

The Cost of Lyme Treatment: Priceless

by *Ginger Savely, DNP* (From the October 2009 issue of *Public Health Alert*)

A critique often voiced by those who don't believe in the existence of chronic Lyme disease or in treating it with long-term antibiotics is that the health care providers who do are motivated primarily by financial gain. Practitioners who specialize in the treatment of Lyme disease are looked down upon by those who would believe that Lyme is an easily - treated condition. "Lyme-literate practitioners" (LLPs) are accused of convincing patients that their condition is chronic yet treatable in order to assure themselves of a steady income source. So, it comes as no surprise that patients question why LLPs do not accept insurance and why they charge higher fees than regular family doctors. Let's take a look at this.

As an LLP myself, I can attest to the fact that there would be far easier ways to make a living if money were a primary motivation. Living under the specter of the ever -looming regulatory boards is wearing and many of us, including myself, have sacrificed valuable time, energy and funds to defend ourselves to these bodies. Furthermore, it is demeaning to be ridiculed by medical peers who often treat LLPs with disrespect and deride them for practicing "fringe medicine." My children are upset when they Google my name and read unkind posts accusing me of being a quack and taking advantage of patients, when they know that nothing could be further from the truth. Moreover, tick-borne disease (TBD) patients are not the easiest patients to treat. As is the case with all of the chronically ill, there is considerable emailing, phone calling and "hand holding" time that never goes onto the record books. There is no charge for the many time-consuming services that occur between visits.

LLPs are few in number and strive earnestly to keep up with the scores of Lyme patients who are desperate for treatment and unable to find it. Consequently, they are overworked and must struggle to fit patients into their already-busy schedules. LLPs overbook their schedules not to increase revenue, but rather to help an underserved patient population that has been disenfranchised by most of the medical community.

All LLPs are volunteer part-time educators and public relations emissaries who donate their valuable time for interviews, public forums, community presentations and speaking at medical conferences to enlighten their fellow practitioners. In order to continue to be able to treat their underserved population, LLPs must work diligently to cover their bases with flawless documentation and find the time to conduct and publish research studies.

Comparing the Cost of LLPs with the Cost of Primary Care Providers

In the world of medicine, all specialists are more expensive than primary care

providers (PCPs) because their training is more extensive and they deal with higher risk populations. LLPs are specialists, but if you look at the cost per minute of a visit with an LLP you see that their costs are no higher, in fact usually less, than those of a PCP.

A PCP charges on the average about \$85 for a regular office visit and spends an average of 7 minutes with the patient. This would translate to about \$750/hour. A survey I conducted of 15 LLPs a few years back revealed charges per hour to be anywhere from \$350 to \$650. And keep in mind that unlike the PCP who deals with simple problems with textbook treatments, the LLP is flying without a net, treating complex patients with numerous infections and a range of debilitating symptoms that must be addressed. Because of the complexity of TBDs and the time needed to handle all of the problems, an LLP is able to see only about 10 patients per day. When I worked as a primary care provider it was typical to see 40 patients per day!

The Cost of LLPs Versus the Cost of other Specialists

Now compare the charges of an LLP with those of other specialists. The following charges have been reported to me by my patients. Half hour yearly physical with an internist: \$500. Half hour visit with a cardiologist: \$395. Half hour visit with a pain management doctor: \$352. Cognitive testing by a psychologist: \$450/hour. Fifteen minute visit with an infectious disease doctor: \$250. Fifteen minute visit with a dermatologist: \$240.

Some of you may be saying "Yes, but at least other specialists are on my insurance plan so I can just pay a co-pay!" Think again. When was the last time that the best specialist in town for a certain problem was actually on your insurer's preferred provider list? People often have to go outside of their insurance plans to see the providers who are the best in their field. If you have a tick borne disease and you want to get better, you will want to see an LLP. You would go outside your insurance plan to see the best cardiologist around if you had heart disease, wouldn't you? Then of course you'd want to see the person who can best help you regain your life after you've lost it to tick-borne disease.

I can think of no other area of medicine where practitioners must squander their valuable time in defensive posturing. LLPs spend countless hours defending their treatment approach to regulatory boards, insurance companies, pharmacies and fellow medical practitioners. Unfortunately, some of the costs of these endeavors must be passed on to the patient. So you are not just paying for your medical care, you are also paying for your right to have it.

LLPs prescribe medications that are FDA-approved but not formally indicated for the diseases they treat. They also prescribe them in higher dosages and for longer periods of time than is approved by health insurance companies. Therefore, an inordinate amount of time must be spent obtaining insurance prior

authorizations for patients' medications. When LLPs finish seeing patients at the end of the day, their work is far from done. Letters and forms must be completed to convince insurers to cover the medications that are being denied to their patients. Furthermore, due to the symptom severity of tick-borne disease patients, many are forced to file for disability insurance. Letters and documentation for social security and private disability insurers is another time-consuming task for the LLP.

Why Don't LLPs Accept Medicare?

Medicare reimburses about \$40 to \$75 per office visit, regardless of time spent with the patient. Since a follow-up visit for high blood pressure will often only take 5-10 minutes, a PCP is able to see Medicare patients and pull in enough income to keep his practice open. Since TBD patients spend 30-60 minutes at their follow up visits, you can see that an LLP would soon go broke seeing these patients. And if LLPs can't make a living, Lyme patients will have no place to turn.

The other downside to treating Medicare patients is the "Medicare police" who have the right to sequester patient medical records based on nothing more than an anonymous tip that there may be wrong - doing. The Medicare police may then proceed to issue huge fines for simple omissions in record keeping, and can easily bankrupt the doctor by these audits.

Dr. Joseph Burrascano, the well-known "Lyme warrior" from New York has told the story of several of his physician friends who were subject to Medicare audits which resulted in their spending \$150,000 to \$250,000 on legal fees, in the end to have Medicare exonerate them with an apology! He knew an entire multispecialty group that went through three years of audits requiring photocopying and submitting tens of thousands of charts. In the end, all doctors in the group were forced to declare bankruptcy while Medicare simply apologized and said they had found nothing wrong. By then, the damage had been done and there was no avenue for restitution. So, it is not hard to see why LLPs, as well as many other specialists who take care of complex diseases, are unwilling to accept Medicare patients.

What About Other Types of Health Insurance?

The reasons that LLPs do not accept PPOs or other private health insurance are that 1) reimbursements for office visits are too low to cover office costs, considering the duration of the visit, 2) office overhead costs are higher due to the extra staff needed to file for insurance and follow up for missed payments, and 3) association with these insurance companies may increase the LLP's risk of being reported to the regulatory boards. Insurers are less than pleased with the amount of money they must reimburse to treat chronically ill Lyme patients and are motivated to see that LLPs are silenced.. Additionally, some LLPs have actually been dropped by health insurance companies due to their non-traditional

prescribing practices.

Summary

Being an LLP is not just a profession -it is a calling. Those who treat chronic Lyme disease devote their lives to the illness with a passion seen in few areas of medicine. Their tireless advocacy work assures that you, the patient, will be able to continue to receive the treatment you deserve even if your LLP has to put himself at risk for providing it. LLPs make sacrifices to a cause on a battlefield that has no place in health care. Far from being overpaid for the work they do, they provide a service that is priceless.