FOR HISTORICAL RESEARCH REASONS WE INCLUDE THE FOLLOWING REFERENCES ON ALS / LYME

Although there is a possibility that some references may be difficult to locate.

Halperin Study
Mattman Study
The Jarusch-Herxheimer Reaction
Lyme Misdiagnosed as ALS
Seronegative Lyme
ALS/Lyme by Kathy Cavert
ALS-like Sequelae in Chronic Lyme
Generalised MND as an Unusual Manifestation of Bb Infection
Lyme-Related Relapsing Motor Neuron Disease
CNS-Borreliosis Selectively Affecting Central Motor Neurons.
Lyme Disease Symptom List
Seronegative Strain of Lyme in SouthEast
A Differential Diagnosis

'But Lyme Isn't Lethal!'
Coinfections- What Are They?
Dementia in MND
ALS Dementia
Dementia & Aphasia in ALS
Neuropsychiatric Manifestations of Lyme Borreliosis
Amyotrophic Lateral Sclerosis Syndrome of Syphilitic Origin. 5 Cases
Improvement of Patient with Amyotrophic Lateral Sclerosis Given Ceftriaxone.
Steroids & Lyme Disease
Dizygotic Twins With ALS
Conjugal ALS

MORE ARTICLES & RESOURCES

BASIC Lyme Information
MUST READ- Medical Abstract- Link Between TBE & ALS
ALS Risk Factors:
FREE Rocephin
FREE Other Drugs
Muscle Weakness & Atrophy in Only 6 Weeks of Lyme!
ALS/Lyme Markers
The 'ALS Is Not Fatal' Site
Reversible Motor Neuron Disease
Neuralgic Amyotrophy & Borrelia Burgdorfia
Help Finding Articles!!!

Article Mentioning Pat Pepper
Case: SLE/ALS
Treatment Failure
Lyme & Flaccid Paraplegia
Lyme Disease Disclosed by Disabling Amyotrophy
Lyme Case: Bulbar Muscles Affected
Diaphragmatic Paralysis Due to Lyme Disease
Paralysis of Abdominal Muscles Caused by Lyme Disease
Lyme & Progressive Supranuclear Paralysis
Evidence of Spirochetal Origin of Sudeck's Atrophy
Paresis, Atrophy Lyme Case
ALS Links
Lyme Links

IN MEMORIAM: STORIES OF ALS/LYME

Michael Cunningham
Terry Allen Wood
Kimberly Wood

Luther Conant
Brian Pierson
Katherine Crowe

LIVING TESTIMONIALS OF ALS/LYME

Pat Pepper
Vincent Sota
Kari Mayne
Dave Marr

Rob Senecal
Dennis Williams
Amie Thornburg
Annette Swanson *Update*
Mike McCabe *Update*

End of 2 articles on ALS/Lyme

WHAT IS THE CAUSE OF DEATH FOR ALS PATIENTS?

A common cause of death among ALS patients is respiratory failure or cardiac arrhythmias due to insufficient oxygen. - *The ALS Survival Guide*

11. "Myositis during Borrelia burgdorferi infection (Lyme Disease) Schoenen J., et al, Journal Neurology and Neurosurgical Psychiatry 1989, Aug;52(8):1002-5.

> Patient developed myopathic syndrome with severe muscular pains, incapacitating weakness of the proximal limb and the neck, as well as the bulbar muscles. Steroids stopped symptoms for a while but only antibiotics improved the paresis.

12. "Central nervous system manifestations of Lyme disease. Pachner AR, Duray P, et al. Achives of Neurology, 1989 July;46(7):790-5

> Weeks to years after this infection, behavioral changes, ataxia, and/or WEAKNESS IN BULBAR OR PERIPHERAL MUSCLES DEVELOPED." All 6 patients in this study were treated with IV penicillin high dose but the length was not mentioned. Four had response and 2 did not... again perhaps due to length of therapy not being long enough? *{Dr. B.: or too low a dose?}*

13. "Multiple Neurologic manifestations of Borrelia burgdorferi infection" [article in French] Author-dupuis, MJ, Revue of Neurology (Paris) 1988;144(12):765-775. Clinique St.-Pierre, Ottignies, Belgique.

> "The neurologic spectrum of Borrelia burgdorferi is still enlarging. The following neuro manifestations are mentioned: meningitis, acute or relapsing neuro symptoms such as palsies, cranial neuropathies, peripheral nerve involvement, acute transverse myelitis and paralysis, encephalitis, myositis, chronic neuropathy, sensory and MOTOR IMPAIRMENT AND SIGNS, recurrent stroke, progressive neuro disease, optic atrophy, DYSARTHRIA, SLOWLY OR PROGRESSIVE ATAXIA, SPASTIC GAIT DISORDER, ABNORMAL EMGs, ETC.

Article 2
from
THE ALS / LYME PAGE

Severe cases of Lyme disease can be misdiagnosed as ALS, Amyotrophic Lateral Sclerosis, also known as Lou Gehrig's Disease. What most people don't know, including the majority of doctors, is that the Lyme tests can be negative and you can still have it and that less than 50% of Lyme patients remember a tick bite or ANY kind of rash. Some professors of medicine in Texas still deny Lyme disease occurs in Texas !

Also, a progressive form of the TBE, Tick-Borne Encephalitis virus, is ALS and can be a coinfection with other TBD. This is very important because the TBE virus is sent into overdrive by most antibiotics- the person will progress (get worse) more quickly. Gentamycin is an exception. There are also herbs which deactivate the TBE. The Russians are researching this and are very clear about TBE=ALS. Go to PubMed and read all you can about TBE, ALS, & Lyme if you are into doing research. If you can translate the original long Russian articles I would be grateful if you could email them to CaliforniaLyme@cs.com If you would like to be on an ALS/Lyme email group, the list is called ALS-Lyme. The email address is alslyme@yahoogroups.com The website is: http://groups.yahoo.com/group/alslyme

VERY IMPORTANT: We have been finding that spouses of those with ALS/Lyme are often infected as well, most likely because they reside in the same area. {*Dr. B.: Lyme is sexually transmitted and in mother's milk*} Please, if you have been diagnosed with ALS, get tested for Lyme disease, Babesiosis and Ehrlichiosis - and have your spouse tested as well. The tests are not definitive but we have had so many spousal positives it is important to emphasize this. Some people may have asymptomatic infection. Spouses with *fibromyalgia, MS, Chronic Fatigue Syndrome, should be aware that these are also common Lyme misdiagnoses.* Anecdotally, Babesiosis is often present in ALS/Lyme.

Articles with relevance to ALS/Lyme are welcome. If you come across an article that you believe may be significant, please submit it to this page by emailing the contact person (Sarah Weiss) at CaliforniaLyme@cs.com

WHAT IS THE CAUSE OF DEATH FOR LYME PATIENTS?

> "Death in Lyme disease is believed to be related to cardiac involvement and to acute respiratory distress syndrome or ARDS," *Dr. Ruoss.*

the patient takes IVs only a few days a week, as opposed to daily, to try and minimize this reaction.

Similarly, those who did not respond, were probably like me. It took me 16 weeks of intravenous antibiotic to get well after my first treatment! I am sure these research patients were given only 2-4 weeks of IV. [After 2-4 weeks of IV, I was so sick from the cyclical immunologic exacerbation of symptoms of the JH reaction that I could barely stand to be in my body from all the strange neurologic things going on. I felt better in some ways, but much worse in others, and it took me 16 weeks straight on IVs to get well!

One case of a 35 year old male who was paralyzed from Lyme and on a ventilator, required a full year of IV claforan to bring him back to living alone and fully-functioning again, able to drive etc. He had severe brain-stem demyelination and encephalitis and was very, very acutely ill. He is fine now, other than the damage from the dysarthria. He sounds as if he has had a stroke.

The results of this study were profound: There was a statistically significant reversal of neurologic function of *classic ALS patients taking antibiotic for Lyme* in this study!!

If I were an ALS patient, this study alone would make me run for antibiotic treatment. Now the Lyme specialists no longer use a short 4-6 week course of abx but rather they individualize your length of therapy depending on the time it takes you to get better.

6. "Neuroborreliosis as a cause of respiratory failure", Journal of Neurology, 242:9, 1995 Sep.604-7. Silva MT, et al. LaneFox Respiratory Unit, St. Thomas' Hospital, London, UK.

Three cases of Lyme causing acute respiratory impairment requiring ventilatory support. TWO OF THE THREE HAD BRAINSTEM INVOLVEMENT. All of these patients also had central apnoea requiring tracheostomy, etc.

7. "Chronic Neurologic Manifestations of Lyme Disease" Logigian et al. New England Journal of Medicine, Nov. 1990.

Neurologic studies and neuropsychiatric studies were performed on a group of Lyme patients. Findings showed that a group of Lyme patients had both proximal and distal paraspinal denervation on electromyographic testing (EMG) with clearly ALS signs. EMG studies revealed neuropathy both proximal and distal with noted denervation, atrophy and weakness.

8. "Pathogenesis of immune-mediated neuropathies" [Immune-medated is a way of avoiding the use of "autoimmune" meaning that something has "triggered" the immunologic damage of the nervous system such as the spirochete infection.] Pediatr Res, 1993 Jan,33(1Suppl):S90-4 Dept. Neurology, University Pennsylvania School of Medicine

In this abstract, Guillain-Barre (GB) disease is the topic with Lyme mentioned as well. NERVE CONDUCTION VELOCITY SLOWING AND SEGMENTAL DEMYELINATION IS MENTIONED. Many patients with Lyme disease have had a hard hit to their immune systems by this immune-suppressing infection and many of us have had to have gamma-globulin intravenously to help us fight the infection. This study mentioned the use of gamma-globulin therapy IV for GB patients as well.

9. "Detection of Borrelia burgdorferi DNA and complement membrane attack complex deposits in the sural nerve of a patient with chronic polyneuropathy and tertiary Lyme disease." Institute of Neurological Sciences, University of Siena, Italy. Muscle Nerve, 1997 Aug;20(8):969-75. Maimone D, Villanova M, et al.

This study delves into polyneuropathies, sural nerve biopsy showing spirochete infection, EMG findings etc.

10. "Lyme Borreliosis neuropathy. A case report." American Journal of Physician Medicine and Rehabilitation, 1996 Jul;75(4):314-316.

This study is significant for ALS in that "electro physiologic studies demonstrate a PROXIMAL AND DISTAL AXONAL INVOLVEMENT." It even suggests that EMGs may show improvement in clinical changes as therapy begins to improve neurologic involvement. This report suggests that some peripheral neuro involvements may resolve while other neuro symptoms may not. Responses vary.

If your disease is something that came out of thin air and has no reason for being there or is caused by a virus then, after about 6 months of antibiotic or 3 months of IV, you have not seen a change in your neuro status you probably have something else. But remember, the studies are out there to correlate the two diseases. So happy hunting and God bless you all with new hope.

For those of you who decide to take the antibiotic and "demand" it from your doctors, should they become stubborn, as we see so often, and you get better, be sure and keep a diary so that we can go on 20/20 and change the world of ALS someday. Promise me that this long letter will not be in vain!

ALS AND LYME MEDICAL JOURNAL REFERENCES

See the listing and then read the comments

1. "Borrelia burgdorferi antibodies and amyotrophic lateral sclerosis" The Lancet. August 8, 1987 Russel Johnson, MD (famous Lyme researcher in the US) et al.

> Case studies are discussed whereby persons who tested positive for Lyme on antibody tests showed classic ALS symptoms including denervation, atrophy, weakness, bulbar involvement, dysarthria, ataxia, and so on. The end of the article states that any person with ALS should be given the opportunity for a Lyme diagnosis based on these compelling studies.

2. "ALS-like sequelae in chronic neuroborreliosis" German newsletter entitled Wien Med Wochenschr, 1995;145(7-8);186-8 Hansel Y, Ackerl M, Stanek G (very well known Lyme European researchers)

[Lyme was very common neurologic disease in Europe, in even the 1800s, but no one knew the organism causing it!

> This study suggests that all persons diagnosed with ALS be suspect for having Lyme disease as this particular case study individual had her diagnosis changed from ALS to Lyme. She had had Lyme for many years and the long-term sequelae of the infection caused an ALS misdiagnosis.

3. "Neurologic Complications of Lyme Disease" Rheumatic Dis Clinical North America, 1993 Nov;19(4):993-1009 Coyle, Patricia K. (Neurologist at Stony Brook University, New York)

> *Quote from the article:* "Lyme disease should be included in the differential diagnosis [editors note: by physicians] of most major neurologic syndromes."

4. "Clinical and electrophyphsiologic findings in chronic neuropathy of Lyme Disease" Logigian El et al., Neurology 1992 Feb, 42(2):303-11.

> 48% had distal neuropathy involvement with multifocal losses. Weakness, hyporeflexia were present in some and motor or sensory nerve conduction showed slowing in 64%. 48% had radicular (nerve root pains). 75-80% of patients , with needle EMG studies showed DENERVATION IN PARASPINAL AND LIMB MUSCLES. 76% of patients showed improvement with intravenous rocephin therapy

5. “Immunologic Reactivity Against Borrelia burgdorferi in Patient with Motor Neuron Disease" Archives of Neurology-Vol 47, May 1990, p. 586-594. Author: John J. Halperin, MD et al. (one of President Bush's doctors) and many others [et al].

> Abstract: The findings of this study are the most powerful of all studies done to date. A group of Suffolk New York "CLASSIC ALS" patients were taken for the study. They were not classic Lyme patients. All were given antibiotic. Some did not do anything, some did very well and the bulbar group deteriorated rapidly.
>
> > **Regarding the above study:** Remember, the reason for this Deterioration was hypothetically due to a very common research problem: back then... the length and type of treatment given to the severe bulbar group was probably not only long enough but the rapid deterioration was a definite sign of the Lyme infection because of the Jarisch-Herxheimer Reaction. This reaction only occurs with infections like Lyme and the *only* way a group could either not respond, or do a rapid decline on treatment, would be due to this endotoxin released by the spirochete Bacteria when antibiotics kill it. The endotoxin given off by the Spirochete causes an immunologic reaction which is very difficult for all Lyme patients but passes with time. No doubt the bulbar group received a short duration of therapy and no one was aware of this reaction and their need for individualized therapy... even oral perhaps as opposed to IV or perhaps pulse therapy whereby

intracellular like tuberculosis which requires a good year of abx and many of the Lyme patients in the country do very well on abx but fall backwards when the abx are withdrawn. In my case, I relapse and do not have "post Lyme syndrome", a way of trying to get out of treating it again and again because each time I take a new round of antibiotic, my serious neurologic symptoms go away. How can they go away with antibiotics if the infection is not still running rampant in there somewhere -- or recurring? Not to mention there are studies out there all over the world to substantiate "chronic Lyme" and even NIH is studying chronic Lyme at this time.

The reason for this lengthy article again is very simple. Lyme borreliosis is often referred to as "neuroborreliosis" because it is mainly neurologic. Lyme is an infection with a KNOWN cause; Lyme is treatable with antibiotics; and symptoms that are neurologic are able to be reversed in most patients with aggressive and close follow-up by ones doctor.

FINDING A DOCTOR IN YOUR AREA

In order to find a Lyme doctor in your area you can consult a very valuable web page on Lyme called Lymenet.org. This is run by some very knowledgeable Lyme persons who provide up to date medical information and on the web page. One can find a word called "search" off to the left of the web page and this will lead to a medical search where you can type in a "key" word such as denervation and find research abstracts that lead directly to this topic.

When you consult the Lymenet.org web page look for support group listings by state and see if you can contact someone in your state listed in this grouping or if not in your state, call someone in a state close by. Begin to make appropriate calls. If you can find a doctor who is very good with neurologic Lyme have your family doctor call that doctor and see if they would be willing to direct them in your treatment trial.

I cannot emphasize enough that with ALS all there is are yearly research solicitations for money to find a cause or cure. There are medical pharmaceutical trials with drugs that may or may not help the illness. Nothing is really grounded in terms of offering definitive help. Almost everyone is told that there is nothing that can be done and that they have "x" amount of time to live.

But with Lyme, there are studies by extremely influential medical journals, and with ALS there are reports that ALS patients have benefited dramatically from antibiotic therapy. The bulbar group has had a more difficult time and for this reason; it is crucial that the bulbar involved group have critical care doctors who can work them through the treatment and Herxheimer reaction without too much adverse reaction.

Lyme is not a "syndrome" or a "disease of unknown etiology". Lyme disease has a stupid name but it a cousin to syphilis and is a neurologic disease attacking our nervous systems and it is TREATABLE! What could be better than possibly having something that is treatable.

There are a couple of books at Barnes and Noble or other book stores and if not, one can order them. One is called *"Coping with Lyme Disease"* in which Denise Lang describes the disease and the odd and varying ways in which it manifests. Some of my research and quotes from my Lyme Aid newsletter were put in this book. The other book is by Karen Forschner and it is called *"Everything you wanted to know about Lyme disease".* Karen's son died of Lyme at age 5: she founded Lyme.net

This book also lists other tick-borne infections that can be in the body as well as Lyme! The books are easy reads and a wealth of information about a disease that HAS A KNOWN CAUSE AND TREATMENT. What could possibly be better. Just think, if Lyme was caused by a virus, there would be nothing to offer you or me. It would be like HIV or herpes. Nothing could be done to cure it up.[2] But it is a bacteria; a spirochete. It is up to you. It is your life and if you want to declare war on it, why not? What do you have to lose. You will know if you were once infected with this bug because either (1) you will remember a time in the past when you were exposed to ticks or when you first became ill and had odd symptoms and perhaps even fevers etc. or.. (2) you will take antibiotics and eventually you will begin to notice improvement of some of your symptoms... gradual but nonetheless improvement.

---

[2] Dr. B.: disagreeing. I would go all out to treat "incurable" viruses too! Latest info is that low glutathione is cause for viral pathology and persistence. There are at least two types of IV therapies for virus: Vit C and also Glycerizen IV.

was irregularly shaped and red or purple or had bumps like chigger bites or looked like herpes, if a doctor saw your rash and documented it, you may have a case of Lyme with NO TESTS NEEDED! Having the erythema migrans or the rash that grows larger with time after a tick bite (whether you remember a tick bite or not), qualifies you to have Lyme and that is that. You need to be treated for Lyme with no questions asked.
Most of us do not remember a bite or rash and tick bites *do not hurt.* They feed and drop off. You could have taken a trip to Estes Park or northern California or Wisconsin one summer years ago and stayed healthy like syphilis patients and HIV patients do, without symptoms - only to become sick after a surgical procedure or childbirth, or other stress. Surgery and childbirth cause this infection and its cousin, syphilis, to come to the forefront. People will have a surgery and suddenly become weak, fatigued and achy and suddenly things are not the same. This is the way this infection works. One can have a healthy immune system but if it is challenged, all heck breaks loose. This is how my disease began. I had carried the infection with all but a few leg pains and a few high fevers and otherwise felt great until I was in a wreck and had neck surgery. About 4 weeks later my entire body began to break down gradually.

The symptoms are migratory for some and they come and go. It may take years to get well. It is considered treatable and so those with ALS who take abx (antibiotic treatment) have the opportunity if they have this infection, to get neurologic function back, but they may not get it all back and they will have a chronic disease that can always go into complete remission as it did with me finally. After several rounds of IV antibiotic and several responses to it, feeling better, I would relapse and again have to have more abx. But this is o.k. I have never been as sick as I was initially back in 1989. I am 98% better now, and this is great, not to mention I had a remission whereby I was able to go from a walker, and too weak to climb stairs or pull a blanket over me, to playing racquetball!

TWO MORE IMPORTANT CONSIDERATIONS

TOXIC DIE-OFF: THE JARISCH-HERHEIMER REACTION

The spirochete bacteria are known to <u>give off toxins when they are killed with antibiotic.</u> This was discovered after WWII when the men were treated with penicillin for syphilis. They had a drop in blood pressure, rapid heart rate, fever and chills etc..

The doctors in Europe called this the Jarisch-Herxheimer reaction. This reaction is nothing to question, deride, or even argue about. It can cause death, destruction and immense pain and suffering as one tries to eradicate this infection. The positive side of this is that if you are one who has a *difficult time with antibiotics and feel that perhaps you have allergies to them, it <u>may</u> be the JH reaction.* I had hives and a fat lip on iv claforan at one point during a drip and it turned out the skin, being an infected organ, was having a Herxheimer reaction. We must stay strong. There will be exacerbation of pre-existing symptoms. For seriously ill ALS patients, this can be life threatening. Breathing may be compromised and ventilation assist may be needed, i.e. critical care hospitalization for a time until one gets through the rough part. Heart failure due to bulbar involvement could occur.

Other than this, the JH reaction simply causes massive periods of intense weakness where one must be fully aware of this coming and not be afraid of it. The weakness passes but it very scary. The weakness may be accompanied by new pains and aching or stabbing pains or more fasciculations. As the treatment continues, many ALS patients begin to notice neurologic functions return that they have not had for months to years. Fingers and arms will gain strength and move. Toes move and internal feelings of energy and wellness begin to occur. It is a long and arduous process and only the most experienced Lyme doctors, or doctors willing to talk with the most experienced Lyme doctors, should take the helm. If you can find a Lyme doc in your area that is the way to go unless you really like your family doctor and he or she is willing to accept the fact that an antibiotic is a small favor to ask in the face of a life-threatening disease with a poor prognosis. Any doctor that would not give antibiotic treatment upon request from an ALS patient for possible Lyme, based on the literature I am enclosing here, is not a doctor who in my opinion really cares. I say this because if they were in your shoes, and they had the information below, I would be willing to bet they would give the antibiotics a try.

I am not a doctor. I cannot tell any of you what to do but I want to share with you all my years of research into Lyme and my own experience with it firsthand. Adding to this, I have also conducted formal *clinical manifestations research* and also into diseases that Lyme mimics like ALS. I have collected some very powerful studies which implicate ALS as having an infectious underpinning. If this is so, then anyone with ALS should be entitled to take antibiotics for a lengthy time period (again because it is slow to respond and is and perhaps have the Lyme urine antigen test done after taking a round of antibiotic and then looking for the dead protein from the bacteria in the first morning urine *(call 1-800-832-3200-IgeneX Lab, Palo Alto, CA..* Even in spite of DNA testing, there is still room for error. *{Dr. B.: Joann Whitaker, M.D., of the former Bowen Research Institute, in Florida, devised the fluorescent antibody test and that is the one I preferred. But the lab, after she sold it to her employees, and she became to ill to work, went for state and national approval of the test and because it was nearly 100 % positive was changed to give about 50 % positivity. The original test showed fluorescent Lyme bacteria in the blood, implying that everyone has some, but was reported as a titer of positive as progressive dilutions. Significance and interpretation or correlation was up to the clinician.}*

Some physicians talk of false positives but most do not buy this. How can one have antibodies to an infection to which you have NOT BEEN EXPOSED? It makes no sense. False negatives, however, actually fill the literature! The pathogen is able to COMPLEX WITH THE IMMUNE SYSTEM, literally hooking up with the antibodies which are supposed to be defending us against it. It is able to then hide inside the spinal fluid and do its nasty work. Sometimes Lyme presents atypically as ALS, MS, polymyalgia rheumatica, Guillain Barre, transverse myelitis, polyneuropathies of unknown etiology, brain swelling and/or tumor, severe eye disease, cardiomyopathy, Parkinson's, hepatitis and so on. Sometimes it mimics lupus and its blood tests. Some families who have picnicked or camped in the same areas or who have lived on the same farm or cottage or traveled together, will become ill, but each with different manifestations. Some will show CIFIDS (Chronic Fatigue Immune Deficiency Syndrome), MS, fibromyalgia, ALS, etc.. It is not a genetic problem. It is an *epidemiologic problem* in that they were all playing in a bed of infected ticks (etc.) sometime in the past.

Lyme has been around since the 1800s and this is documented. However, the current epidemic began in 1975, after an accident at an Army-USDA lab called Plum Island. When you begin to look back at your own illness, you might want to look back to a time when you first noticed signs of illness... perhaps a temperature and a headache or a time of fatigue and weakness followed by feeling normal. Perhaps you began with stumbling and typical ALS weakness and fasciculations. It all varies quite a bit, person by person. No two people with Lyme ever show the same set of symptoms but there are always common threads unless one has classic ALS. I am stressing this information because I have seen a study performed by President Bush's neurologist, John J. Halperin, MD. And this study, along with others to follow and others that preceded it, implicated classic ALS patients as having an *infection triggering their neurologic damage to the brainstem and to the nervous system in a gradual predictable, degenerative way*. The study showed that a STATISTICALLY SIGNIFICANT number of CLASSIC ALS patients had REVERSAL OF NEUROLOGIC FUNCTION UPON TAKING AN INTRAVENOUS ANTIBIOTIC, CALLED ROCEPHIN, USED WITH LYME.

Almost all persons with severe neurologic Lyme disease are first given intravenous Rocephin antibiotic because it has a powerful ability to cross the blood brain barrier, get into the brain and spinal fluid and it also has good tissue penetration and ability to kill this particular bacteria. The beauty of Lyme vs. ALS is that Lyme has a known CAUSE, *thus* a potential cure. ALS is *just a name for a syndrome* whereby the body becomes denervated and muscles atrophy and the brainstem becomes engaged with disease. Lyme is capable of doing the same. Lyme can denervate, cause demyelination of the brainstem, caused respiratory distress syndrome, cause partial and total paralysis, seizures, weakness, tremor, need for walkers and wheelchairs and fasciculations, to name but a few.

Those of you with ALS have a disease with no known cause and this bothers me personally. I had many diagnoses prior to getting the correct diagnosis. Many of my diagnoses were autoimmune and I was told that it was just something that happens *where the body turns on itself.* It did not buy this, as I could not see my body turning on itself without something "triggering it". I felt that something was "causing" my body to go downhill. I just could not buy *a pie in the sky illness* that had no known cause. It took 27 specialists but I finally was diagnosed with this infection, not by tests although some of them were *positive at times and some negative at times,* but by "CLINICAL DIAGNOSIS". Although our government is not doing much to make awareness about this disease known, they have published in no uncertain terms that this is a "clinical diagnosis". They speak with a forked tongue and I will tell you how.

Surveillance, for CDC epidemiologic purpose, requires a specific blood finding on Western Blot or other such test and to get a positive on the Western Blot takes an act of congress. I will say this: if any of you in the past has ever had any kind of lesion like a bull's eye or even any other rash that did not go away right away and was odd-looking, (even one where the tissue fell off in the middle and it was not a recluse bite) or one which

Patricia A.D. Braun, M.D.
Nutritional and Preventative Medicine - Chronic Illness Care
ALS - Lyme Connection ©2011

Lyme Neurologic Infection as a Possible Cause of ALS[1]

NEUROBORELIOSIS

submitted to the ALS Digest by Kathy Cavert

Dr. Braun's notes in { italics }

This information has been gleaned from 10 years of running a Lyme hotline and talking with thousands of patients, and from medical school library research into medical journals re: ALS and Lyme, and based on my own 14 year experience with having had Lyme myself and the way it caused me to be too weak to get up off the floor, cause nocturnal dyspnea, fasciculations, profound fatigue and polio-like weakness, inability to pull a blanket over my body, inability to climb flight of stairs, dysarthria during periods of extreme sleepiness and weakness, dysphagia, severe motor impairment of the right hand and moderate of the left, hospitalization in a rehab facility with ataxia, foot dragging and a walker. And after antibiotic therapy, racquetball and a complete turnaround.

This is a discussion of neuroborreliosis (Lyme neurologic infection) and includes *13 medical journal articles* that correlate ALS with the spirochete infection of Lyme Disease, and thus as the possible cause of the neurologic syndrome called ALS. Some of the articles simply discuss the EMG findings of Lyme that correlate with ALS EMG findings. When looking over these studies it becomes apparent that a parallel exists between the two diseases, one with a known cause and one without a known cause. Perhaps they are both the same illness, and ALS is an immune-mediated disease with an infectious underpinning.

If Lyme is a bacterial infection and equivalent to ALS, then the neurologic bulbar and neuro weakness and atrophy of ALS should be treatable with antibiotic therapy! *{Dr. B.: Not to imply that Lyme is so easily treated, but attempts certainly should be made.}* Before listing the journals, I have launched into a very lengthy explanation of Lyme, the way it is treated and the reason for this article.

LENGTHY EXPLANATION OF LYME

The nickname for Lyme disease (Borrelia burgdorferi) or its cousin, syphilis, is "The Great Medical Imitator". Both illnesses are multi-systemic infections caused by chameleon-like, intracellular pathogens called spirochetes. As many of you know, syphilis was able to destroy the nervous system and other organ systems. Lyme has been doing the same but the diagnosis of Lyme is more often missed than not. Most physicians are either not familiar with the symptoms or the way it can virtually mimic other autoimmune diseases like MS, including demyelination, and exact parallel spinal fluid findings, etc.. Most physicians are well-intended but ill-informed, partly due to a political cover-up. Having Lyme disease running rampant in the tick population in resort areas and areas of high value homes is not a popular notion. Also insurance companies are not eager to pay for the antibiotic therapy which is often required *{Dr. B.: or, was thought to be required}* intravenously in order to get through the blood brain barrier. Lyme is primarily a neurologic disease and is called "neurotrophic" as it moves toward and attacks the nerves, both peripheral and central (spinal cord, etc.) Lyme can have an arthritic component perhaps depending on the individual's immune system or perhaps due to the strain variant. Lyme is a worldwide epidemic, found in all countries except Antarctica. It is transmitted by blood-sucking vectors, ticks, fleas, biting flies, and mosquitoes.

Few doctors in the country understand how to treat Lyme, and how aggressive they must be in the attack with antibiotic therapy. Reason? The organism causing it is intracellular like tuberculosis. TB requires a year or longer of antibiotics with a cocktail of 4 drugs used concomitantly. Lyme physicians often use combination antibioitic (abx) therapy to treat it as well. My disease was mixed before diagnosis. I had ALS symptoms, arthritic symptoms, fibromyalgia symptoms and eventually short term memory loss and at times, confused states. The most common symptoms of Lyme are often headache, stiff neck, backache, weakness, fasciculations (rapid twitching of muscles), profound fatigue, migratory symptoms like diarrhea, chest pain, shortness of breath, myalgias, hand or foot pain, stiffness in the morning or if sitting too long, connective tissue weakness, anxiety disorder, mood disorders, sleep disorders, etc..

Unlike other diseases we often read and hear about, this one is identifiable by *clinical response* to antibiotics. The testing for Lyme is often unreliable. One can get the ELISA and WESTERN BLOT done simultaneously

---

[1] ALS, means amyotrophic lateral sclerosis, i.e. "Lou Gerhing's Disease", and is called Motor Neurone Disease (MND), in England and Austrialia. Currently the "hedge term" is CIPD (chronic idiopathic peripheral neuronal disease).