

Dr Jemsek's Comments to the North Carolina Medical Board, 2006

Dr Jemsek's fight to treat Lyme patients successfully has been fraught with legal obstacles and discrimination. Below is a selection of some of his comments to the North Carolina Medical Board in 2006, abridged by LDUK in 2019.

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. My life changing experience in HIV/AIDS taught me several lessons, the most important of which was to learn to practise 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 unpredictable 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.

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 numbers.

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. And the ultimate source of learning...and 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. 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.

HIV work has had the benefit of roughly \$3 billion in public funding every year, counting Centers for Disease Control (CDC) and National Institutes of Health (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. 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. As a wise person once told me, Lyme academic physicians create their 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. Patients suffering with advanced Lyme Borreliosis Complex have an inferior quality of life compared to those with HIV/AIDS. 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. In the Infectious Diseases Society of America (IDSA) there are only about 15 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.

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.

Regrettably, there is an unconscionable lack of accountability for 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. "Chronic" is chronic. The guidelines for testing were set up in 1994 and were meant to be temporary. 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.

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 is going full speed. If you want to know something about how to fix your car or learn about something in medicine, you Google. 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. They are not satisfied with what they're being 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.

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 with doctors who are just overwhelmed with bureaucracy.

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. As an example, my respected friends in the specialty of Rheumatology don't know the cause of anything they treat, except for gouty arthritis. This is a theme in all fields of medicine ... other examples include MS, ALS, Crohn's disease, irritable bowel, endometriosis and the list goes on. Everyone has heard of these common and devastating chronic illnesses, but we don't know the cause of any of them.

When the patient has neuroborreliosis and it's advanced and debilitating - particularly so, in our view, if the patient has a coinfection - 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.

We find we can now provide treatment more efficiently, with more durability, which means more profound and lasting benefit 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. We are at the foot of the mountain on this issue. 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.

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 as an opportunist. I'm far from being an opportunist. 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.
