am merely surmising -- who knows how he felt, or if  
> he even can feel at all -- he was wrong, tragically wrong, and he was  
> deluding himself. His own career had too much to gain -- and his patients  
> too much to lose -- for him to think that he could be objective in such a  
> belief. I did call him once (when I was taking my second course of  
> medications -- the very ones he had denigrated and now they were the  
> standard treatment -- but he had nothing to say - other than something such  
> as "we didn't have the data then". The man clearly has no people skills).  
>  
> Rick -- I just don't think that there are "charges" here. The bastard did  
> to me what so many do. The problem is the ethics and the view of science  
> and the way researchers are rewarded. Perhaps Dr. Steere did actual damage  
> to others and you may share this story. Perhaps he did actual damage to me  
> that I have failed to see and still don't see and I am open to advice here.  
> At this point I no longer need to punch the guy -- I still feel he owes me  
> an apology, and I am angry to learn that he is still up to his old cold and  
> arrogant ways -- ethical awareness of patients rights are more advanced  
> today than they were in the mid-1970. I will never like the guy, that is  
> for sure. I hope and pray that other patients have a better experience  
> with Dr. Steere and his "colleagues" than I did.  
>  
> I also hope and pray that things go well with you and your children.  
>  
> Michael