

**Summary of  
Letters of Testimony**

which were sent to Assemblyman Richard N. Gottfried, Chairman, New York State Assembly  
Committee on Health, for inclusion with the records of the hearing on

**Long Term Antibiotic Treatment of Lyme Disease**

which took place at the New York State Assembly, November 27, 2001

Compiled by

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## **Description of this compilation**

We read nearly 450 of the letters of testimony which were sent to the NY State Assembly hearing on Long Term Antibiotic Treatment of Lyme Disease, held November 27, 2001, and we collated information contained in a random selection of 344 of those letters to look for patterns. One third of the testimonies were in questionnaire form, but most were written as letters. Our forms for recording the information were set up first based on the questionnaires, and additional fields were added as we found additional groups of data. For a few categories added later in the analysis, fewer letters were reviewed. A total of 264 letters were reviewed for all categories. We did not design the questionnaires; we only compiled what is in them. That so much of the same information that is tabulated in the questionnaires is also written in the letters indicates how much consistency there is in the type of problems reported, even without prompting by a prepared questionnaire.

While we do keep in mind that this patient population is selected for their need for longer-term antibiotic treatment and for their willingness and ability to write letters or their capacity to have letters written on their behalf, they are very representative of a whole group of people who are suffering in frustration and despair. There are lots more out there - we hear new stories all the time. As many of us know, this is a big problem.

On the positive side is evidence that there are some incredible physicians who have saved a lot of these people from complete disability, and, sometimes, even death. These physicians deserve the highest commendation for their persistence in the treatment of their patients with protocols that they have seen work repeatedly even in the face of harassment by other physicians, health insurance companies and Departments of Health.

## **Geographical distribution of the testimonies**

The letters we have compiled have come from 30 states in the US (Figure 1); there are 4 from Europe and 1 is from Canada.

## **Presenting symptoms of Lyme disease**

Lyme disease presents with a wide range of symptoms making it difficult to diagnose. Figures 2 and 2a represent data from 290 patients. Symptoms are listed by frequency with which they were reported. The most common are at the top. As you can see, there is a pretty consistent group of symptoms at the top, including fatigue, joint pain and swelling, difficulty concentrating, headaches, muscle pain or cramps or fibromyalgia or tendonitis and unexplained fevers. Of particular interest is that the rash at the bite site, or Erythema Migrans rash, is only 35th on the list. Patients also reported if they found a tick, a finding that was only 27th on the list. The length of the list illustrates the vast range of physiological systems that can be affected by this infection.

## Count of Patients by State

State	Count
AL	1
CA	36
<b>CT</b>	<b>34</b>
DC	2
DE	1
FL	6
GA	1
KS	1
LA	1
MA	25
MD	16
ME	7
MI	17
MN	3
MO	1
NC	2
ND	2
NH	3
NJ	15
NY	80
OH	25
OR	1
PA	24
SC	3
TN	2
TX	7
VA	9
VT	1
WA	2
WI	5

Figure 1

## Symptom Frequencies

Fatigue, tiredness	213	Cardiac Arrhythmias	13
Joint pain and swelling / Arthritis	194	Trouble with words (Word finding, letter reversal, spelling, v	13
Difficulty concentrating, thinking, reading / Brain fog	176	Sinusitis	13
Headaches	164	Blood pressure Abnormalities	7
Muscle pain / cramps / Fibromyalgia / tendinitis	160	Edema	7
Unexplained fevers, chills, sweats (fever)	145	Damaged heart valve / murmur	7
Eyes/Vision: double, blurry, pain, floaters	143	Acrodermatitis (Peeling skin, skin sensitivity)	6
Tingling, numbness	141	Fainted	6
Insomnia/disturbed sleep - too much, too little	138	Leg paralysis	5
Dizziness / Vertigo	135	Liver abnormalities	4
Neck creaks and cracks: neck stiffness	132	Hyper / hypo thyroid	3
Stiffness of the joints and back	125	Contemplated suicide	3
Ears/hearing: buzzing, ringing, ear pain	121	Bugs under skin feeling	3
Depression	119	Burning of feet	2
Chest pain/ heart palpitations	119	Coma	2
Irritability, Rages, Agitation	118	Heart attack	2
Difficulty walking / leg weakness	114	Prostatitis	2
Confusion	113	Hyperesthesia (Touch sensitivity)	2
Poor balance	113	Scleroderma	2
Sore throat	109	Hot weather makes symptoms worse	2
Trouble speaking	107	Spontaneous abortion	1
Cough, shortness of breath	101	Immune compromise	1
Swollen lymph nodes	100	Allergies Developed multiple	1
Mood swings	99	Altered sense of smell or taste	1
Eyelid/ facial twitching/ Bell's Palsy	99	Arm weakness	1
Disorientation: getting lost, going to wrong place	98	Pericarditis	1
Tick bite	96	Bruising	1
Nausea or vomiting	95	Paranoia	1
Photophobia	95	Stroke	1
Unexplained weight changes (loss or gain)	94	Diabetes Exacerbated	1
Stabbing sensations	94	Congenital cataracts	1
Tremors	90	Developed high cholesterol	1
Diarrhea or constipation	90	Increased susceptibility to other infections	1
Personality changes	87		
Rash at bite site	86		
Irritable bladder or bladder dysfunction	82		
Gastritis	82		
Rashes at other sites	81		
Loss of libido	79		
Abdominal cramping/ pain	77		
TMJ	73		
Difficulty swallowing	67		
Hair loss	57		
Memory loss	55		
Loss of appetite (difficulty eating)	54		
Other pain	53		
Menstrual irregularity	52		
Swelling around the eyes / Dark circles	50		
Cystitis	35		
Flue like symptoms / Malaise	35		
Seizure activity	31		
Pelvic pain	27		
Neurological symptoms (general reference)	22		
Anxiety	18		
Weakness not limited to arm / leg	18		
Reduced coordination / weakness	17		
Muscle Twitching	16		
Hyperacusis (Sensitive to sound)	16		
Testicular/pelvic pain	14		
Back pain	14		

**Figure 2**

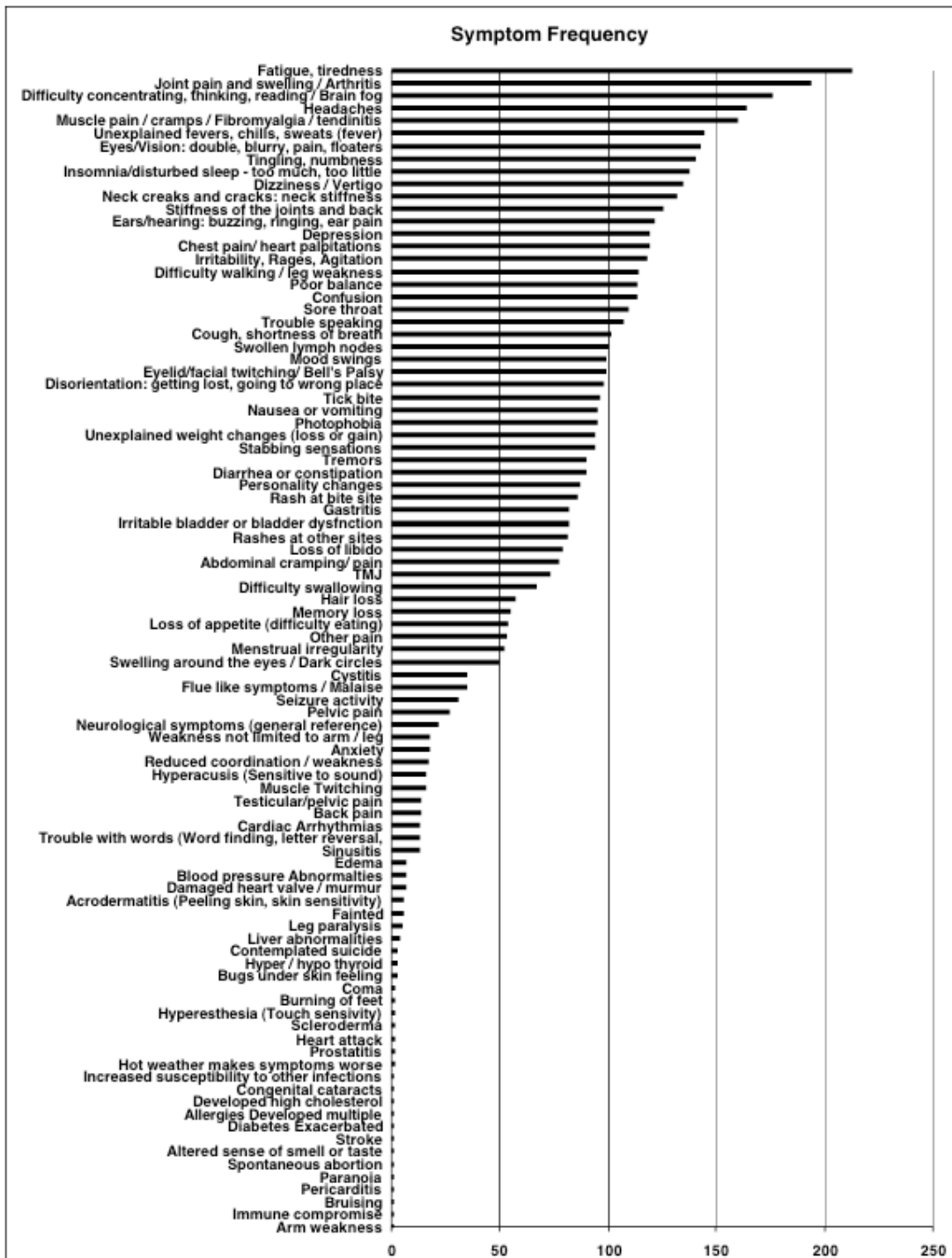


Figure 2A

## **Serological Testing for Lyme disease**

Since many physicians don't understand Lyme Disease well enough to be able to diagnose Lyme from symptoms, there is a strong inclination to rely on serological testing in order to make a diagnosis and even start treatment. This is done even though the CDC specifically states that Lyme should be a clinical diagnosis, and it is well known that serological testing for Lyme is notoriously unreliable. Among the group of patients who discussed their Lyme serological test results, there was inconsistency in the response to the results by physicians. Even a "CDC positive" test was sometimes read as a "false positive" and treatment denied.

Some doctors refuse outright to test a patient for Lyme Disease, even if they request it. Patients are often ridiculed for making the request and at least 22 patients were assertively told, "there is no Lyme here" (even one is too many, especially in this era of widespread travel). In at least one case this defiance and denial of Lyme persisted even when on autopsy *Borrelia* was demonstrated in the brain of a patient who had died in their care after being denied Lyme tests repeatedly (letter # 293).

## **Misdiagnosis of Lyme disease**

Resulting from this confusion, and compounded by a dominant set of "official guidelines" (Practice Guidelines from the Infectious Diseases Society of America and The American College of Physicians) for diagnosis and treatment of Lyme Disease which don't necessarily correspond with what doctors see in presenting patients, a lot of the patients who ultimately respond to antibiotic treatment for Lyme are initially misdiagnosed. Figure 3 illustrates the array of misdiagnoses given to Lyme patients and the frequency with which they were reported. The consequence of misdiagnosis is delayed treatment or worse, a treatment for the wrong illness, which causes them to become sicker.

## **Finding a physician who is knowledgeable enough to diagnose and treat Lyme disease**

This problem with diagnosis has caused too many patients to have to go from one doctor to another without finding relief. Patients reported seeing between 1 and 50 doctors (2 reported 50) before receiving a diagnosis that resulted in more successful treatment (figure 4). The median number of physicians seen was 8 (mean, 10)\* and, frequently, each physician gave a different diagnosis. This should not be the case with a disease that is so widespread. This reflects a major problem with medical education.

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\*We have chosen to report both the mean and the median because of some extreme numbers that skew somewhat the mean. In these cases, the median is probably a more reliable statistic for comparison.

## Misdiagnosis Frequencies

Fibromyalgia	87	Neuropathy (nerve problems)	2
Chronic Fatigue	71	Obsessive compulsive disorder	2
Stress	69	Chondromalacia	1
Other psych problems (Hypochondria, etc.)	53	Cellulitis	1
Multiple Sclerosis (MS)	42	Stroke	1
Depression/anxiety disorder	30	Chronic UTI	1
Not Lyme-don't know what	28	Sun rash	1
Arthritis	21	Cancer	1
Lupus	18	Bug Bite	1
Doctors baffled	17	Bronchitis	1
Sinus infection	15	Sun sensitivity	1
Bipolar/Manic depression	13	Swimmer's ear	1
Anxiety Disorder	10	Back problems	1
Rheumatoid Arthritis	9	B12 deficiency	1
A Virus	8	Tonsillitis	1
Allergies	8	Tourette Syndrome	1
Migraine	7	Ankylosing spondylosis	1
Gastritis	6	Vision problems	1
Mononucleosis	6	AIDS / HIV	1
Osteoarthritis	6	Whiplash Injury	1
Tendonitis	6	Brucellosis	1
IBS Irritable bowel syndrome	5	Guillain-Barre	1
Asthma	5	Myofascial Pain Syndrome	1
Menopause	5	Mycoplasma fermentans	1
Spider bite	5	Orthopedic problems (surgery suggested)	1
Post Lyme syndrome	4	Ovarian Cysts	1
Cardiac Arrhythmias	4	Mercury toxicity from fillings	1
Ear infection	4	Poison Ivy	1
Epstein Barr	4	Meniere's disease	1
Pneumonia	4	Problems from a car accident	1
Thyroid disorder	4	Yeast infection	1
ALS/ Lou Gehrig's Disease	4	Reflex Sympathetic Dystrophy Syndrome	1
Interstitial Cystitis	3	Reynaud's Syndrome	1
Flu	3	Scleroderma	1
Diabetes	3	Hodgkins Lymphoma	1
Chron's Disease	3	Skin Infection	1
Chronic pain	3	Gout	1
Brain Tumor	3	Glaucoma	1
ADD / ADHD	3	Rheumatic fever	1
Disc displasia	3	Rocky Mountain Spotted Fever	1
TMJ	3	Scabies	1
Old age	3	Endometriosis	1
Senile Dementia	3	Encephalitis	1
Parkinson's	3	Sciatica	1
Shingles	3	Hypotension (Low blood pressure)	1
Gall bladder problems	2	Sjogrens Syndrome	1
Cardiac problems	2	Cytomegalovirus	1
Eye infection	2	Hypoglycemia	1
CNS disorder (Incl. Brain damage)	2		
Schizophrenia	2		
Heart disease	2		
Epilepsy	2		
Fungus (rash)	2		
Chostrochondritis	2		
Growing pains	2		
Anemia	2		
Ulcerative Colitis	2		
Strep Throat	2		
Myaesthesia Gravis	2		
Conversion Rx	2		

Figure 3

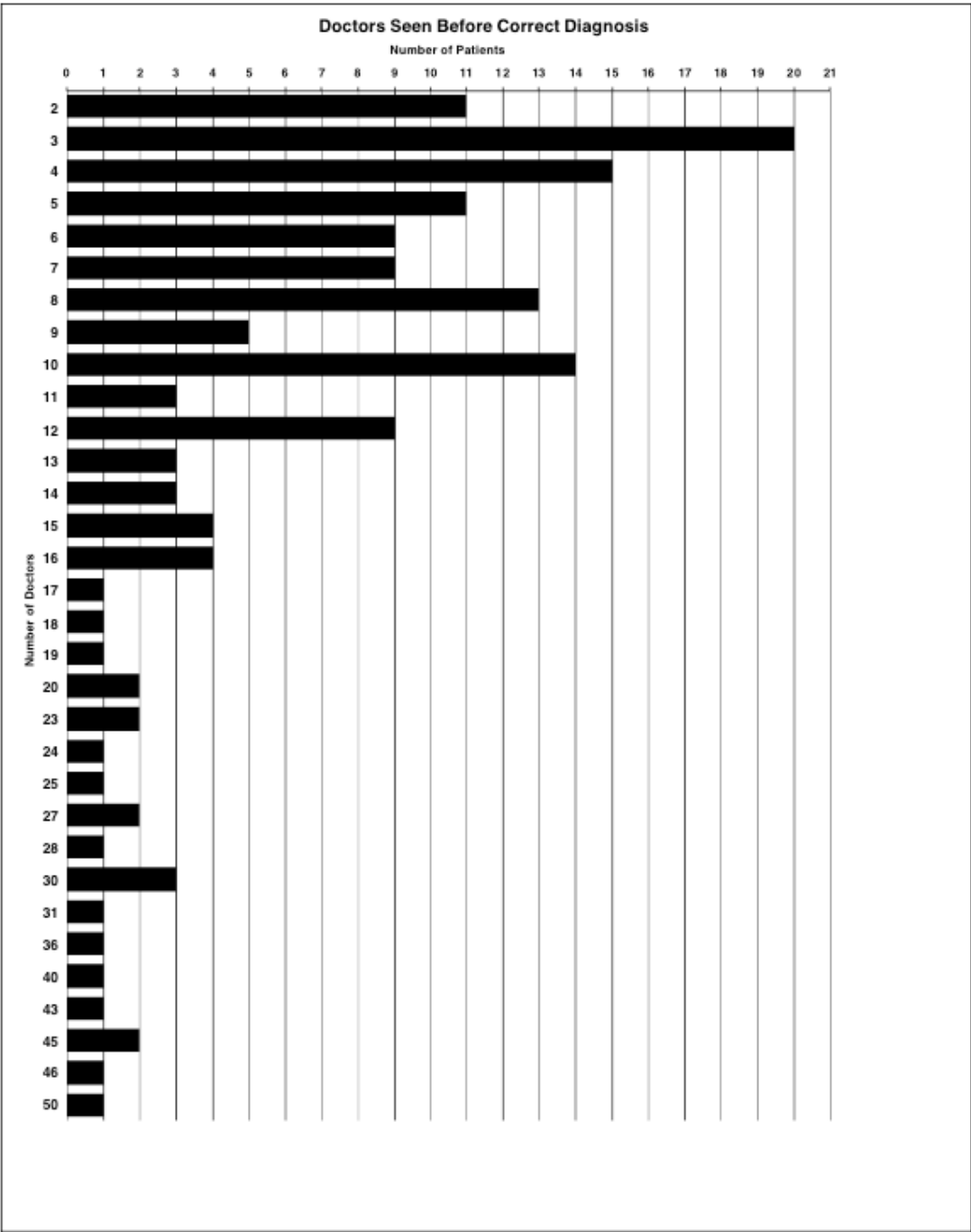


Figure 4



Because of the dearth of doctors around the country who could diagnose or treat these patients, at least 53 patients reported having to travel long distances (sometimes hundreds or even a thousand or more miles) to receive care that finally helped them, after they found no relief from local doctors.

### **Treatment delays**

As a result of these delays in diagnosis and treatment, the length of time it took from the onset of symptoms to when patients were finally diagnosed and treated ranged from 0 to 46 years with a median of 4 years (mean, 6.1 years)\* for 246 patients.

For 145 patients who reported that they lost their ability to work, the median delay to diagnosis was 5 years (mean, 7 years)\*. For 18 patients who reported that they partially lost their ability to work, the median delay to diagnosis was 3 years (mean, 4.5 years)\*. For 32 patients who never lost their ability to work, the median delay to diagnosis was 2 years (mean, 5 years)\*. Although delay to diagnosis affects disease severity, another important factor is the extent of treatment that a patient receives once they are diagnosed, and whether treatment is continued or reinstated when symptoms either do not resolve or return.

### **Undertreatment of Lyme disease, symptom persistence, symptom relapse and disability, sometimes death**

Once Lyme is diagnosed, patients often do not receive enough antibiotic treatment to eliminate their symptoms completely. 77 patients were told after six weeks or less of antibiotic therapy that they could not have Lyme Disease any more even though their symptoms had not completely resolved. 62 of these reported that they lost their ability to work, and 22 of those reported that they never regained their ability to work.

In some instances, patients have resolution of their symptoms at the time of treatment, but the symptoms return, without reinfection, within varied periods of time following treatment termination. This relapse can happen after a few days or after years. 89 patients report this phenomenon of relapse. The relapse may occur after one or more courses of treatment.

Some individuals who were denied retreatment either were able eventually to find someone to retreat them or deteriorated, sometimes becoming irreversibly disabled. Furthermore, so far we have found records for 5 patients who died from Lyme Disease, two of them children. The stories of incompetence and callousness in these cases, and, in particular, the philosophical regard of her experience by one of the children, reduced us to tears.

Of the patients we have entered so far, 167 lost the ability to work (or to attend school, in the case of children) because of Lyme. Of those, 67 regained the ability to work and 13 partially regained the ability to work (could now work part time or at least could do household chores).

### **Antibiotic maintenance required in some cases in order to function**

A total of 56 patients report still being maintained on antibiotic treatment, because without it, they would be unable to function. Some of these people never lost their ability to work, but some did. However, as a result of continued treatment, most are able to lead productive lives. Such is the significance of their antibiotic treatment.

### **Infection in-utero**

We found 8 reports of infected mothers who delivered children who had been infected in-utero.

### **Humiliation of Lyme disease patients by physicians**

Coupled with underdiagnosis and undertreatment of Lyme is a reprehensible and remarkably unprofessional position taken by too many doctors that Lyme patients must be exhibiting all these symptoms because of some psychiatric problem. The number of patients who were humiliated by their doctors for having Lyme symptoms is astounding. We have counted 60, and some of the records we looked at earlier were not included in this count, since this was not one of our original categories.

While depression and an assortment of neurological problems can be organic symptoms of the disease itself, too many doctors tell their patients that the depression and other symptoms are the result of some hypothetical emotional problem in their lives. They are accused of hypochondria, told to improve their sex lives, or directly referred to psychiatrists. In more than one case when a patient was sent to a psychiatrist, the psychiatrist was the person who diagnosed their Lyme Disease and got them proper treatment. What is shameful is the number of children, sometimes honor students, who are accused of malingering and are humiliated deplorably. Parents are fighting exhausting battles to get their children treatment and an education, some of those parents are sick with Lyme themselves.

### **Some would rather die than live with symptoms, with some suicide attempts**

Another relevant statistic is that 16 people volunteered that they would have rather died than continued to live with their Lyme symptoms. Several contemplated suicide, and two actually did attempt suicide. In a similar context, many stated that they felt their Lyme Literate doctors had saved their lives with their treatment (see pages of quotations below).

### **Representative letter**

We are including the following excerpt from a letter from a Connecticut resident (letter #305) because it is a clear representative of the type of story which was written repeatedly in these testimonies.

I was diagnosed with Lyme in 1997. The diagnosis came after almost a year of misdiagnoses involving many doctors and costly treatments. Unlike the doctors before

her, the doctor who finally diagnosed me carefully considered my clinical history, not just my seronegative blood work. This was fortunate. Others I know with similar stories are less fortunate, enduring years before being diagnosed and treated. Seemingly, the longer the patient goes undiagnosed, the more difficult the Lyme case is to treat.

When I was told I had Lyme, I could barely walk. The nerve pain that I had experienced in my neck and arms for almost a year had moved to my legs. Nothing helped. Not the physical therapy. Not the pain medication. And the MRI's and CT scans lead nowhere. Within three weeks of taking Biaxin, my nerve pain began to subside and the pain seemed to relocate itself into my wrists and knees. Though I experienced debilitating weakness, this and all of the nerve and joint pain gradually subsided over time while on the antibiotics. But it took a long time - - on the order of years, not weeks. Whenever treatment was stopped I could distinctly feel the symptoms reappear, at first immediately, but with each successive treatment it gradually took longer and longer for the symptoms to reoccur until I ultimately achieved nearly one hundred percent. I was fortunate to have found an open-minded doctor who persisted and continued to treat me until I remained symptom free when off antibiotics. This helped facilitate a relatively normal life for me and minimize the loss of time at work, a fortune 500 company, where I now head up a legal department as Chief Patent Council.

### **The value of scientific and medical information published on the Internet**

We have found that patients or their friends or relatives often found solutions by searching on the Internet trying to understand symptoms, which were not properly managed by doctors they have seen. In this way, some finally found relief. It was heartening to hear that some of these patients had empathic physicians who were willing to follow a different treatment protocol once they learned about it. Other patients found new doctors once they realized the type of treatment they needed to look for. This reinforces the observation that doctors don't have enough training about effective recognition and management of Lyme disease. In one case, once a California physician saw her patient improve on antibiotics prescribed by a Lyme literate doctor, she was able to diagnose and treat 6 other patients successfully. However, as a result, her peers ostracized her at her local hospital (letter #336).

### **Patient quotes about their Lyme Literate Physicians**

Since the NY State hearing was intended to defend physicians who are treating Lyme with long-term antibiotics, many people commented in their letters about how they felt about the doctors who had finally treated them successfully (also referred to as "Lyme literate" doctors). Included in the following pages is a list of exact quotations from many of the letters about how these patients felt about their doctors.

## Statements made by Lyme patients about their Lyme Literate Doctors

Letter number – Patient number in letter \*

Quoted Statement

1-1\*

I am DNA positive for Lyme infection and receiving prolonged antibiotic care with decreasing symptomology all the time. Without this prolonged antibiotic protection, the spirochetes would repopulate within me and cause further deterioration and damage.

2-1\*

Now, because of the OPMC investigations, my physician is pulling me off my medication, despite my progress, for fear of losing his medical license. I don't know what will happen to me now.

3-1\*

No LLMDs in Louisiana. Doctor and I following studies from national library of Medicine; but with no LLD to talk to, we are missing the boat. Getting worse. Could easily die.

4-1\*

LLMD was prosecuted in 1993 and again in 99/2000 by NY and NJ OPMC. He won. The OPMC appealed. He won again at his personal expense. If it weren't for the dedication of our Lyme doc all would be deathly ill. With treatment we are all back in school. I would be dead now and so would be my husband.

5-1\*

My LLMD has saved my life. I almost died several times while treated by Lyme illiterate physicians.

6-1\*

I just started going to an LLMD 2 mos ago. Finally feel as if I'm seeing a real doc. Worried insurance won't pay all treatment.

7-1\*

The Lyme doctor (I found through a Lyme support group right away) treated me for only 10 months and got rid of me because he was harrassed and got rid of all his Lyme patients. My treatment wasn't over. I was getting on my feet, now I'm going back to the way I was.

8-1\*

Without them we would be devastated. Perhaps we would be attending a funeral right now if not for the doctors. Now you know the difference between life and death? That is the difference between having a Lyme doctor and not having one.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

10-1\*

[Is being treated by a known LLMD] I have tolerated the treatment well and have lived a productive and full life. Had I not been able to take antibiotics, I'd probably have deteriorated medically, to have a condition that looks similar to MS. In fact, I might not even be alive.

11-1\*

He has helped to get me on my feet. If he stops my treatment, I will become extremely sick.

12-1\*

My LLMD is a godsend to me. She understands the difficulty of treating this disease in its entirety. She never considers me a hypochondriac or my symptoms bizarre ... I would feel helpless and devastated if she could not treat me. She has made a huge difference in my life and so have the 24 months of antibiotics.

15-1\*

I feel much better now thanks to the doctors who believe that the antibiotics would help me. Please don't take our help away.

15-2\*

Please don't stop our only treatment.

15-3\*

Without all of these antibiotics and doctors who believed, I would not be as well as I am today.

16-1\*

My doctor has stuck with me for the last nine years. Originally, I was treated with short courses of antibiotics, but always got sick again. Until I found her, I never felt as good.

17-1\*

I was referred to the best Lyme physician in the country immediately after I was diagnosed with Lyme in 1993. At that time, I was an invalid on my way to the nursing home. Now I am able to be a productive and vital member of society. My physician saved my life.

18-1\*

My doctor has given me hope that I will get better. My quality of life greatly improved while I was on IV antibiotics. My doctor will continue to help me no matter how long it takes me to get better. If my doctor was not allowed to treat me for Lyme, my quality of life would be horribly diminished. I would not be able to function at all because the nausea, vomiting, chills, pain and fatigue would consume me.

19-1\*

My LLMD saved my life. I would be dead without his treatment.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

20-1\*

I would probably be close to death and unable to walk, move, think, speak, or function at all.

21-1\*

If I had not found doctors who were knowledgeable, I would be in a wheel chair or dead.

22-1\*

If I could not be treated for Lyme, I would feel more hopeless and somewhat doomed to possible worsening health problems which would impede my ability to work and function normally.

23-1\*

No one could help me until I found [my LLMD]. Now after four months of treatment with Rocephin and Flagyl I am able to do light chores and spend time with my children. 5 months ago I was bedridden 24/7 with great difficulty even to go to the bathroom.

24-1\*

[My LLMD] has helped me regain my health through long-term antibiotic treatment, even though I am still unwell I am much improved.

25-1\*

My doctor now is amazing. He saved my life.

26-1\*

Would probably have gone crazy or killed myself by now without treatment. I thank God for my ability to function now. All I wanted to do was get better. At 31 I felt 85. Doc kept me from becoming completely deaf in one ear and if it weren't for treatment, I know I would be dead.

27-1\*

LLMD is an angel doc. Would not now be alive without the treatment I am receiving.

30-1\*

If I could not be treated by this wonderful doctor, my life would be over. He has saved me from a lifetime of dependency. I already have a lot of permanent brain damage and may one day have to depend on others for my care. This is a terrible disease to be stuck with forever. Our LLMDs are our only hope.

32-1\*

Our doctor saved our lives. We have resumed nearly all our former activities and enjoy life. At least 3 of us would have been permanently crippled.

33-1\*

If I hadn't been treated for Lyme the way I was, I know for certain that if I weren't dead, I'd want to be. I was in incredible pain and confusion for a long time and had to drop out of school. Thanks to my treatment, I'm well after three years of injections.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

35-1\*

He saved my life.

36-1\*

I would most likely not be alive today.

39-1\*

Saved my life. (Kid says my doctor has helped me a lot.)

40-1\*

My doctor has helped me to get my life back. I am so much better than I was. I am able to do things with my family that I haven't done for years. Without tx I can only guess what my life would be like. I can see improvement as the months go by. Thank God for long term antibiotics.

42-1\*

Eventually, I got good treatment in New York State however, without this treatment, I believe I would be dead.

43-1\*

I had one Dr. since ....who treated me 3 years ago aggressively orally for 6 mos. after a relapse from a flu shot. He died and no other Dr.[in Georgia] will touch me.

44-1\*

If I could not find a doctor to continue to treat my Lyme Disease, I would have to go onto disability and probably be homebound.

46-1\*

I thank him for every "good" day that I have. I hate to think how I'd be feeling if I had listened to the other specialists when my symptoms were worsening.

47-1\*

If my Lyme Disease doctor was not able to treat me with antibiotics, I would probably not be able to walk, drive a car or take care of myself and family and household duties. I would also be in severe pain. The pain could be all over my body.

48-1\*

I would probably be dead.

49-1\*

I would be dead if I did not have a LLMD. This is the only hope I have to continue to live and have any decent times.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

50-1\*

[My LLMD] began my return to health and functioning. His care was the first to give me back my life. Thanks to [my other LLMD] I am able to walk and live a normal life.

52-1\*

I would still be so sick.

53-1\*

If it wasn't for my Lyme Literate doctor, I would not be back working at my teaching job, and I would not be functioning at all.

54-1\*

I wish to thank [my LLMD] for his concern and care for my family and myself when we were so critically ill.

55-1\*

When I finally found a physician who understood the serious nature of the disease my health had deteriorated drastically. I have had to travel over 30 miles for treatment with Lyme Literate doctors, because there were none in my area. Local doctors' ignorance on tick-borne disease has caused my family and myself an unnecessary toll of inhumane suffering.

56-1\*

Thanks to the Lyme knowledgeable physician, I have my health back and I live a meaningful and productive life.

61-1\*

Long term antibiotic therapy gave me back my health and a meaningful life.

62-1\*

I saw a Lyme specialist who listened to my story with knowing appreciation. In subsequent consultations, it became clear that this was the first person who had seen my combination of symptoms before (many times!) and had some tools available to help. This is in marked contrast to all the other doctors who were puzzled from the very beginning. The Lyme specialists I have met are, to a man, caring, dedicated professionals who are as prudent and responsible as the many other doctors I've seen. To suggest otherwise is at best ignorant or at worst malicious.

63-1\*

Thank God there are some doctors that will do what is morally and ethically right...treating patients in the best way they know how, even if it is at a great personal and financial expense to themselves. If it weren't for [my LLMD's], the Rusk Institute of Rehabilitation as well as other doctors that treat chronic patients, I don't know where I would be.

\* Note: Doctor's names have been removed for their protection.



## Statements made by Lyme patients about their Lyme Literate Doctors

64-1\*

I have already lost one doctor who had his license taken away in 1999 and now my current physician, [...], is in danger of losing his simply because he advocates long term treatment for this chronic disease.

65-1\*

[had one physician who diagnosed and treated and was improving; went to another who said it wasn't Lyme, wouldn't treat, and he deteriorated to where he left his family and now has to live in an assisted living community]

66-1\*

I'm sure that had my doctor not provided quick and aggressive treatment, I would have become incapacitated and unable to keep my job. Because of the continued intervention, I have missed only 2 days of work in over 2 years.

67-1\*

I owe [my LLMD] a huge debt of gratitude for the care he has given me. My greatest fear is that my current health and success will be lost as a result of inability to obtain treatment for this chronic illness.

69-1\*

My family has been fortunate to be under the care of several of these brave and compassionate physicians. It has cost us a small fortune in medical costs, lost time at work and school, tutoring and special education, but we have regained a quality of life that can't be measured in dollars. We will be forever grateful to the physicians that worked so diligently to help us regain our health.

71-1\*

Within six months of continuous treatment I was finally back to my old life. I thanked my lucky stars that I found a doctor with the knowledge to treat this awful disease. My life depended on this treatment and I'm lucky. Please do not turn your back on the controversy of properly treating this fast spreading disease.

72-1\*

If physicians who do not adhere to the three week approach for treatment are being accused of medical misconduct, how will Lyme patients find a doctor willing to treat them in the method that has proven so successful for me?

73-1\*

Finally I decided that I would go see a Lyme doctor, no matter what other doctors said... Little by little I have been getting better. If I didn't get treatment I truly believe I would be in a home being cared for. In March I couldn't cut my own meat or fasten the buttons on my coat... I was looking into wheelchairs, hospital beds and invalid toilet seats because I just kept getting worse.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

74-1\*

I never could have regained a closer relationship with my children, improved my company's stability level, or lived a much fuller life if it wasn't for the antibiotic treatment and other Lyme therapies I received from my Lyme doctor.

75-1\*

We must now necessarily travel out of state for what we consider to be appropriate treatment... after we finally find doctors who actually take the time to listen to our histories, and who are open-minded enough to treat us with a protocol that works, even if it flies in the face of mainstream practice, these very doctors (and some of their progressive peers) are being targeted for investigation?... These progressive practitioners are all that stand between us and an awful, miserable existence.

76-1\*

[does not have an LLMD and is getting sicker]

77-1\*

My doctor who treats me for Lyme was able to take me from a non-functioning person to someone who can contribute once again to my family. I am not well enough to work, but at this point I can care for my three children.

77-3\*

My daughter is 10 years old and antibiotics have returned her childhood to her. Her LLMD relied upon symptoms to assess treatment, not tests.

79-1\*

Without the support of these Lyme-literate physicians, without their knowledge, their compassion and their determination to treat us in the face of a hostile medical establishment, my daughter would be left to wither and die, in pain.

80-1\*

Researchers who look into Lyme and physicians, who treat it, are knocked out of business. Do you understand how terrified I am? In addition, almost daily I meet people I believe may have Lyme disease. I can't help them, though. Where do I send them for a valid test, a knowledgeable physician, and medicines that offer them a cure?

81-1\*

Please support the only doctors that are helping other Lyme victims and me. If these doctors are unable to practice we have nothing but suffering and misery. We cannot live like that. I completely support all the Lyme-literate doctors who are trying to help us. I hope you will join me in this effort.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

82-1\*

It was through [my LLMD]'s never ending attempts and research into finding the right answers for me that I am able to claim any of my life back at all. I fear that without the support of [my LLMD], and small handful of other Lyme-literate doctors, that I, and others will fall back into the deep sick wells of these diseases.

83-1\*

[Their three doctors are LLMDs who are being investigated by the OPMC] We are asking your help in having the legislature put a moratorium on the hearings of our LLMDs until hearings can be held on the fallacy of the OPMC's position that three to four months of treatments is sufficient to cure Lyme disease.

84-1\*

After months of searching, I found a doctor who could treat me. [Inadequate initial treatment] has cost me thousands of dollars more than it would have if I had received sufficient doses of antibiotics immediately. ... I have complete financial hardship as a result of these circumstances.

85-1\*

In the spring if she is not better, she will begin a frightening and uncertain treatment with a variety of antibiotics. We hope that the OPMC does not target her doctors and prevent her from having this option.

86-1\*

We have a wonderful Lyme literate doctor and he is not being investigated but he may not be around forever. He is 74 years old! I would like to know that some of these very fine New York Lyme doctors WILL be around to treat my daughter if she ever needs them.

88-1\*

I am fighting to regain as much of my old self as I can and I know with my Lyme doctor's help, once again, I will win this battle. I have cried tears of joy almost every day this week because I feel alive for the first time in over ten months! God bless my Lyme doctor.

89-1\*

Courageous! Admiration for the individual that persists in the face of overwhelming adversity! ...I cannot imagine what hell our lives would be without the help of the three doctors that have offered confirmation, medicine, and hope. Without them we would be absolutely devastated. Perhaps we would be attending a funeral right now if it weren't for the doctors.

90-1\*

If it wasn't for his willingness to go the distance, I'd probably still be totally incapacitated.

93-1\*

I'm thankful for finding this doctor who I feel saved his life.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

94-1\*

Our doctor is being investigated by the office of medical conduct within the New York State department of health for prescribing long term antibiotic therapy. [He] is a wonderful, dedicated doctor trying to help his patients live normal lives. His approach is committed to preserving traditional conservative medicine.

95-1\*

I am appalled and terrified by medical authorities' attitude towards advanced disseminated Lyme patients and their struggling doctors. Without constant antibiotics, I would have died several years ago, slowly and painfully.

96-1\*

I have to travel over 400 miles to see the doctor who correctly diagnosed and has been successfully treating me. We have no tick-borne knowledgeable doctors in my area.

98-1\*

Finally, I found doctors that did treat more aggressively and there was some light at the end of the tunnel. Although all my symptoms didn't go away, I was 75% better. I could function on my own with limitations. My quality of life has improved significantly. My doctor, [My LLMD] literally saved my life.

99-1\*

Thank goodness that I have found a physician that will treat me when my symptoms become unbearable and will not let me waste away in bed. These physicians that treat persistent Lyme infection must be allowed to heal us without fear or retaliation.

100-1\*

I owe my present robust health to exactly that [aggressive antibiotic] treatment. I feel I owe my health to doctors who were gutsy enough to go against the "over diagnosis and over treatment" mentality that in time became so pervasive.

101-1\*

I hear that [an LLMD] is accepting new patients. After researching his web site, I know this is the place to go. ... In two months, it will be two years of fighting to be heard and treated properly from the medical community, but at least I know some day, this whole nightmare will subside and I then will get my life back again.

102-1\*

If the doctor I have now wouldn't have seen me or treated me, I cannot imagine where I would be now. I know that the medical community is against long term antibiotics, but until a better treatment for Lyme disease is found, there is no choice.

103-1\*

We will be forever grateful to a doctor who listened to our son and us and did the through investigation to obtain appropriate diagnosis and treatment.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

104-1\*

I am most appreciative of [my LLMD]'s following my progress and his understanding of LD as a chronic and insidious illness which requires more than the two weeks of antibiotics ordinarily prescribed. I have been profoundly impressed with his interest, concern, kindness and thoroughness in his treatment of myself and my family.

105-1\*

There is no way to shorten the seven years of hell I have been living in. It is so frustrating to go to doctor after doctor who can't help me, or refuse to help me, because they are afraid of going against the insurance companies and the medical establishment. What is even more frustrating is finally finding doctors that understand and treat Lyme Disease being investigated and having their licenses revoked. This leaves me and other patients with nowhere to turn but to you.

106-1\*

[I was able] to go to the handful of good doctors that would help. It wasn't easy finding them... The doctors who say Lyme cannot be chronic are wrong. I am living proof of it, and I have met and spoken to hundreds of others like me, many crippled, and brain damaged by this illness. Many are misdiagnosed with illnesses that have no treatment, losing valuable time and life, because Lyme may not be curable, but it is treatable.

107-1\*

Now, because this Lyme Literate Doctor has cared enough to provide me with the length of treatment needed to treat my chronic Lyme Disease, I have been given so much of my life back. Many of my symptoms have disappeared or improved dramatically. I am back to work part time, which is something I didn't think I would ever be able to do.

108-1\*

I am outraged that the excellent doctors who have diagnosed my Lyme Disease, and treated me comprehensively, have been subjected to investigation by the OPMC, while the doctors who fail to diagnose Lyme, and/or treat it as a simple infection, subject to quick "cure" by short-term antibiotic treatment, are not under any scrutiny.

109-1\*

There are doctors that are being investigated for using the same protocol for Lyme Disease that improved my condition. I do not understand this.

110-1\*

Recently, I have had a relapse of symptoms (typical of Lyme Disease) and have had treatment. However, the negative actions of the OPMC on Lyme Disease doctors like [two LLMD's] have put pressure on doctors to not treat chronic Lyme Disease symptoms.... Please help us.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

111-1\*

If it had not been for the care and concern of the doctors who "believe" in this disease as dangerous and life-altering, I would probably have wound up on a couch, on disability and a burden to my family, friends and community.

112-1\*

In addition to worrying about what Lyme is doing to my body, I now have to also worry (and it is scary) about what to do if my doctor is forced to stop treating me.

113-1\*

Today, with the backup support of my physician who truly understands the effects of Lyme and other tick-borne diseases on us humans and the help of the Hyde Park Lyme Disease Support group for many years, I am alive and dealing with life the best way I can.

114-1\*

My doctor recommended continuing treatment until I was symptom free. After eight months of treatment I finally started to see results... This illness impacted my life in a way I will never forget. It hurt me physically, emotionally and financially. The insurance companies would not pay for my treatments, I almost lost my business and it affected my entire family.

116-1\*

The only thing that has helped me is long term antibiotics both oral and intravenous. It has put me back to wanting to be alive. If my medicine is taken away, so is my life and the lives of hundreds of thousands of Lyme patients.

118-1\*

I have found my physician to be dedicated, compassionate and willing to help those like me who had been neglected at the risk of his very livelihood. It was due to dedicated doctors such as he that I was able to return to my profession, programming work, after 18 months of unemployment, to become a productive member of my family and society once more.

119-1\* At present, [my daughter] is twenty-one years old and able to do college work, as long as she stays on high dose oral antibiotics. ..If it were not for the availability of this treatment and availability of doctors courageous enough to administer them, even in the present climate, I do not know if my children would be functioning at all today.

121-1\*

[My daughter's] doctor suddenly refused IV treatment. He did offer to refer her to my doctor [LLMD], indicating that he did recognize the need for such treatment. Why the sudden change? I found out that the OPMC had just revoked a NY State doctor's license for treating Lyme patients more than three weeks!

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

122-1\*

I would be bedridden if not for treatment.

123-1\*

My LLMD has given me some hope. Prior to my being treated by him, I had no hope. I was wasting away.

124-1\*

My son was treated at Children's Hospital in Washington, DC. I am not satisfied with his treatment.

125-1\*

I owe my life to my LLMD! He is the one who diagnosed me and has continued to treat me since 1997. Thanks to him for putting his license and career on the line for all of us, I am able to function at a much higher level than previously. .. If my LLMD were no longer allowed to treat me, it would mean my stopping antibiotics and sliding backwards until I lost my quality of life and returned to being bedridden and/or housebound a majority of the time, like I used to be before finding my LLMD.

126-1\*

I have been on antibiotics for four years and tapered off to 2 per month now. If I had not been given treatment for long term, I can assure you I would not be 95% better and functioning. Experienced several relapses in early treatment without antibiotics.

127-1\*

Believe care now being received has brought me back to be able to walk better and definitely has reduced pain and swelling of ankle and in one foot.

128-1\*

My LLMD definitely improved my well being, and made me realize that good health takes more than luck.

129-1\*

My LLMD saved my life and my husband's life. We would be bedridden by now with[out] his help and unable to work.

130-1\*

This physician literally has saved my life and without his treatment I suspect I would be totally disabled and have no quality of life.

131-1\*

It was an enormous relief to find a doctor who was not only willing to listen, but who understood the seriousness of my condition. I will be forever grateful to the Lyme Literate Doctors. Without their help, which I have received, my quality of life would be unthinkable!

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

132-1\*

Only just started but when not taking high dose antibiotics I am bedridden

133-1\*

Both my son and myself have Lyme Disease. My son became a different little boy after being infected. We were facing behavior problems & learning disabilities labels, but With [LLMD's] help, we are enjoying our little boy again.

134-1\*

I feel very fortunate to have a rheumatologist who is Lyme Literate and thought to further investigate my arthritic and fatigue and depression symptoms by testing for Lyme. I am also grateful that she is willing to treat me and her burgeoning Lyme practice with long term antibiotics even though she had indicated some others in the local medical community do not approve. I am greatly concerned that the OPMC decision in NY may affect my ability to be cured of LD.

135-1\*

Hasn't found an LLMD and says she feels very bad.

136-1\*

I have Lyme symptoms brought on by Lymerix vaccine and don't know if I would get better or sicker from autoimmune LD. Positive HLA DR4 test also.

137-1\*

I feel that I would be housebound if not bedridden

138-1\* Hasn't found one.

139-1\*

Loss of great comfort given by these doctors would be disastrous.

140-1\*

I had to quit my job before I started seeing the doctor who finally treated me.[she was able to return to work, but now retired]

142-1\*

Because I was in the south when I was diagnosed, my doctor was not Lyme Literate, she was following Steere's protocol. She told me a few years ago that she would have treated me for longer if we had.[.rest is illegible.]

143-1\*

Had I not known a LLMD who was treating my wife I may have not received treatment or would have had to cope with the ravages late stage Lyme causes.

\* Note: Doctor's names have been removed for their protection.



## Statements made by Lyme patients about their Lyme Literate Doctors

145-1\*

[My LLMD] has given me a chance to get my life back. 7 years and 28 doctors later he finally diagnosed me with not only Lyme, but also (3 more). I have just started treatment with him but I thank God that I found him. I already see great improvement. He sets an example for all to follow!!!

146-1\*

Without the care of my doctors I cannot imagine how terrible my health would be. Several months of antibiotics is a long time, though I hate to think what my symptoms may have progressed to during this same time span without antibiotic treatment.

147-1\*

The Lyme doctor I had been seeing...said he would not treat me with long term IV antibiotics as he was afraid to lose his license. I have finally found a Lyme specialist who will treat me with long term antibiotics....I don't know what I'd do if my LLMD were not allowed to treat me anymore.

148-1\*

I am extremely grateful there are physicians who care enough about a patient's welfare to provide me with the needed care - I would be disabled without the antibiotics.

149-1\*

I finally found someone who will listen to me and not make me feel like a hypochondriac. He has made me feel that I will someday have a life. I have not felt that for the past seven years.

150-1\*

I would be bedridden or dead by now.

151-1\*

If untreated, I would not be alive.

152-1\*

I have chosen this opportunity ..to acknowledge and praise [my LLMD] for the treatment I received from him. I believe that, without his expertise in the complexities of this disease and its diagnosis and treatment, my condition would have continued to deteriorate and worsen... It was not until approximately 6 months after receiving his treatment that my physical and mental (central nervous system) symptoms began to improve. I cannot thank him or praise him enough for restoring the measure of health I have now.

153-1\*

My doctor who diagnosed my Lyme and treated me appropriately is an angel of mercy who gave me back a near normal life & enabled me to work again.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

154-1\*

I feel if it were not for my LLMD I would be out of work and unable to care for my family. Thank God for my LLMD. He listened and treats based on my symptoms and progress. He has been compassionate, ethical and extremely professional and most of all he has helped me tremendously.

155-1\*

We are very happy with the care of our LLMD - he listened and affirmed and seemed to understand what we were saying about feeling better while being treated with antibiotics - and able to function pretty normally - and understanding what we said about regressing when former MD stopped treatment because "six weeks is enough - you should be better".

156-1\*

My doctor that is treating me now is wonderful ... She is treating the Lyme's aggressively. I'm considered in the late stage neurological area.

157-1\*

[hasn't been able to find one]

158-1\* I love my Lyme doctor. He found I also have Babesiosis and is helping with that... I know I would be very sick today without my Lyme doctor. God bless him for his courage.

159-1\*

If it weren't for the few LLMD's out there and the treatment I received from those LLMD's, I would either be in a nursing home with severe dementia or be deceased.

160-1\*

I would hope to die if I couldn't see my doctor and have hope for recovery - I'd rather die than be this sick  
all the rest of my life.

161-1\*

I am 17. I would not have lived to be 18. I was so ill I was on the verge of either harming / killing myself or another person.

162-1\*

My doctor has learned about LD from me. He has seen me improve with treatment, and now after four years of skepticism, he encourages me at last.

163-1\*

Incredibly grateful! He is valued by all his patients.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

164-1\*

I believe I would have died.

166-1

A late diagnosis has now resulted in this disease being more difficult to treat by my LLMD. Also, this disease seems to continue to progress very slowly even with antibiotic treatment (oral and IV), but at least there is some glimmer of hope left that the right antibiotic combination will be found to cure this strain of Lyme Disease eventually before it results in further paralysis, additional medical problems or death.

167-1

Relieved they would finally help me. Someone took all my symptoms seriously. They are willing to help and are concerned.

168-1\*

I was lucky to find a doctor that was willing to treat me with antibiotics long term. However he made me sign a form stating that it was unconventional treatment due to his fear of persecution.

169-1

Don't yet have an LLMD but if I did, I imagine I would feel great despair and hopelessness if an effective treatment was discontinued.

170-1

I am grateful that there are physicians who know how dangerous and insidious this disease is. My son, who is now 5 is doing so much better. I am frightened to think where he would be without proper treatment.

171-1

I would be dead. I owe my LLMDs who treat long-term my very life.

172-1

With long term antibiotic treatment it gave her her life back.

174-1\*

My treating LD physicians have been terrific. My life would have been a living nightmare if I hadn't been fortunate enough to have been in their care. I am determined to regain my health, and long term antibiotic therapy has been an indispensable part of the process. It is so important that these doctors be allowed to practice. Many people's lives depend on them.

175-1

I am very grateful to be on long term antibiotics and feeling much improved! I am angry that I cannot think as clearly and multi-task the way I used to. I was a very high energy person who loved to be extremely busy. Now I am afraid to take on too many projects. I cannot concentrate in the same way or do as much.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

176-1

After I found a doctor who properly diagnosed, I received very good care. If I had not been treated for Lyme Disease, I would not be able to function at all today!

177-1

[once she received proper treatment from a good doctor, she regained energy she hadn't had in 38 years and] "I could vacuum the living room without resting two times" and "I enjoy working". "My hope is that good medical help should be available to everyone who needs it for the tick-borne diseases and no person should ever suffer even for one year.

178-1 I admire my Lyme Dr. for his courage and conviction to treat my Lyme. I do not know what I would do without him, I would probably, no doubt, die, if I didn't have him treating me.

181-1

Antibiotic treatment was helpful, however my mother and father divorced because of her severe LD and manic depression. I live with my father and he took us off antibiotics.

182-1

I would be in a vegetative state. Antibiotics have helped me with my bipolar disease.

184-1

I feel I would be a vegetable. Cognitive impairment and fatigue are my biggest problems. When I get off antibiotics I feel non-functional. Please let our LLMD's treat us with long term antibiotics.

185-1

I would probably be very sick and probably not functioning at the level I am now.

186-1

My LLMD absolutely saved my life. I could not have functioned indefinitely in that condition.

187-1

Just diagnosed and want option of long term antibiotic treatment. It is appalling to me to think that I could be denied any form of treatment I chose which would help me to feel better.

188-1

Because I am not on medication, I can feel myself deteriorating. This reduces my effectiveness at home and work. Due to the pain in my foot, I am now in a walking cast. I need medication now!

189-1\*

[My LLMD] has tried to help but the distance between us has made it difficult. He will continue to treat me & my daughter on a monthly basis.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

190-1

I have seen great improvement in my symptoms while under the care of my LLMD. I have at least a somewhat normal life back and can enjoy living again. I am no longer suffering every minute of every day. I think I would be severely disabled or dead without treatment. ...before I got sick I was a happy healthy 21 year old college student. LD took away everything that was good in my life. I was getting progressively sicker at a rapid rate. I had no hope for a while and find no options from doctors. When I finally got treatment from my LLMD, I finally found hope for my future. It has been a slow tedious recovery and I am still not the same as before Lyme, but I have a life again and it is due to the prolonged treatment with antibiotics. Before the antibiotic treatment, I was getting worse and worse. Since the antibiotics I have slowly gotten my health back. The problem is that my doctor is afraid and wants me off antibiotics because of the pressure. This is wrong and cruel. We need to have the option of long term treatment with antibiotics. It has made an immeasurable difference in my life. I am afraid that I will not have the opportunity to see further improvement.

191-1

I am grateful for my LLMD. I would have to lose all hope. As it is, I need to be driven out of state to get the treatments I need.

192-1

... I am grateful he has investigated my case in order to help me. .. Why would anyone want to deny a person any treatment that would improve their quality of life and help them regain function?

193-1

I would be dead!

194-1

It would be devastating if I could[n't] see my doctor.

195-1

If I could not be treated my quality of life would be severely affected. I had constant pain and irritability along with profound fatigue. My physician treats based on symptoms and response....I support my physician for aggressively treating my illness. I watched as my wife and children suffered through an unknown disease -- we are once again on the road to be healthy and happy.

196-1

[doesn't have one]

197-1

If not for my LLMD, I fear to think where I might be today.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

198-1

My LLMD provided me with individualized care that was monitored and adjusted based on my symptoms and progress. He helped over 1000 LD patients lead normal lives after being orphaned by other doctors.

199-1\*

My doctor is great and trustworthy. Without his help I would despair.

200-1\*

Honestly, I would be dead. I was at a point where I felt I could no longer continue and was contemplating suicide. I'm lucky -- the person who diagnosed me is an LLMD.

201-1\*

It was serentipity that led me to my LLMD -- bless his soul for he has since died. Paul Lavoie MD was able to give me my life back because he understood short term therapy would not be enough, especailly for a long neglected case. Without Paul Lavoie, I'm sure I would be dead.

203-1\*

I found [my LLMD] to be very conscientious and supportive and persistent in his efforts to effect a resolution that many patients like me are desperately seeking. As a physician [patient is a physician], it was very insulting and disheartening when even my internist suggested that perhaps I was depressed and prescribed Prozac. I reassured [my LLMD] that I fully understand the limitations of our scientific acumen in this area of tick-borne diseases and was very grateful for his open-mindedness and commitment to his patients.

204-1\*

About one year into my illness we had our first consultation with my wonderful Lyme Literate doctor in New York. He felt that it was highly likely that I was suffering from Lyme Disease. However, he wasn't quick to give me that diagnosis. He wanted to run more tests on me first...[after many many tests that came back positive, she was finally treated and has been able to keep her symptoms suppressed with antibiotics]

205-1\*

I must impress upon you the difficulty with finding a doctor who will openly admit to treating Lyme Disease. After much searching, I finally found a compassionate physician willing to treat me. I was on several different antibiotic regimens for approximately one year. I finally found some relief after many months of antibiotic trials.

206-1\*

It was fortunate that my doctor was "Lyme Literate" and perceptive enough to recognize the symptoms. Otherwise, I believe I would have gone into a coma and died. He saved me life by diagnosing and treating me quickly as well as continuing treatment for many months. (This same doctor no longer treats Lyme because of the fear of losing his license and being thrown off certain insurance plans).

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

207-1\*

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208-1\*

It took almost two and a half years to get correctly diagnosed... Then, I was undertreated by one doctor, turned away angrily by several others. One said "you do not have Lyme Disease and I won't test you." This was in spite of having a bite in an endemic area and a multitude of serious symptoms, all consistent with Lyme Disease. Imagine a doctor so frightened that lying to patients and refusing treatment for a serious illness was employed to get rid of them. I later found out that this doctor, who had previously treated Lyme patients, was now dumping them and refusing to diagnose new cases.

209-1\*

[Husband had EM rash but not being treated and has serious symptoms. Can't even get tests.] A doctor trained in infectious disease took over the treatment ... It helped. It was amazing. I began to think I would survive this.

210-1\*

[My LLMD] was my thirteenth doctor. Thank God I found him! After an examination and testing, he helped diagnose my Lyme Disease. He did not treat me, but advised my physician on treatment.... I saw big improvement with extended IV therapy. I know I would still be suffering horribly if not for the care of [My LLMD] and my own physician.

211-1\*

[Was finally diagnosed and properly treated by a medical student after receiving many misdiagnoses from "highly rated" physicians.]

212-1\*

We were told the state medical authorities had threatened the best Lyme physicians, leaving only the less proficient, who knew ways to "stay below the radar" [in Oregon]. We sought treatment out of state.

213-1\*

I cannot explain the sense of relief experienced during the initial evaluation visits. I feel truly privileged to be treated by such a respectful, thorough, conscientious and expert physician as [my LLMD]. All aspects of evaluation, diagnostic workup and oral/IV antibiotic treatment have been carefully considered and embarked upon in a spirit of collaborative effort. As a result of [my LLMD's] clinically judicious treatment, I am happy to report that based on clinical test results, subjective reports and clinical evaluation, there is a dramatic improvement in my condition. I am well on the way to the restoration of health.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

214-1\*

My greatest concern now is that my doctors will be taken away from me. What would I do?

215-1\*

Up to this date I have seen some 20 doctors, in different fields of medicine and have been on antibiotic therapy for Chronic Lyme Disease for the last 13 years... I am 66 years of age, and the past 13 years have been the best of my whole lifetime.

216-1\*

My HMO does not recognize or treat Lyme Disease...so I pay out of pocket to see a Lyme Disease specialist. I have not been able to afford IV antibiotics. After two years of aggressive oral antibiotics I regained functionality and returned to work. After four years of almost continuous treatment, I still relapse if I go off antibiotics. I am willing to take them for the rest of my life if it means I can have a life. But obviously a physician is needed to write those prescriptions.

233-1\*

My Lyme doctor saved my life. He is caring, dedicated and extremely knowledgeable about Lyme Disease. His long term treatment plan has brought me from totally disabled to almost completely symptom free.

239-1\*

My Lyme physician is my hero.

240-1\*

He is a superb internal medicine physician.

243-1\*

Excellent care from my LLMD has turned my life around and I have hope of an independent life now instead of steadily progressing illness.

251-1

I owe what is left of my life to my LLMD.

252-1

I feel extremely lucky to have found a doctor who understands LD. Long term therapy has improved my quality of life. Without it I would probably be an invalid.

253-1\*

I don't know where I would be today had I not gone to NY to seek help in getting well again. I owe my life to this NY Dr. who went above and beyond for me to find out what was wrong with me. Local doctor's ignorance on tick-borne diseases has caused my family and myself an unnecessary toll of inhumane suffering.

\* Note: Doctor's names have been removed for their protection.



## Statements made by Lyme patients about their Lyme Literate Doctors

254-1\*

Without the continual treatment from my LLMD, I would be completely dysfunctional and probably in a nursing home.

255-1\*

I live in California, but if not for my NY physicians' wisdom, experience, and courage in treating late stage Lyme disease, I would not be around to bear this witness. ... Without this treatment, my extended family and I are convinced that I would now require institutional care.

256-1 I am working half time for a hospital and am also beginning to rebuild the private practice that I lost. This would not have been possible if I had not been diagnosed and competently treated by my physician who was one of the few who were willing to treat me for chronic Lyme disease.

259-1\*

Fortunately for me (and the rest of us), [my LLMD] possessed the courage to take a stand against this unacknowledged disease and for that I say THANK YOU!

260-1\*

We need our doctors; leave these brave physicians alone and pursue instead those who cowardly refuse to diagnose and treat this most serious, insidious, and widespread infectious disease in our nation.

262-1\* I am extremely hopeful and grateful that my daughter may be over her illness as a result of an aggressive and knowledgeable physician, however, I am still dismayed that she was subjected to so much suffering as a direct result of the incompetence of the vast majority of the physicians who treated her over the years.

264-1\*

My physician and many other Lyme physicians are being taken to court [investigated] by the OPMC to have their medical licenses taken away, only because they correctly treat Lyme patients!

266-1\*

It's inappropriate for the state to step in and take sides in a difficult, multifaceted, medical controversy which knowledgeable honest and clear thinking medical and scientific experts admit has no clear answers as yet. Please protect the people of New York by leaving their medical care in the hands of their own doctors.

267-1\*

Luckily, I found a doctor in Ohio who helped me improve tremendously.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

268-1\*

The Cleveland support group [got me] to a doctor who specializes in Lyme disease and his care has spared me from total mental and physical disability. But he has not been able to reverse the considerable neurologic or joint and connective tissue damage already done.

269-1\*

It is a two hour drive in one direction once a month but I am glad to know this man.

270-1\*

My doctor is very complete before diagnosing Lyme and when these doctors treat so many Lyme patients, they know what to expect. Leave it up to them to diagnose their patients. [sic]

271-1\*

I credit my LLMD for saving my life.

278-1

I was finally able to meet the person who would help us.

282-1\*

I thank my doctors for being educated and able to treat me for this disease.

283-1\*

I can't imagine what my life would be like not to have the wonderful doctor that I have now and to not have the antibiotics to help keep me going.

284-1\*

I COULD FIND NO DOCTOR IN CLEVELAND WHO WOULD TEST ME FOR LYME DISEASE EITHER AT THE CLEVELAND CLINIC OR AT UNIVERSITY HOSPITAL!!! I learned of a doctor in PA who was knowledgeable about Lyme. I went to this doctor and my very first test from the lab, both blood test and urinalysis came back positive! I wasn't crazy!

288-1

Please offer these doctors some protection for doing their job, saving my life.

289-1\*

I have been very lucky ... for having an informed supportive doctor. I have had tremendous medical support from a respectful, knowledgeable and reasonable infectious disease doctor and from another hematologist as well as from a wonderful home health agency that provides caring nurses who really seem invested in my getting 100% better.

290-1\*

I still have bad days, but slowly and surely, after almost a year with the genius [LLMD], I am returning to the person I was, a dynamo!

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

292-1\*

I am an example of how well long term antibiotics work, and I am almost completely better due to my doctor's care. Without him, I would be without the very physician who saved my life.

294-1\*

My greatest fear is not whether or not I will be cured. I do not know if that is possible. I accept this reality. My fear is that my doctor will face charges and no one will treat me for this disease. Where will I go?

296-1\*

My NY doctor has saved my life with his treatment of my Lyme disease and now he is being persecuted by the OPMC.

297-1\*

I found him to be extremely thorough and very knowledgeable. He explained my treatment options, warned me of possible side effects, and reviewed his recommendations at great length.

298-1\* I thank God for my doctor.

299-1\*

I owe what is left of my life to Dr. Burrasnano. His treatment protocol was the catalyst which led my doctor to check for coinfection and order long term antibiotic treatment.

300-2\*

If not for these Lyme literate physicians who listen to their patients and don't blindly follow notoriously unreliable tests, my entire family would never have gotten diagnosed with Lyme Disease and thus treated sufficiently to maintain a quality of life worth living.

301-1\*

Under the care of these Lyme specialists, and because of their willingness to listen to our health issues with an open mind and make treatment recommendations based on our individual needs, many of us who were basically disabled prior to correct diagnosis and proper treatment by them, are now able to lead productive lives.

303-1\*

I elected to fly 3000 miles to NY to one of the top Lyme experts in the country for thorough evaluation.

304-1\*

Had I not found a wonderful Lyme literate doctor who finally put me on the medication I needed to get well, I would not be here today.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

305-1\*

Unlike the doctors before her, the doctor who finally diagnosed me carefully considered my clinical history, not just my seronegative blood work. This was fortunate.

307-1\*

My LLMD's treatment protocol has taken me from a part time researcher struggling to keep my job and maintain my position, back to a full time employee who conducts research and publishes at the PhD level.

311-1\*

Those of us who have found doctors willing to treat us owe them our lives because most of us had very little lifeleft when we found them.

312-1\*

The doctors who have continued to treat Lyme patients in spite of everything from harassment to extended legal action are NATIONAL HEROES! They should be HONORED and FUNDED, not pursued and degraded.

313-1\*

I am slowly getting my life back thanks to my antibiotics and my Lyme knowledgable physician.

315-1\*

I thank god for my doctor and Dr Burrascano whose guidelines my doctor follows. I cannot thank them enough.

316-1\*

I have to travel five hours to see the doctor who rightly diagnosed me and is able to treat me. Doctors in my area are not knowledgeable about Lyme disease, although some think they are and are a danger to patients with their tragic level of misinformation.

317-1\*

I'm thankful I have a doctor with knowldege and experience. I have to travel over 2.5 hours each direction to see him.

319-1\*

I was able to find a Lyme Literate MD ... If it were not for that lucky connection, I would now still be in a wheel chair and would have had to give up my home because I was fast becoming completely disabled and unable to care for myself. ... My doctor follows Dr. Joseph Burrascano's protocol and this is the reason I am feeling better. THE ONLY REASON.

320-1\*

My daughter of [My LLMD], and if not for him, she would have lost her life long ago.

\* Note: Doctor's names have been removed for their protection.

## Statements made by Lyme patients about their Lyme Literate Doctors

322-1\*

[My LLMD] should be given the highest award in medicine for his life-saving findings.

324-1\*

Finally, she was directed to [Her LLMD], who literally saved her life.

330-1\*

I finally found a doctor, and under his care, I have gone from a low point of being unable to do even basic functions to almost normal functionality. I have been on antibiotics for ten months now.

333-1\*

I am writing to tell you that [My LLMD] has probably saved my life. To me, he is a hero.

335-1\* [My LLMD] of East Hampton saved my life.

336-1\*

We need more doctors like [My LLMD] to treat chronically ill patients and not sweep us under the rug. Someone with his knowledge could prevent many, perhaps millions, of chronic illnesses by early diagnosis and treatment.

337-1\*

I can only thank my current treating doctor for having believed in me and for having an understanding of the serious implication of Lyme disease gone untreated.

340-1\*

Every month I worry that my doctor isn't going to be there for me for my next appointment. If the state medical board would stop this harassment, I wouldn't have to worry.

342-1\*

...referral to a Lyme Literate physician. That's when my life really turned around.

\* Note: Doctor's names have been removed for their protection.