

Dr. Jemsek: late Lymies have an inferior quality of life compared to those with HIV/AIDS

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He is a good man and a good doctor– like so many–!! I did break up the paragraphs into smaller ones because they were huge–

These remarks were prepared by Dr. Jemsek to read to the North Carolina Medical Board during his final appearance before them on July 20, 2006.

My Compliments to North Carolina Medical Board

I would like to take a moment and compliment the Board Members, particularly those who practice medicine right now. Your efforts as unpaid Board Members represent important stepping stones for working physicians to regain control of their profession – which I believe is an extremely important thing to do.

Many of us feel like we've earned a second degree in the medical field in the last two decades, as we negotiate with the insurance industry and those who try to litigate our efforts and the medical needs of our patients. We desperately need to have physicians engaged in the social and political aspects of medicine so that we can effect change for the good of our profession. You have my respect for the time you put in to this job.

Change in Medicine ... my experience with HIV/AIDS

Lyme is an emerging illness and, as we all know, the world changes constantly. In my early work in the 1980s with HIV, I watched as thousands of my patients, mostly young people, died from an incurable illness. Many of these deaths were horrible to behold and I remember dwelling on feelings of helplessness, confusion, anger and then finally a sense of resolve to stay with my patients.

As a young doctor, I went into the specialty of infectious diseases as a feel-good specialty. Suddenly, there was this devastating disease which was both fascinating and horrifying and I was lost.

At the beginning, since I was homophobic, it took me a while to get used to taking care of "gay men". But after a year or two, I did get used to this. I changed ... I changed a lot. I recall that, in too many situations, the nurses and I became our patient's confidant and trusted friend, since many had been abandoned by their family, lovers and others.

I remember hugging patients every day because we both knew we didn't have the luxury of playing at life ... it would be over soon. So, as you can see, I had quite a transformation twenty years ago. And this experience – a pattern of unimaginable suffering and then welcome death – profoundly changed the way I look at life and the way I look at medicine.

The Importance of Humility in Our Profession

My life changing experience in HIV/AIDS taught me several lessons, the most important of which was to learn to practice the humility necessary to appreciate what we don't understand about medicine.

Medicine is a vast landscape and a wonderful opportunity to throw your mark out there and try to make a difference, but you can never conquer it. In this world, we seem to want answers from a system that puts all problems into a neat algorithm, guidelines, or treatment reviews. We as physicians love what we call our "care maps." That is all well and good where we can do it, and where it is the overwhelming consensus of the day.

However, generational change of the practice and standards in medicine is predictable and sometimes dramatic. And so, in my view, knowing what you don't know, that is ... an appreciation for the search of the profound and undiscovered, is more important than what you may know.

In this perspective, standards of care are an anachronism at any moment, but they comfort the insurance reviewers and rule-makers who yearn for stability, easy solutions, and, in the case of the insurers, guaranteed profits ... so it is small wonder that it has always been much easier to label an illness than to ponder the real physiology behind the patient complaint.

In my case that has been brought before you, it has been often said that I am treating "outside the NC standard of care and don't follow the IDSA guidelines".

I would respectfully remind you that there is no NC statute or case that indicates a NC standard for the treatment of Lyme disease. The

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accomplishments of medicine in NC do not at this time include expertise in each and every one of the tick borne illnesses found in the state.

Regarding the IDSA, last year I corresponded extensively with them, suggested that a clinical Lyme literate physician sit on their guidelines committee, and warned them of the widespread acrimony caused by their rigid and dogmatic approach in their interpretation of this area in medicine.

Medicine is a Lifelong Obligation

Medicine is a profession, not a job. This is a lifelong educational obligation, is it not? We learn every day, and never do we have the opportunity to learn more than when the physician interacts with patients who do not fit the standard diagnostic box. It is a constant learning process, thank goodness, because I never want to work in an environment where we color by the numbers.

Physician–Patient Relationships and the Art of Listening

In my 23 year career in HIV/AIDS, I have witnessed the best and worst of patient emotions and expectations when dealing with uncertainty in very stressful situations. As a younger physician, I was not prepared for this task. After all, the doctor is the one person to whom patients look for answers, and so how does the doctor handle it?

After only a short time practicing medicine, I learned that the best and most beneficial approach for all is just to be honest with everyone, and that the bitter truth of a sad situation requires compassion. Say what you can do -- what you expect you can do for a patient and what will likely become of the patient. Don't say you can do more than you think you can do. Patients understand and appreciate this approach, but I think that as doctors we often forget this simple thought.

Misguided Ideology – an Oxymoron

Academic physicians tend to work in a relatively dissociated environment and their interpretation of a disease process tends to be predicated not only on their own experience, but also on their sphere of influence.

Regrettably, this circumstance tends to promote the dictum that "they" can't possibly be wrong", but the historical and social truth is that they are commonly wrong, or at least less than helpful in dealing with patients whose complaints don't fit their existing clinical algorithms or research interests.

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Some of these physicians admit to their limitations, telling the patient "It's not this or it's not that; sorry, I can't help you, I've done all I can do." However, other physicians cling to dogmatic practices, or an inflexible ideology, which doesn't allow for a difference of opinion.

In the constantly changing and imperfect world of medical science, this attitude is flawed de facto. Scientific truth and dogma tend to part ways very quickly. He who holds rigid to a belief and is inflexible will soon be proven wrong.

I have seen the evolution of a medical standard happen countless times over the past 23 years in HIV medicine, so much so that I learned not to hold on to any precept for more than a few months, knowing that it would soon change. And the ultimate source of learningand I've learned this more from my encounters with the mysteries of Lyme disease than anything else ... is at the "bedside" and not out of a textbook or journal article. It comes from listening to the patient.

Unfortunately our medical system conspires against physicians giving quality time with a patient. We really have been corrupted and manipulated into accepting a definition of medical "care" that prevents time to listen and learn from our patient.

If we don't know what's wrong with the patient, we tend to blame the patient. Any action which undermines the opportunity of the patient to be heard, to have quality care, and the right to free liberty and choice in their treatment is an objectification of the patient. This is inherently immoral. We do not want objectified care for ourselves or our loved ones. So it is also not proper for others in our state.

What doctor wants to see a complex patient with a grocery bag full of charts who has come in for a fifteen-minute visit? But, every so often, an interesting thing happens should the provider decide to invest themselves in that patient.

Amidst the typical rambling and disconnected thoughts presented by the patient, the physician may begin to learn and appreciate that the patient is doing their best to communicate their pain and suffering ... and clings to the hope that they may still find help. But this requires vulnerability from the physician. It requires a willingness to accept that standard entrenched answers have failed.

Recognizing Lyme Disease Early On

In early 2001, I began to see more patients with an illness possibly attributed to infective Lyme Borrelia. I was struck by the profound

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suffering and impairment that was common in these cases. It took me about a year to appreciate and accept the validity of this disease, even though I had seen and treated a handful of patients going back to the mid 1980's.

At that time in 2001, I was naturally very involved with HIV/AIDS medicine, and didn't really want to deal with these patients. But they kept coming, and eventually I got a reputation as somebody who would listen, admittedly in a begrudging way on occasion.

After all, these patients were taking time away from my HIV/AIDS interests. As I listened, I began to see a pattern that, over time, became sharper. And I was shocked to see how little published science existed, and was dismayed at the quality of work that had been published. I thought it was all rather incongruous and incredible that, in our time, 20 years after HIV/AIDS had rocked our world, here was this devastating disease about which so little was known, and which was being mocked by many in medicine as "a new religion", among other unflattering descriptions.

Money Equates To Better Quality ... Eventually (Lyme Research Leaves a Lot to be Desired)

You know, HIV work has had the benefit of roughly \$3 billion in public funding every year, counting CDC and NIH funding, with this level of monetary support growing until it peaked in the mid 1990s. Clearly, excluding cardiovascular and cancer research, there is a huge difference between HIV research funding and almost every other area of medicine. Of course, it wasn't always this way. Magic Johnson, Ryan White, and over a half million deaths finally touched our society's soul.

In comparison, the quality of scientific work in clinical Lyme related issues today is unsophisticated, with commonly stated medical beliefs and guidelines based on seriously flawed assumptions.

As one who sees both worlds, I can say that, compared to the HIV academic world we're in now, those scientists working on Lyme can be considered to be functioning at an elementary level.

They vigorously defend their beliefs and ridicule and attack those who oppose them, but they have not consented to, or participated in, vigorous open scientific debate. If we had continued with this type of sociological rigidity with HIV/AIDS, we would still be 20 years behind current innovations and knowledge.

As a wise person once told me, Lyme academic physicians create their

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own cabal, hold power and limit debate. And so I began to understand a little bit, not a lot, but a little bit about the power of politics in medicine and the government agencies managing medicine.

I appreciated more about the wisdom of our founders who believed in the aggressive limitation of power, since it destroys liberty in society, and in evolving areas of science, it steals lives.

Lyme Disease, HIV/AIDS and Quality of Life in 2006 in NC

Most of my HIV patients used to die ... now most don't ... Some still do, of course. My Lyme patients, the sickest ones, want to die but they can't. That's right, they want to die but they can't.

The most common cause of death in Lyme disease is suicide. In the current day, if one compares HIV/AIDS to Lyme Borreliosis Complex patients in issues of 1) access to care, 2) current level of science, and 3) the levels of acceptance by doctors and the public, patients suffering with advanced Lyme Borreliosis Complex have an inferior quality of life compared to those with HIV/AIDS in NC.

This statement may seem heretical to some of you, I'm sure. But I can say this with authority — and I am really the only one in this room today who has the intellectual and experiential authority to do that.

IDSA and the Power Base in Lyme Policy

I will briefly go over with you some of the fundamental controversies in this area — with Lyme Disease; there are two standards of care. I don't want to belabor this point because we have already discussed this.

What you need to understand is that the IDSA, to which Dr. Rhyne and I both belong, is a wonderful organization, with wonderful people offering many brilliant insights into the entire spectrum of infectious diseases. My idols in this field are those who practice medicine and also engage in the politics of their society.

This, I believe, is the best situation in which a physician may grow and contribute to their profession. In this context, it is important to realize that the IDSA is much like any organization, in that the organization is divided into a number of smaller groups, some with very limited interests and responsibilities.

IDSA's experience with Lyme can be described in such a way. If an

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issue about Lyme disease is presented to the IDSA, the natural response is "Oh, if you have a Lyme question, give it to so-and-so." Because in the IDSA, there are only about fifteen people who have had control of policy and opinion in this area for the past fifteen or twenty years.

Some of these 15 individuals consult for insurance companies, some of them consult for vaccine development, and, as I suggested, the clinical research produced by this group thus far isn't very good and there's not much of it.

We're just not getting enough answers, and there is no urgency to change this; this political state maintains the tired old status quo, which would be fine if our patients weren't experiencing incalculable suffering. In my opinion, the maintenance of the status quo is simply alarming and borders on the unethical.

The IDSA has a history of being intransigent and inflexible in their views on Lyme disease. Meanwhile, we have this information stream from the Internet that goes straight to the public.

Fortunately, the basic science stream of information has not been truncated, and patients are connecting the dots, just as we do at the clinic.

I didn't learn what I learned about Lyme disease from the latest clinical report from Dr. Steere -- who is a rheumatologist, by the way. I learned it from listening to patients, noting patterns, noting responses and by constantly reviewing the animal and human microbiology and immunology literature. From this you hope to learn what could happen, what are the means of survival of this organism, what are the pathogenic virulence factors of these organisms, and so forth.

Chronic is Chronic

We have only a few clinical studies in chronic Lyme disease in the world literature. Dr. Fallon, who was here at the Board meeting last month, presented the third controlled trial. Two of these NIH sponsored controlled studies, including Dr. Fallon's, show the benefit of prolonged antibiotic therapy.

Lyme disease, the tick borne infection spreading the spirochetal organism *Borrelia burgdorferi*, is estimated by the CDC and others to infect at least 200,000 people a year.

Regrettably, there is an unconscionable lack of accountability for

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the lack of distinction between acute Lyme disease and the chronic symptoms which may follow, often dismissed by the IDSA group as post-Lyme syndrome not related to chronic infection. The IDSA continuously ignores the several dozen papers that show persistence of the bacteria in treated patients or in animal research.

"Chronic" is chronic. The patient with chronic disease from Borrelia moves from Connecticut to New Jersey to North Carolina. "Chronic" is cumulative and adds up, then may change and become worse.

In our experience in Lyme Borrelia Complex, seldom do patients get better without therapeutic intervention. Therefore, in my view, we are just adding sick people to the population. And of course many of them have very complex symptoms that don't fit into IDSA precepts – they don't fit into simplistic small diagnostic "boxes".

Testing and Lyme Disease

The guidelines for testing were set up in 1994 and were meant to be temporary. And here we are twelve years later and here is the CDC, in their recent website revision, saying the guidelines for testing are great and the two tier approach is "highly recommended".

The testing guidelines aren't great. They're old and don't work and someone at the CDC and IDSA knows this, and knows much more than is being published. The CDC hasn't been called out on that.

In a letter to the CDC by ILADS early this year, in which I was a contributing author, we went point by point addressing the guideline items that are wrong, and keyed the items added or embellished which were either highly misleading and/or about which there is inadequate existing scientific support.

Our Modern Day Paradox

We live in a paradox in this modern age, as reflected in the current day relationships between patients and physicians.

Two powerful and growing forces are running counter to each other at full speed. On the one hand, the information age – and you know this if you have children and grandchildren — is going full speed.

If you want to know something about how to fix your car or learn about something in medicine, you Google. You Google this, you Google that. I do it like everyone I know. It is great. In five minutes it's possible

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for me to pull three articles on a rare infection a patient caught in a distant traveling experience.

So what do you guess the patients do? If they have new back pain, they look up back pain and then, my Heavens, in 15 minutes they know twenty causes for lower back pain. That's good and bad, of course. But the point is that anyone can access this information.

And let's face it, some of our patients are as smart as we are, maybe much smarter than we are, and so they can do their own research with this tool. And they will get to the answers because they are highly motivated ... and that is what a lot of patients with Lyme Disease will do.

If they have the money, the time, the interest, the support system, they will find a way to figure this out because they are not satisfied with what they're being told. Far too often, even if the patient is obviously impaired, after presenting with chronic and unusual or vague complaints, many are told that they have something that is in their head, or that they've got chronic fatigue syndrome; or, if they hurt all over they are told it's fibromyalgia. In the end, the patient gets some sort of useless label to describe their malady which offers no etiology.

In contrast, let's look at what's happening in medicine and to the practicing physician. Treating physicians are subject to more and more regulatory guidelines, formulary testing restrictions, certifications for this and that, and have demands to see more patients to generate the same income.

Doctors are not in control of their profession. The doctor's ability to deal with complex medical issues is severely compromised by the time available, and access to non-biased information. The doctor ought to be able to filter what the patient got off the Internet, but often can not.

What the doctor too often says to the industrious patient is "don't read that trash." or "that's nonsense because it doesn't have the needed evidence." The doctor has to, at some point listen and say "You know, I hadn't heard that before, let me look -- let me look at that." Doctors must do this or face consequences. These consequences are that patients will become angrier and less tolerant of arrogance and perceived incompetence, the former always aggravating the latter.

So right now we have a tremendous tension between patients who are unhappy because they're not satisfied with the doctor's state of knowledge or interest about the symptoms they describe to their doctor, and doctors who are just overwhelmed with bureaucracy.

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The system doesn't work for patients who have chronic and poorly defined illness and the economic impact is huge. In our world today, we do an inadequate job in stressing preventative health measures and taking care of chronic illness, issues which, on the whole, have a much greater impact on the quality of health than anything else.

Perspective Paper from the CDC ... the Increasing Role of Chronic Infections in Chronic Illness

A "Perspective Paper " was published by the CDC in June 2006 — I brought copies and recommend you read it and will be happy to hand it out — concludes that infectious agents have emerged as notable determinants, not just complications, of chronic disease. This paper also notes that 90 million Americans suffer from chronic disease. There's a palpable irony here, since few of these well-known chronic illnesses have a known cause. There's a palpable irony here indeed.

As an example, my respected friends in the specialty of Rheumatology don't know the cause of anything they treat, except for gouty arthritis (elevated uric acid under pressure in the afflicted joint).

They don't know a single thing that causes the illness they treat. This is a theme in all fields of medicine ... other examples include MS, Lou Gehrig's disease, Crohn's disease, irritable bowel, endometriosis, and the list goes on and on and on. Everyone has heard of these common and devastating chronic illnesses, but we don't know the cause of any of them. Maybe we're not so smart after all, despite the grand medical centers, the white coats, and the diplomas on the wall.

In the CDC publication just mentioned, neuroborreliosis, that's central nervous system Lyme, is discussed as one of the chronic infections that is causing chronic illness. And of course that means IV therapy for best clinical results.

When the patient has neuroborreliosis and it's advanced and debilitating — particularly so, in our view, if the patient has a co-infection — our debilitated patient "can't find their way home" or, once they are there, forget where the doorknob is ... their life is in the proverbial toilet. They want to die, but they can't die.

I just mentioned an important CDC paper, but the CDC has sent conflicting messages for the past decade and essentially ignored the chronic form of Borreliosis. If the CDC or IDSA had been more forthcoming on this subject matter earlier, I wonder if I would be here today.

My Treatment

Most of those individuals who have brought complaints against me were treated early in our experience with chronic Lyme Borreliosis. We do things differently now than we did then, of course. Anybody who is paying attention and learning from their experience would report the same. Similarly, any one who jumped into the early 1980's and treated HIV/AIDS would certainly admit that each year they improved on their care and treatments.

As we have learned a great deal in these endeavors, we find we can now provide treatment more efficiently, with more durability, which means more profound and lasting benefit, and which thrills the patients and thrills us.

We have learned that our most seriously ill patients generally have multiple co-infections. The infectious ticks carry multiple pathogens.. This is a key to understanding the disease complex, and we're just beginning to learn about this. We are at the foot of the mountain on this issue. We're just starting to get a clue.

We are most anxious and willing to collaborate with a scientific or academic groups of distinction, such as Johns Hopkins or Duke University, when they finally wake up and realize that LBC is a real and serious syndrome.

We understand very well where this must lead in terms of scientific advance. We'll do what we can but eventually this has to go to the "big boys", ... to the pure scientists, and we understand that the government has to buy in at some point because they will pay for a lot of the work. I know this. It's what happened with HIV/AIDS. I've always known this.

Our Patientswhere they come from and how they are treated

At this time, most of our patients are doctor referrals or visiting with doctor approval. About 80 percent of our folks who are diagnosed have gone through an antibiotic program by mouth, not through an intravenous program.

Even though we do not practice in a traditional Lyme endemic area, we likely access more new patients at the Jemsek Clinic in Huntersville than anywhere in the world simply because we have four or five providers seeing patients at our clinic. I have learned that certain of those in power take exception to our work and visibility. Maybe that's a significant part of the reason I'm here today.

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When patients come to see us, the sick folks have usually been seen by up to ten to twenty doctors and have often been referred to major medical centers, ranging from Mayo to Cleveland Clinic, Duke and others. They have had numerous tests, trials of therapy, and are often left with labels such as depression, fibromyalgia, chronic fatigue. They're not happy because they've already spent up to or exceeding \$150,000 and they are suffering and/or dysfunctional.

Commitment to Science ... the HIV Story and How Lyme Research will Pay Dividends

I remember quite well that in 1983 nobody knew what HIV was, and then that explosion of research took off ten years later. Why did research take off in the 90's?

Socially because the US had recorded almost 500,000 deaths at the time and because Rock Hudson, Magic Johnson and others were public cases. Scientifically because the money commitment insured that you get the best minds in the country in organized research centers working on it. It's been incredibleover a million scientific articles in press and we're still debating fundamental issues.

In my opinion, the benefit of this effort in the study of HIV/AIDS has been to medicine what NASA in the 1960s was to the physical sciences. That sort of effort is what it will take in the study of Lyme Borreliosis Complex, another complex and devastating illness. I also believe that insight into LBC will benefit many chronic illnesses, as is the case with HIV research, once the commitment to research is underway.

Chronic Illness ... A Major Engine in the Consumption of Healthcare Dollars

We have to get serious about learning about chronic illness. And when we do intervene, of course, one of the most gratifying aspects will be that the patient is not only better, but they stop spending on healthcare, they stop going to doctors, they stop taking all these pills and you know, they're just so happy to have their life back. Practices like ours should be recognized as one of the insurance industry's most valuable assets.

My Patient Support for our Work ... Proportionality

I've got four hundred letters of support here, many single-spaced and several pages long, from people who say that they support what the clinic does and that we have helped them or their family members in profound and durable ways. In addition, there is an online petition of support generated on my behalf with twenty-eight hundred signatures. This petition was organized by the National Capital Lyme group in

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Washington DC just two weeks before the last Board meeting.

What these letters and signatures say, or should say, to you is that Dr. Joe is not passing out Kool-Aid, but it says he is helping many people. Compared to the four hundred that wrote in support, the Board lists 10 patients in their complaint against me.

Please note that five of those records that were reviewed are from people that I helped and who have in fact written to support me ... their letters are included in the stack of letters in front of you. So, in fairness, I think proportionality is something I'd really appreciate for everyone to consider. I would respectfully ask if each of you would look privately into the realities of your own medical service.

Would you agree that few physicians in NC could you find only five people who were displeased with their care, compared to 3,200 letters or petitions of support?

Between our HIV/AIDS and Lyme disease patient populations, we have been dealing with very complex and difficult patients, and so you work hard and do the best you can. I'm sorry for those we have treated who are bitter about their outcome, but would like to make it very clear that our patient's welfare was always our primary concern.

The Money Factor

It should be obvious that I didn't go into medicine with a priority goal to make money. You know, you don't enter into HIV medicine and dedicate yourself to HIV/AIDS for twenty years in order to get rich. It's never been about money.

I've been portrayed by some in this room as an opportunist. I'm far from being an opportunist. Those who know me understand that I continue to pledge my energies and resources to that in which I believe, the art and science of medicine. In the end, if we're honest with ourselves, we're still more about art than science.

Our new facility in Huntersville was carefully designed to create a space of calm and dignity for the body of patients for whom we provide private care. These groups of patients are routinely marginalized and rejected by the medical community. That is all I wanted to do – to create a special place for these marginalized patients.

Your Decision Last Month and Now

To conclude, I acknowledge that the Jemsek Clinic, under my supervision, employed long term IV antibiotic care in a small number of patients where, in retrospect, and despite our best efforts, little

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We note that a written informed consent policy was in place at the time that the claimants were treated and that all patients were specifically advised of the options for treating Lyme disease, either with oral or IV therapy.

We note that, in rare cases, multiple PICC line malfunctions occurred, including infection and sepsis, but in all cases clinical improvement was our goal.

Whereas, we would like to resolve this matter without the need for more formal hearings, we have drafted a consent order which speaks forcefully to the factors considered by the Board in coming to their decision of last month. We've agreed to a 13-point disposition, which we would respectfully submit to the Board today by Counsel Jim Wilson.

I will accept the Board's decision, but want the Board to recognize that I've done a great deal of good for the citizens of North Carolina in my 26 years of practice here.

We are all on a journey in life and every physician wants the opportunity to fulfill the oath that he or she took in becoming a physician to benefit their fellow human being. For these opportunities, I'm humbled and grateful as I realize these are not necessarily available to everyone. I feel very fortunate to have had this opportunity.

Invitation to NC Colleagues

Last fall, before I was aware of impending Board action of this nature, I wrote a letter to all the heads of Infectious Disease departments at all the universities in the Carolinas and invited them to collaborate with me in HIV and Lyme research, given our special populations and research personnel in place.

Months earlier, I was honored to deliver Grand Rounds at Duke University on the subject of Lyme Borreliosis. I now offer a standing invitation to any academic gathering under their forum of choice, in order to discuss the issue of Lyme Borreliosis Complex.

In closing, I would like to continue that offer of collaboration with those Members of the Board who are sitting here today. You're welcome to come see me at any time and see for yourself what we do. Thank you very much.