

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

## Part 1

*by Tina J. Garcia June 2009*

Cognitive dysfunction. Excruciating pain. Crushing fatigue. These are the daily aches and pains of suffering Lyme disease patients. Medical board prosecutions and costly lawsuits. These are the daily aches and pains of Lyme medical practitioners who honor the medical profession by serving those infected with *Borrelia* and other vector-borne disease. These are the soldiers who have been forcefully thrust into this saga called the Lyme Wars. The Lyme disease community is an army with limited resources, limited strength and the limited ability to have our voices heard amid the roar of the mighty Giant. We are like young David from days of old-facing formidable foes which show no mercy or compassion for our plight, but only disdain and contempt for our resilient survival. We are painfully experiencing the dominance of government agencies, the wealthy insurance industry and influential medical societies, all of which wield power capable of crushing anything and anyone who stands in the path of their objectives.

In defending our position, the Lyme community must aim carefully so as not to miss our mark. We are armed only with a slingshot and the Stone of Truth. But don't underestimate our weapon, for Truth hits hard and squarely between the eyes. It paralyzes the gut. It stings sharply and jolts the senses. Many a Lyme soldier has run in fear from the Giant named Monopoly. But a few brave warriors have stood their ground, taken aim and slung the Stone of Truth. One of those valiant Lyme warriors is Dr Joseph Jemsek. Dr.Jemsek began treating Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) patients in early 1983, when he is believed to have diagnosed the first case in North Carolina. By 2006, Dr. Jemsek had cared for more than two thousand HIV/AIDS patients.

In 1998, showing gratitude for service to the HIV/AIDS community, North Carolina Governor James Hunt presented Dr. Jemsek with the Governor's Award, a Certificate of Appreciation. In 2003, Dr. Jemsek formed a non-profit that provided case management and education financial assistance to HIV/AIDS patients to help them with the cost of their treatment. Governor David Easley, who succeeded Governor Hunt, also awarded Dr.Jemsek with the Governor's World AIDS Day Volunteer Service Award in 2004.

Over the years, Dr. Jemsek and his staff were leaders in FDA clinical trial research for new therapies in HIV/AIDS, participating in almost one hundred FDA approved pharmaceutical trials, of which twenty-two became established treatment protocols for those suffering from HIV/AIDS.

In 2001, shortly after establishing the Jemsek Clinic as an HIV/AIDS clinic, one by one, another abandoned patient community approached Dr. Jemsek for help. Those suffering from Lyme Borreliosis Complex desperately sought what Dr. Jemsek had provided to his HIV/AIDS patients - an open mind, a listening ear and the ability to research and analyze the complex infections that were destroying their lives.

Quite sadly however, in 2006, despite his research and philanthropic efforts, Dr. Jemsek faced political and legal battles related to his involvement with treating Lyme disease. These actions resulted in the loss of his HIV/AIDS practice, which at that time consisted of more than one thousand patients. Dr. Jemsek tried to salvage his practice to continue serving the HIV/AIDS community, but ultimately, the circumstances separated him from the patient population on which he has built his entire career, and left many of these patients without suitable options for health care.

Fortunately, Dr. Jemsek's experience with the HIV/AIDS epidemic has had a long-lasting and positive impact on his current view of medicine and the way in which he now focuses his resurrected practice on those suffering the ravages of Lyme Borreliosis Complex.

**Tina:** Dr. Jemsek, on March 20, 2009, you hosted an event in Charlotte, North Carolina to bring awareness to Lyme disease. Would you please tell us about your awareness event and its success as such?

**Dr. Jemsek:** We hosted the Into the Light Gala and it was a huge success! It was a landmark evening! We came up with the idea after I attended the Unmask the Cure Gala in New York in November 2008. It was the second time I went to that event, where I had the good fortune to become acquainted with Staci Grodin, founder of the charitable foundation, Turn the Corner, which sponsored the New York Gala

To my knowledge, Turn the Corner has been the largest fundraising organization for the Lyme cause in the country for the past several years. Like so many others, the Grodins were impacted by Lyme Borreliosis Complex and decided to take assertive action for positive change. Turn the Corner is head and shoulders above everyone else, both in their success and their ability to inspire, because they conduct themselves with integrity and do it for the right reasons. So, I was inspired by Turn the Corner and felt that we should do something similar in Charlotte, not so much as a fundraiser since that requires much more infrastructure and time, but more as a major awareness campaign and a way to feature the film Under Our Skin.

When I told Staci we wanted to do a gala for Lyme awareness in North Carolina and asked if her organization would be supportive, she jumped on board right away. That's one thing I love about Staci -- she agreed to help without hesitation. Turn the Corner graciously agreed not only to sponsor our Gala, but also agreed to be the surrogate charity for the event. In this way, all donations to support the Gala went to them as a charitable organization and offerings became tax deductible. In short order, I then asked National Capital Lyme, who has 2000 members from their DC area, to become a co-sponsor. They agreed, also, and it worked out great.

With our major sponsors in place, I put a team together and started by assigning our research coordinator, Michelle Thomas, to head up the Into the Light Gala committee. Michelle, along with Mark Pellin, a journalist and editor, put in hundreds of hours and made several key contacts important to the Gala, including arranging the involvement of a skilled graphic arts professional. This group was joined by my wife, Kay, and they came up with the amazing tri-fold invitation, along with the beautiful banners displayed at the event, among many other things.

Very early on, we also worked closely with Kathy Fowler in DC, a media journalist with great experience in the Lyme issue and featured in the documentary. In addition, Staci generously allowed us to work with a chief staff member for Turn the Corner, Darren Port. In the end, rather quickly, we had a professional organization and marketing team that communicated regularly and functioned very well together.

Even in the beginning, I had a sense that we were going to have a successful event. We started in November, with the Gala held in March, so there wasn't a lot of time to pull it off, but I just had this calm sense that it was all going to come together. It did come together and I believe it was the time in our history when it was meant to happen. And more things like Into the Light need to happen and will happen.

The Into the Light Gala hosted over 450 people, some traveling from a great distance. It was a very powerful evening, as one can glean from the DVD overview of the Gala. In remembering the evening and looking at the DVD images, there is definitely a sense of energy, mass and purpose coming out of the event. The Gala gave us a chance to come together to support each other in spirit and have that physicality there, too. It gave us the opportunity to honor some wonderful people with a category which we termed our Courage Award. Most of the award recipients have suffered from this illness and then done extraordinary things to try to help others with the illness. Among the recipients were PJ Langhoff, author of the incredible, recently published book *The Baker's Dozen and the Lunatic Fringe* and Kathy Fowler, who I mentioned earlier.

We opened the doors at 6pm but by 5:30 we already had about a hundred people in the lobby. The movie began around 7:15 and people hung around until midnight. We filled two theatres by using a simulcast operation. It was very exciting! I wanted to invite as many people who weren't aware of the epidemic as possible, so as to create awareness to people who can make a difference, whether it was friends of friends or business community and political leaders. Several Charlotte city council members were there, as was a representative of the Governor of North Carolina, an individual who suffered from Lyme disease years ago. The media coverage was definitely there and was particularly good for a first time event. We're going to have a professionally produced DVD made of the production by Andy Abrahams Wilson of Open Eye Pictures. You'll see that eventually. We want the photos and the DVD, in particular, to be our legacy to open doors down the road.

Jordan Fisher Smith, the park ranger portrayed in *Under Our Skin*, who is now working professionally as an author and lecturer, was our Master of Ceremonies. He did a wonderful job of tying the evening together. Mandy Hughes gave a moving acceptance speech on behalf of our Courage Award recipients. In another awards category, the Vision Awards, Turn the Corner Foundation, National Capital Lyme represented by their founders and leaders, Gregg and Monte Skall, and Andy Abraham Wilson, producer and director of the documentary, were all honored for their priceless contributions to promoting positive change. And everyone was blown away by the movie.

After the film concluded, I said a few words. I called on my profession to do better for its patients, to regain its mission for putting the patient first. I also called for the outing of our corrupt health insurance industry. This was an opportunity to speak in a clear and civil manner about the debacle of our health care system and the disgrace promulgated by certain physicians in power, who have exacerbated and prolonged the suffering experienced in the Lyme epidemic. I tied together the Lyme epidemic and some of the issues we're experiencing in our economy, with regard to the excesses we observe all around us, fueled by greed and arrogance. In the end, I hope everything tied in together, and I do think it really resonated with the audience. All I really did was say out loud what everyone already knew.

**Tina:** I do appreciate this event from a distance, because it opens doors for every one of us. Thank you for holding the Into the Light Gala and for sharing it with the readers. On a different note, I'd like to ask you for your opinion on pulpit sermons on Lyme disease that emanate from the Infectious Diseases Society of America (IDSA).

**Dr. Jemsek:** I do belong to the IDSA and it's a really excellent organization, but like any large organization, it depends on leadership, truth and integrity in leadership. Their leaders have done everything they can do to be denialists, and I think their leaders have put them on the path to perdition. The IDSA body has just been bamboozled by this 'Lyme Cabal', which consists of only one or two dozen individuals.

**Tina:** As a member of the IDSA and acting Treasurer of the International Lyme and Associated Diseases Society (ILADS), you could, under the right circumstances, act as a facilitator. You could be someone who could bridge the gap between the two organizations. It is outrageous that your attempts to do so, in the form of letters written to the IDSA about what you were seeing with Lyme disease, fell on deaf ears. This speaks volumes about the IDSA agenda.

**Dr. Jemsek:** I think those attempts are what got me into "trouble". In a series of letters over several weeks that began in late 2005, I communicated to them with comprehensive and referenced reviews of the arguments at hand and pleaded for change. I made it very clear to them that, not only was I concerned about my patients but also the IDSA Society, if they insisted on staying on their path.

One day my letters will be public and in them can be found my statements to them that said, "You're vilified around the world for your policies, so please consider this. I'm proud to be a member of this organization, but you need to open things up." It would certainly appear that they came after me, because I was spoiling their party, and I think we'll learn much more about the ruthlessness of their actions over time.

However, I had no idea that these people and others would so ruthlessly guard and advance their agenda. And there is a sickening sense of evil connected with their actions. At any rate, the bloom is definitely off for me now.

This whole experience and the actions of groups in power is now 'up close and personal' with me, and frankly still leaves me incredulous. I thought I knew a lot about human nature and it turns out I knew very little. You see, I had this wonderful medical experience in HIV/AIDS for over two decades, and I've witnessed incredible cruelty to suffering patients and I've also seen incredible kindness and giving. So, I thought that I had already seen the best and worst of human behavior before the Lyme story happened. But I never fathomed that the corporate world and their counterpart in medical politics could be as ruthless and evil as they are. They really wanted to take me out. For me, what's happened is I've learned about things that I didn't want to learn about.

Since they blew me up, I've learned about trial lawyers and lawsuits, medical boards, insurance companies, malpractice companies and academic physicians and their motivations. I didn't want to learn about any of this stuff, but now at least it's all demystified for me. Nothing rattles me too much now. Of course, there's always going to be something else to learn about, but trust me, I've learned about being in the courtroom, filing bankruptcy, foreclosure on my building and the near loss of my house. My family went through all that with me and my wife stuck with me throughout it all. But I'm just that much stronger, and I'm a big problem for them now.

Let me tell you something funny. One patient said they were watching a show late at night, Golden Girls. It was from 1985 and it was about Lyme disease. The patient was sick and tired of getting brushed off by all the doctors. But the upshot of the show was that the woman was finally diagnosed and got better, but then raised hell with a doctor in a public place saying, "You should listen to your patients!"

And the same patient brought me an old magazine tear out from a home health guide, probably from Jackson, New Jersey, talking about Lyme disease and how it could be passed to the fetus, how it could be chronic and how it can require long term antibiotics. And this tear out was from 1991.

Then there was a total shift by these arrogant individuals. Sometime in '93 or '94 there was an embargo on the truth. Overnight, things turned around and white became black and vice versa. For example, in the infamous 1994 Dearborn meeting, Allen Steere pretty much turned everything around and said there was too much Lyme disease being diagnosed, and as PJ Langhoff writes in her book, they hijacked the truth and turned Lyme into junk science in order to promote their vaccine and other interests. It was all about their own motivation. It was just incredibly wrong, and we're still living with this fifteen years later.

**Tina:** How are doctors able to ignore ethics and put their own agenda above the patients they promised to heal?

**Dr. Jemsek:** As I spoke of at the Into the Light Gala, our mission has been lost in medicine. Our doctors have lost their way. I think it came about in a lot of complicated ways, such as the increasing change in the independence of the physician and their failure to invest in their own profession by integrating with all the disciplines that deliver healthcare. In other words, doctors have always had this tremendous ego, which I think is a huge protective bubble for them. Unfortunately, I think it is unearned and misplaced ego. And what that does is create a situation wherein if the doctor doesn't understand something, they make the patient the problem. It's kind of dummed-down medicine to the point that, if they don't understand or listen to what a patient with complex medical issues tells them, they put it in one of three big buckets-fibromyalgia, chronic fatigue or crazy. That's really sad because life and medicine are more complicated than that.

One of the things I said in my speech is that arrogance trumps reason. So, if you are arrogant for whatever reason, it totally corrupts the doctor-patient relationship. In addition, the doctors have been brought under pressure economically because of the restructure of medicine with the HMO's, Medicare and paperwork. They have to jump through many hoops to satisfy the leaders of American health, the insurance companies.

I really am very sad about doctors having lost their profession. We're now working for insurance companies and hospitals. Instead of turning our energy outward to try to change things, we often turn it inward against each other. Often doctors are jealous of the one who is more creative, disagrees, who has new ideas, who makes more money or who seems to be more popular. As a group, we as doctors are really small-minded people. And the chasm between patient and doctor has been magnified since we've gone full bloom in the information age, so that patients have access to information they didn't have in the past.

**Tina:** Unfortunately, this occurs at a time when chronic infections are rampant. You've certainly made your case for something you expressed in your speech at the Into the Light Gala, when you said, "The delay in recognizing our nation's Lyme epidemic presents a prime example of our broken health care system. The way in which a society deals with a marginalized population is the signature and indelible stamp of that society's character...give the U.S. health system an F grade for its work here."

**Dr. Jemsek:** Yes, we do a horrible job of dealing with chronic illness. In a strange way, the Lyme epidemic may be the tipping point for making significant change, because it is so painful and so complex that it's going to force us to finally work it out. It's not going away, no matter how long Gary Wormser holds his breath. We need to think about the whole picture of interaction and interrelationship of chronic infection and epidemiologic control and examine why we have so many other co-morbidities. Could chronic infections be at the root of a lot of our rheumatologic and other diseases?

**Tina:** Does what you refer to as Lyme Borreliosis Complex or LBC include Lyme and co infections?

**Dr. Jemsek:** Yes. You see, one thing I noticed with HIV early on, is that we have a different paradigm in that the virus replicates every thirty minutes or so. With LBC we have what we call pleomorphism and polymorphism. Pleomorphism has to do with different life forms and polymorphism has to do with different genomic patterns within the same species. So, as organisms evolve and multiply in a host, they're not carbon copies.

When I talk about the Lyme Complex, what I mean is that I realized early on that our patients are multiply infected. Because I came from an AIDS background, I saw the immune system melt. Although we have a different model with Lyme Borreliosis Complex, the concepts are similar. And what happens is that the immune system melts and we get opportunistic infections that come up after a while. What we saw in the early days of HIV medicine was absolutely bizarre back in the early 80's, because we only read about these things in textbooks. Like, - pneumocystis pneumonia, for example. That was something only kids with leukemia at St. Jude's Hospital in Memphis got after they had received high-dose steroids for months. Or, it was also seen in the malnourished in Auschwitz. But then we started seeing this regularly, and it became by far the most common life-threatening infection in HIV/AIDS.

We also saw the yeast infections and shingles (herpes zoster) come on in twenty year olds. We saw people go blind from cytomegalovirus (CMV) infections. We saw mycobacterium avium complex in blood cultures and as sheets of mycobacterium in stool samples. We saw bizarre stuff, but after a while, it all started to fit into a big pattern. And so, after you see a few hundred patients, you start to realize that when you see a certain CD4 count, the patient's going to get this or that. And we started to get better at that. And we realized how many other systems were affected whether they be metabolic, hormonal, malignancies and so forth.

With Lyme disease, there is absolutely no reason to believe that there are simple answers and simple solutions. When people are really sick, they are multiply infected. And I learned a lot from the animal studies, which indicate that if you're infected with Lyme, you're going to get weak and dizzy. But if you add babesia or bartonella, the animal will die. So I learned that and in my own practice, I started looking for signs to tell me why people relapse or do not get well. And in the early years, I came to the conclusion that they're multiply infected, and you have to treat it as a group or conglomeration of infections and regard it as an immune suppressive illness. In other words, we have a Lyme Borreliosis Complex syndrome and a multi-systemic chronic illness.

**Tina:** In your experience with Lyme patients, have you seen anyone who has exhibited AIDS-type symptoms from immuno-suppression?

**Dr. Jemsek:** Well, I had some AIDS patients who had Lyme. And you know what? The Lyme was worse on the patient.

**Tina:** Do you currently treat any HIV patients?

**Dr. Jemsek:** No, I pretty much had to close it down because of the insurance cancellation and lawsuit against me. When that happened, when the dominant insurance company in North Carolina took away our contract, it spelled the end of my HIV practice. When the insurance company sued me, I lost any reasonable chance for a turnaround. What was clearly vicious and premeditated is that they were just trying to take me out; they didn't have to sue me nine months after the news of a medical board review. That was a kill shot, and as I said, they were just trying to take me out.

Basically, their actions assured that a thousand HIV patients were put out on the street. And we had one of the largest HIV practices in the U.S. and the world, and we were going to double our patient population in four years. We did this with a high standard of practice and very good care in a really good setting. It was our dream to do that. As I say on my website, since there were six practitioners seeing new Lyme patients, we probably also had the largest Lyme and tick-borne illness practice in the country. In late 2005, we were seeing eighty to one hundred new patients a month for possible tick-related illness.

Our case is still ongoing and it will probably take another two to three years to resolve. History will judge us for what we've tried to do and I'm fine with that. I don't totally understand it and I don't try to understand it anymore, but there's a reason I've been put in this position. I also have a sense that people are attracted to my story because Americans like underdogs and resiliency. So, I believe that there's a reason I lost my HIV practice, but now I have a new love in medicine and an incredible challenge.

One of the real tragedies about this epidemic is to think about all the sick people who are clueless about their illness and lead wasted lives, or worse, know their illness and can't access care. And then to consider the sheer size of the epidemic is simply staggering. Even with more efficient models of treatment at our clinic, it still takes a couple of years to get people really better. So, anyone can do the math. It's horrible to consider, but this epidemic can bring our nation to its knees.

The Lyme epidemic is going to forever change how we look at chronic illness. We're going to have to get out of the patch-and-pay model that we have and get into real answers. And if we were all really pulling together and trying hard to get answers for complex patients, we would be well on our way to making significant progress. As it is, the politicization of this epidemic and the corporatization of health care have literally put us twenty years behind, and in the end, this indifference to the human condition will have victimized millions.

**Be sure to read Part Two in July**