

# The Power of Truth Spoken by Joseph G. Jemsek, M.D.

## Part 2

*by Tina J. Garcia June 2009*

Tina: Dr. Jemsek, what is your approach to patients and your method for treating Lyme Borreliosis Complex?

Dr. Jemsek: With regard to my approach to patients, I am unable to accept insurance, so there is a financial challenge for patients, which I regret and always appreciate. Almost all patients completely understand this situation, and we do everything we can to help with HICFA forms for insurance filing and so forth. But we all know that health insurers are terrified of the 'black box' which LBC represents, and that their business model is essentially 'anti-patient'.

There is also a travel challenge in most cases, because I see patients from all over the country and quite a few from Europe and other continents. For example, I've had patients come from Russia, Lebanon and Australia to visit the clinic in South Carolina. I've had a dozen to fifteen or more patients come from the Scandinavian countries, as well.

Tina: So despite all the problems forced upon you, patients still come to see you for help.

Dr. Jemsek: Yes, because it's a worldwide epidemic. In fact, we get emails from patients, several per week on average asking, "Can you help me?" People are desperate. It really breaks my heart. I currently only see Borreliosis patients, but I'm seeing sicker patients than I've ever seen before.

Tina: How does the office visit unfold when patients see you for an appointment?

Dr. Jemsek: A new patient intake is a two-hour visit. We ask that the patients complete a clinical medical history form, and they typically bring in an inch or two of records which we review thoroughly. I usually start the patient interview with the question, "Are you doctor referred, or are you here with your doctor's approval or understanding?" Then I ask the patient which doctors they want copied on my consultative note. Some patients say none, some want several doctors copied, and some decide later, so we're happy to do that for them and really encourage the communication.

For as long as I can remember, I have made a practice of providing a copy of the consultative note to each patient, so the patient gets our whole summary with recommendations right away, and of course, I copy any physician who referred the patient or to whom the patient wishes records be sent. Ideally, we want exhaustive but well-organized reviews up front, because if you don't get it on the first or second visit, you likely will never have a history that serves the patient well. In most cases, we set several actions in motion immediately after the visit, and it really isn't until later when laboratory tests and procedures are concluded, that we get a more complete picture. These are extensive documents that I create.

Tina: That's a great help to someone with cognitive dysfunction.

Dr. Jemsek: Exactly. Everyone's from somewhere else, so if someone's on IV therapy, for example, they have to have a collaborating physician at home, no exceptions. And if the patient is going on an oral antimicrobial regimen, we still very much encourage collaboration with a local physician, but we don't demand it.

Patients always have the discretion of taking their records and going to the next physician or finding a physician. I am currently able to interview about five new patients a week on average. That's about all I can do. On the first follow up visit or with a patient that I haven't seen in a year or two, we devote forty-five minutes. On a routine scheduled office appointment, the scheduled time is thirty minutes. So as you can see in that way, from the time allotments, I can only see ten to fourteen patients a day max. If I see more than one new patient a day, it's a really long day.

I just think that doing as much up front and doing it as thoroughly as possible pays tremendous dividends in terms of patient care, organization, and mutual understanding of what the goals are. We're booked out about four months now, but the consistent trend continues to be for this period to grow longer. We have approximately seventy-five new patients on the waiting list and the list is growing every day. However, very soon I intend to bring in two nurse practitioners, and that should significantly expand our new patient intake. As appropriate, we're going to be able to charge considerably less for the nurse practitioner visits, which will help our patients access the clinic, but I'm going to promise that I will always see the patient on the next visit.

Tina: What about your clinical staff and other areas of practice?

Dr. Jemsek: I am up to about fifteen employees now, whereas at the Jemsek Clinic in 2005 I had seventy employees serving the twin epidemics of HIV/AIDS and LBC. Some of those folks were research PhDs and we really miss them, and not that we are semi-resuscitated, but we're going to start our research again. I recently brought back some really outstanding people who worked with us before. My head clinical research RN is coming back, along with another RN whom I worked with in infection control when I was the epidemiologist at Carolina Medical Center years ago. With these outstanding individuals back on board, we're going to start doing respective chart reviews and thorough data collection. I'm also teaming up with a Ph.D. in chemical engineering who's incredibly bright and very well-connected, and has this wonderful model for database collections, among other things.

Our research efforts will follow two or three different paths. One path is basic data collection and the other paths will involve much more sophisticated research, both clinical and basic science in orientation. This will require collaboration with a number of scientists and we're confident we can make this happen. What our clinic provides, above all, is the patient population and an excellent knowledge of which questions to ask. The real trick is knowing how to prioritize what is most useful now and what can wait, since there are literally thousands of potential projects that need to be explored. I'm very anxious to turn over some of this process to people who are much smarter than me who can run with it. It's just incredible, because we're at the beginning of a new frontier. It's as though we're starting all over again. The only advantage we have is that we have the experience of HIV/AIDS, and if this research project ever gets capitalized, we can jump start this thing. We will use the HIV/AIDS epidemic as a model, although as most recall when it first started, no one was interested in all the gays who were dying. But soon it became a

national agenda, things picked up and the government did do the right thing by starting the ACTG groups. That was a really smart thing to do. They asked the clinical trial, basic science questions and did the research, the grunt work so to speak. Then pharmaceuticals and NIH became heavily involved, and of course they brought in money, and it became a multi-billion-dollar enterprise, attracting the best minds in infectious diseases.

So really, at least from a scientific point of view, once the commitment is made, the jump to understanding LBC should come from a tremendous platform built on the back of the HIV/AIDS pandemic, or at least it should work that way. On the realistic side, however, my research associate made the remark that a seasoned immunologist recently admitted to him that we know next to nothing when it comes to most chronic illnesses. And really, nothing is as easy as I have just described, so it may take decades to fully understand the epidemiology, molecular biology and nature of the disease states associated with LBC.

I expect my experience in HIV/AIDS and LBC to parallel each other, if I am around long enough. In HIV/AIDS, I came from one world where I grew up and spent the first decade or more of my experience dealing with the human aspects of a deadly disease, and so I got a crash course during part of my career getting in touch with my own mortality and who I was as a physician. Then, during the next decade, as the money rolled out and thousands more became involved in research and treatment, the science was simply incredible.

I was involved with HIV and attending and presenting data at very well-funded meetings and that sort of thing. Then I went from that world to the Lyme world, which in the beginning was pictures of raccoons and deer ticks on the wall at a meeting in some New Jersey lodge, lectures on pulling out amalgams as a cure and saying that was what was causing all your troubles and listening to lecturers who had never used a PowerPoint presentation. It freaked me out.

Tina: Are you aware of any research that's currently being performed or are you planning to do any research with regard to sexual transmission of Lyme disease?

Dr. Jemsek: No, not in the beginning. That's just too hot to handle. But I'll tell you something interesting about sexual transmission. Every married couple asks me that question. It's at the top of the list. "Can I pass this on?" So, if something is that high up in the consciousness, why is it that we've never done a study? It's obvious the CDC has an agenda to avoid this issue as long as possible. People are intimidated from even mentioning the possibility. What I tell people is that, between sex and ticks, we're all infected. And I believe that. I think the spirochete is part of our endogenous flora. Our biosphere has sort of made that transition, and I think we're all infected. So, we have this whole new paradigm in medicine, this whole new jump-shift logic.

And even though people don't smoke as much and we don't have as many smoking-related deaths, we have way, way too much chronic illness. I think that between these new infections that have emerged over the last several decades, which are relatively new in terms of penetrating the society, and what we're doing to the environment, we're in for trouble. I can't even bear it. Intuitively, we know the stuff we've done cannot be good for us, and it can only go one way -- it's got to be bad to some level. So between all the chemicals we use in our environment and the

chronic illness, it's a whole new moving paradigm. Right now, all we do is just treat symptoms with very expensive drugs and shut down the immune system. What if some of these things are reversible?

Here's the ugly fact and the ugly truth: This disease is a TSUNAMI. The disease is so prevalent and it's affecting so many decision-makers and their families, that this will force the change. And I predict that in the next year or so we're going to get some big names involved. Congressmen and CEO's are being affected, and I've seen doctors and their patients for this illness, so it's bound to happen. And at some point somebody with some outrage will step up and there will be questions answered. I think the film *Under Our Skin* has done more than anything before it, or anything that may come, to change the consciousness of America about Lyme disease. We all get comfortably numb with what's going on, but not for long, and we can't be indifferent and ignore it anymore.

We need to change the way we approach medicine, and it's frightening that we're talking about nationalized health care. As horrible as our current health care system is, with nationalized health care, medicine would be a death knell for any hope in the revolution needed for diagnosis and treatment of LBC and other chronic illnesses.

Tina: Do you ever see acute Lyme disease infection?

Dr. Jemsek: No, I essentially only see early accelerated illness or longstanding illness. I check to see if the patient has a defined tick event, with or without a rash, and has an illness compatible with an evolving, persistent, neurocognitive and musculoskeletal illness occurring within a few weeks of the recognized bite. If so, then they pretty much have a deeply embedded infection, a chronic illness, and will need to be treated like anyone else with chronic illness. Or, I'll see someone who got bitten three months ago and they're sick, going from doctor to doctor, and they manage to get an appointment because they have an awareness.

Mostly, I see chronic illness. When I get some data together, I'll be able to tell you the mean duration of illness, or give it a good try. But even more fundamentally, when you go back to determine how this disease activates, I think most of my patients are infected well ahead of the defining or recognized clinical event and sustained illness is generally associated with a tipping point from a life stressor. This may or may not be related to a tick bite or to a defined tick event. This is oftentimes related to a prolonged period of stress, another illness, physical trauma or childbirth, etc. This happens because, even though we can't measure it, there is a clear and certain immunologic frailty associated with subacute infection with Bb and co-pathogens. There's a tipping point and sometimes people stair step.

What I tell my patients to help them understand is that we're trapped by this illness in two ways. One is by the biologic nature of the illness, but we're also trapped by our health care system. So, when people get really sick, there's no way out. I see early accelerated illness, and by that time I consider the infection to be embedded. Spirochetes get in the brain within thirty minutes. By the way, IDSA has no basis for their guidelines. This illness is going to force people to 'IQ up' with regard to our approach to this disease and to medicine in general. We need to put medicine back on a cerebral and compassionate plane that works for our patients.

Tina: What are some of the most important clinical observations and treatment recommendations you have made with regard to Lyme Borreliosis Complex?

Dr. Jemsek: What I learned a few years ago is that you don't have to treat every day. And with my HIV and infectious disease background, I learned the virtues of combination therapies. When you're dealing with a complex group of infections, there's no one drug that's going to satisfactorily handle the infection unless you're not that sick. It's all about putting your immune system back in charge. And to the extent that you can eliminate the source of the immunosuppression and your immune system recovers, you've done your job.

Everyone who's trapped by this illness needs nutritional support, metabolic support, and they need antibiotics. Some people are negative about antibiotics, but you can't evaluate antibiotic therapy in a vacuum or as 'all the same'...that's patently intellectually dishonest. We are, after all, treating multiple, stubborn infections in an immunocompromised host where, by definition, the immune system cannot handle the problem. And our goal is not to see how many days of antibiotics we can administer, but to administer the fewest days needed in order to restore immunologic control. Towards that end, we need to understand the triggers to keep patients out of situations that are going to perpetuate the patient's chronic illness and/or make it unwise to attempt therapy until these destabilizing stressors are reduced, whether the stressor is as basic as a bad support system or involve psychiatric, pain or sleep issues.

In treatment models, I've learned that pulsing makes sense, and I think everyone who's really sick has multiple infections. When I treat the three major infections, which are *Borrelia*, *Bartonella* and *Babesia*, and do that in a certain sequence and in a certain combination, people get better. And I think it's very important for people to go off therapy on an intermittent basis for one or two weeks at a time. Those windows are very important times to see how much immunologic security they have. Patterns develop, and the better the patient is, the longer they can go off drugs. For many years now, we have learned to pulse combination antimicrobial medications in certain patterns, and I have modified our clinical approach from learning the tempo of the disease.

Often you learn more about your patient when they're off treatment than you learn when they are on active treatment. These 'holidays' provide valuable windows for observation and after a time, you learn that cycles of therapy and the way they are sequenced show reproducible patterns of response. You also learn a lot from aspects of the treatment period, whether it's being on treatment, when it's the time to take Flagyl, and certainly the time that they're off treatment is a very important window for you to see how the patient is doing immunologically. And once you learn patterns and understand them, then you know when to intervene and when to back off. One of my patients said, "You're doing a dance with this disease, aren't you?" That's not a bad analogy.

I learned a long time ago that the most common reason for people not to get better is inadequate treatment of co-infections. It's very important to address the co-infections and to do so in an overlapping way, so you're not just treating one thing and then going on to treat something else. I only treat three days a week whether it's oral or IV, and have been doing it this way for at least five years, and exclusively this way for almost three years. And on all my programs, I give a week

off of therapy on average every two to four weeks. I don't do it so much at the beginning, but after we get into it, patients get immunologically revved up.

In treating patients at the clinic, we are constantly striving for a balance point in terms of clinical efficacy and manageable toxicity, the latter being an inevitable sidebar to the highly immunogenic and inflammatory lipoprotein storm we see with *Borrelia lysis*. When the immune system activates, a patient can actually get more toxic, so we have to balance that. It's part of the art of medicine in terms of learning how to balance the toxicity generated and the fact that the patients need to detox. And I prefer to think there's a 'back door' to this illness as regards to the detoxification issues. If the 'back door' is closed, patients may remain unwell for protracted periods. Without question, there are considerable variations in the segment of the population with this illness who are going to be very sick, in terms of the ability to detoxify. This, in fact, may be as critical to outcomes as the infectious load and immunologic/genomic factors. That's the way it was with HIV, too, in a sense.

Tina: Dr. Jemsek, you are a beacon of light, a hero, to many of us in the Lyme community. You are thought of in this way, because you have established yourself as a Lyme-literate physician who is able to guide patients back to health. In addition, you have faced your difficult experiences with the North Carolina Medical Board and Blue Cross/Blue Shield with a calm demeanor and resolute determination. What has helped you to remain centered and focused during the challenges you have faced with all these legal battles?

Dr. Jemsek: Thank you for those kind remarks, Tina. My response would be family and patients. I get boatloads of affirmations every day. The other day I got four hugs, so how can you not like doing this? I really mean this. We can help people in such a profound way just by our ability to understand. It all starts with listening. I honestly didn't always have an ear for listening, but I learned this skill in caring for the very ill with HIV/AIDS. When Lyme patients first walked through my door, they said, "I hear you treat Lyme disease." And I said, "Well, yeah. So what?" But they kept coming, and believe me, I didn't get it for a long, long time. It took me about six to eight months to really understand.

As a doctor, you have an understanding about how patients are trying to paint their picture for you, and even if you listen, you may not understand it the first or second time. But when you hear it enough, you begin to form your own belief constructs and interpretation of it. And then you get reinforced as your impressions and concepts are molded. In many ways, it's like learning a new language, a language with a new alphabet, like Chinese or Arabic. And you don't learn it overnight. But the patients learn it and we talk in this strange new way with terms not found in modern medical text. And if another doctor's in the room and is listening, they don't know what the heck we're talking about. The patients get it, but to state the obvious, a lot of the doctors become very uptight about not understanding, and the patient then becomes the problem.

So, if doctors would just let their hair down a little bit and take a big dose of humility and honesty, they'd be so much happier. It would set them free. You know, I never worry about not knowing something any more. I worry about those who feel they must always be right. AIDS taught me that, because we didn't know anything. We were up to our asses in alligators, and we were just trying to do what we could.

It was a very creative period for me and a lot of other people. But some people look at you like a reckless cowboy when you do something different, because it makes them uncomfortable, even if they have no answer and even if the patients benefit.

When it comes to my patients, I always ask, "What made them better? Why did they get better?" We can grow and evolve this way, as our patients are our ultimate laboratory for progress. And so now, as complex as Lyme patients are with their 150 complaints, their symptoms and physical findings now make recognizable patterns. And I can see the patterns, and I'm very comfortable with all these complex issues. But I realize how much we still have to learn, and that's really what's fascinating. I'm having a certain amount of success, and I'm learning what questions to ask. But my constraints, of course, are time and money in trying to get answers to everything.

And I see so many neurological manifestations in LBC and I use more seizure drugs than almost anybody, because that's what I have to do. I have a whole plate of medications I use in terms of seizure, potent antidepressants and mood modifying drugs. You just have to. But I can tell you this -- I think that this is going to be fascinating as this thing unravels. And I'm telling you, people are going to discover things that I've known in my head and other doctors, like Richard Horowitz and Bernie Raxlen, have known implicitly for years. We've all known about stuff that hasn't been written down yet, all sorts of strange clinical facts. In five or ten years, they're going to say "Oh well. This happens and blah blah blah." And we're all going to say, "Well, yeeeeeeaaaah."

For example, I saw some case reports from Europe on ocular palsies being prominent as the presenting sign in early or advanced Lyme. And these were case reports, but on some clinic days, none of my patients can coordinate their eye movement. It's things like that that I know already from the clinical setting. The complexity of the illness has prompted many of us to learn a great deal more about neurology, endocrinology and dermatology. And while I know that the doctors in these specialties that I've mentioned are incredibly bright, they seem sort of frozen and locked into their ideology. And the more intense the ideology, the more hostile the specialist becomes when confronted with something not in their comfort zone, or something which challenges them. Doctors have lost control of their profession in a mission lost, and the prevailing attitude of false pride is part of the pathology we see contributing to the failure of today's medical system. As I stated in my speech at the Into the Light Gala, arrogance trumps reason every time. It's sad really, and doctors need to break out from this or be eternally miserable, because this epidemic is going to make fools of a lot of arrogant physicians.

You have to put yourself in a position to understand that it's okay to say that you don't know something. What's really important is that you continue to try to learn. If you do that, it all comes together. Patients really get that. Then you don't have posturing and antagonism that creates a chasm. It's just so much easier to say "I don't know, but let's learn. But here's what I do know about this." I know doctors are frustrated, but they turn their anger inward instead of looking at the real problems and getting together to try to bring the profession back where it should be. And if you don't have a passion for it, get out of medicine.

In particular, I think the infectious disease doctors have been hoodwinked, in part because their source of information has been compromised by the Lyme Cabal. The ID docs, for some reason, have a characteristic that I just don't understand. More than any other specialty in the LBC debate, they are consistently rigid. You just cannot be rigid, for we need to just admit that we only know a fraction of a percent of what we need to know about the human body and medicine. Much of what we know now is going to change anyway. So, you just try to keep learning and if you have success, you try to understand your success and understand your failures, too. And if you can do that, then you grow as a doctor and you get so much satisfaction out of seeing patients.

When you get into this ritualistic practice, like having a certain algorithm for treating this or treating that, how boring. I acknowledge that we must have some guidelines and some semi-rigidity to our beliefs and the way we practice medicine, of course, but always understand that we need to grow and learn every day when we go to work. Most doctors will view a patient based on their own experience and their empiricism rather than what's printed in a textbook, I'll tell you that. I mean the really good ones.

My message to doctors is "Get real!" Learn some humility, be honest, and it will set you free. Then you will be the kind of doctor you wanted to be when you started out from day one. But if you cover yourself up with false pride and arrogance, then you're doomed. It doesn't work, never has, never will.