



# PUBLIC HEALTH ALERT

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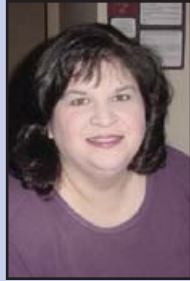
Investigating Lyme Disease & Chronic Illnesses in the USA

September 2007

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## The Psychiatric Symptoms of Lyme Disease

### What Psychiatrists Need to Know

by *International Lyme and Associated Disease Society* ([www.ilads.org](http://www.ilads.org))

#### When Should a Psychiatrist Suspect Lyme Disease?

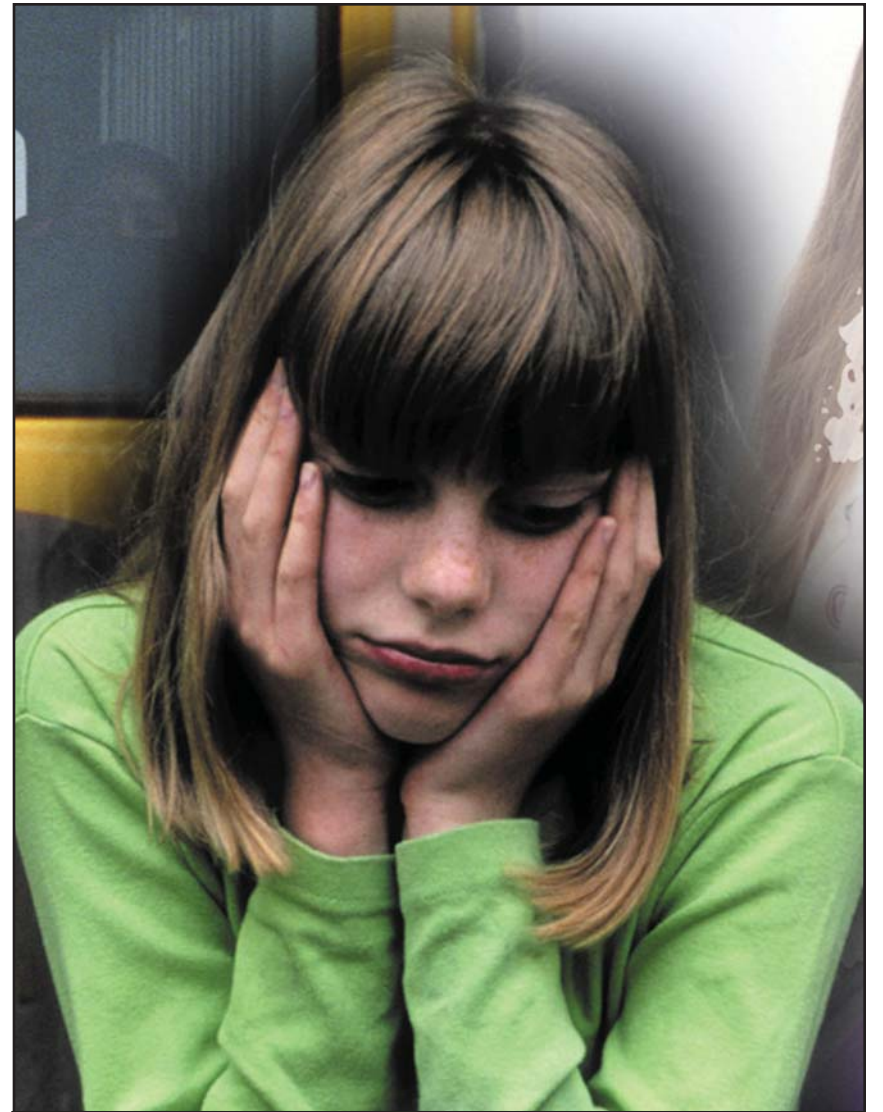
In a published study (Hajek et al, Am J Psychiatry 2002; 159: 297-301), one-third of psychiatric inpatients showed signs of past infection with the Lyme spirochete, *Borrelia burgdorferi*. The International Lyme and Associated Diseases Society (ILADS) has found that even severe neuropsychiatric behavioral symptoms in this population can often be reversed or ameliorated when antibiotics are used along with the indicated psychiatric treatments.

#### Don't miss this crucial diagnosis

Patients with late-stage Lyme disease may present with a variety of neurological and psychiatric problems, ranging from mild to severe. These include cognitive losses such as: Memory impairment or

"brain fog", dyslexia and word-finding problems, visual/spatial processing impairment (trouble finding things, getting lost), slowed processing of information, psychosis, seizures, violent behavior, irritability, rage attacks, impulse dyscontrol, anxiety, depression, panic attacks, rapid mood swings that may mimic bipolarity (mania/depression), obsessive compulsive disorder, sleep disorders, attention deficit/hyperactivity disorder and autism-like syndrome.

Lyme disease is one of the fastest growing infectious diseases in the nation. The Centers for Disease Control and Prevention (CDC) reported over 23,783 new cases in 2002, and the government agency estimates that the total number may be tenfold higher. The disease is caused by the bite of a deer tick infected with the *Borrelia burgdorferi* (Bb) spirochete and may be complicated by other parasites or coinfections. It is hard to diagnose because fewer than half of all Lyme patients recall a tick "*Psychiatrists*"...con't on pg 9



*Chronic Lyme patients experiencing cognitive and emotional symptoms will quite often end up seeking psychiatric help before being properly diagnosed with Lyme. Poor diagnostic tests are to blame for the difficulty in catching Lyme before it is disseminated into late and chronic stages of the disease.*

## Gabapentin Shown Effective for Fibromyalgia Pain

by *NIH News*

New research supported by the National Institutes of Health's National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) shows that the anticonvulsant medication Gabapentin, which is used for certain types of seizures, can be an effective treatment for the pain and other symptoms associated with the common, often hard-to-treat chronic pain disorder, fibromyalgia.

In the NIAMS-sponsored, randomized, double-blind clinical trial of 150 women (90 percent) and men with the condition, Lesley M. Arnold, M.D., director of the Women's Health Research Program at the University of Cincinnati College of Medicine, and her colleagues found that those taking Gabapentin at dosages of 1,200 to 2,400 mg daily for 12 weeks displayed significantly less pain than those taking placebo. Patients taking Gabapentin also reported significantly better sleep and less fatigue. For the majority of participants, the drug was well tolerated. The most common side effects included dizziness and sedation, which were mild to moderate in severity in most cases.

NIAMS Director Stephen I. Katz, M.D., Ph.D., remarked that "While Gabapentin does not have Food and Drug Administration

approval for fibromyalgia, I believe this study offers additional insight to physicians considering the drug for their fibromyalgia patients. Fibromyalgia is a debilitating condition for which current treatments are only modestly effective, so a study such as this is potentially good news for people with this common, painful condition."

Fibromyalgia is a chronic disorder characterized by chronic, widespread muscle pain and tenderness, and is frequently accompanied by fatigue, insomnia, depression, and anxiety. It affects three million to six million Americans, mostly women, and can be disabling.

The precise cause of fibromyalgia is not known, but research suggests it is related to a problem with the central nervous system's processing of pain. As with some other chronic pain conditions, people with fibromyalgia often develop a heightened response to stimuli, experiencing pain that would not cause problems in other people. Yet, unlike many other pain syndromes, there is no physical evidence of inflammation or central nervous system damage.

Although Gabapentin has little, if any, effect on acute pain, it has shown a robust effect on pain caused by a heightened response to stimuli related to inflammation or nerve injury in animal models

of chronic pain syndromes. Researchers have suspected that it might have the same effect in people with fibromyalgia. The new research, published in the April 2007 edition of "Arthritis & Rheumatism", indicates the suspicions were correct.

Although the researchers cannot say with certainty how Gabapentin helps reduce pain, Dr. Arnold says one possible explanation involves the binding of Gabapentin to a specific subunit of voltage-gated calcium channels on neurons. "This binding reduces calcium flow into the nerve cell, which reduces the release of some signaling molecules involved in pain processing," she says.

How Gabapentin improves sleep and other symptoms is less clear, and there are probably different mechanisms involved in fibromyalgia symptoms. "Gabapentin improved sleep, which is an added benefit to patients with fibromyalgia who often report unrefreshing or disrupted sleep," Dr. Arnold says.

What is important is that people with fibromyalgia now have a potential new treatment option for a condition with few effective treatments. "Studies like this give clinicians evidence-based information to guide their treatment of patients," says Dr. Arnold.

The mission of the National Institute of Arthritis

and Musculoskeletal and Skin Diseases (NIAMS), a part of the Department of Health and Human Services' National Institutes of Health, is to support research into the causes, treatment and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases. For more information about NIAMS, call the information clearinghouse at (301) 495-4484 or (877) 22-NIAMS (free call) or visit the NIAMS website at <http://www.niams.nih.gov>.

The National Institutes of Health (NIH) -- The Nation's Medical Research Agency -- includes 27 Institutes and Centers and is a component of the U. S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical, and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit <http://www.nih.gov>.

--- Arnold, LM et al. Gabapentin in the treatment of fibromyalgia; a randomized, double-blind, placebo-controlled multicenter trial. *pha*



# Hypotheses Regarding Autoimmunity in Lyme Disease and Multiple Sclerosis



by Megan Blewett

The concept of autoimmunity was first demonstrated by the work of Paul Ehrlich in 1892 and throughout its history has been highly controversial. Over half a century after Ehrlich's experiment, in the 1950s and 1960s, mainstream immunologists were only beginning to seriously consider autoimmunity.<sup>1</sup> In fact, early immunologists Noel Rose and Ian Mackay stated in their book *Autoimmune Diseases*: "...1955-1965 [was] the decade marked by the question, 'Does autoimmunity exist?'..."<sup>2</sup>

Today, that autoimmunity exists seems clear, though in which diseases autoimmunity is the primary culprit has still to be determined. Indeed, classifying any disease as an "autoimmune disease" should be done only after thorough consideration. A fatal immune error is a weighty matter, as the immune system is so key to the survival of an individual and the human species.

Evolutionarily, autoimmunity is hard to grasp. It is tempting to believe that the immune system is as obliged to follow the Hippocratic Oath as the doctors who study it. The first rule is always: Do no harm. However, studies have shown that autoimmunity has a genetic basis. According to immunologists Fu-Dong Shi and Luc Van Kaer, "Naturally occurring mutations in genes that cause a defect in [Natural Killer] cells ... can predispose individuals towards autoimmune disease."<sup>3</sup> Why, then, should these individuals not have been selected against evolutionarily? How have groups with this severe, and often fatal, predisposition survived to the current day and age?

With regards to diseases such as multiple sclerosis (MS) and Lyme arthritis, which are known to have environmental components, a follow-up question becomes: Has the immune system made a fatal error and started to attack self material or is it correctly combating a stealth pathogen that we have yet to detect? The spirochetal etiological agent of Lyme disease is infamous for being difficult to spot. A similar agent could be at work in MS.

My previous geographic work supports the hypothesis that MS and Lyme share a common environmental agent. MS and Lyme co-occur in the United States; regions with high incidence of MS also have high incidence of Lyme ( $p < 0.001$ ). The control diseases did not correlate with MS or Lyme distributions. Both MS and Lyme cluster around coastal regions, suggesting a

marine agent. Migratory seabirds can carry avian retroviruses and spirochetal bacteria, among a range of other pathogens.

While these geographic studies can only confirm a common vector, biochemical evidence suggests that MS and Lyme are in fact influenced by a spirochetal bacterium. I will take a brief detour from autoimmunity in the following paragraphs to discuss several biochemical hypotheses regarding etiology. The *Borrelia burgdorferi* bacteria are unique in their lack of lipopolysaccharide (LPS), a lipoprotein found on the surface of many other Gram-negative bacteria.<sup>4</sup> LPS stimulates macrophages to produce interleukin-1 (IL-1), a

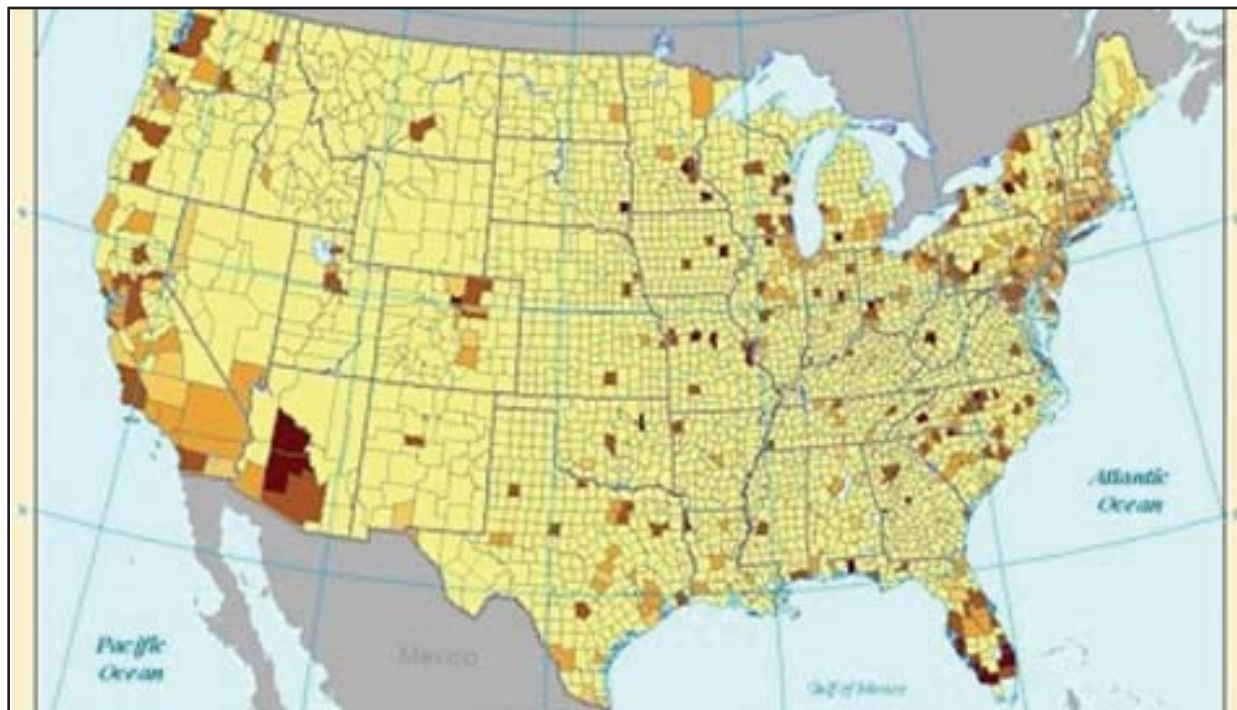
lar matrix, including collagen,<sup>11</sup> which is a component of the blood-brain barrier. This provides one mechanism for central nervous system infiltration in MS patients.

These geographic and biochemical similarities are just some of the points of overlap between MS and Lyme. Now, we must return to the focus of this essay: autoimmunity, or the lack thereof, in these two diseases. Are LPS-lacking Gram-negative bacteria at the root of MS and Lyme arthritis or is autoimmunity entirely to blame? The prevailing opinion among researchers is that MS is an autoimmune disease. However, the environment clearly also plays a role in MS susceptibility.

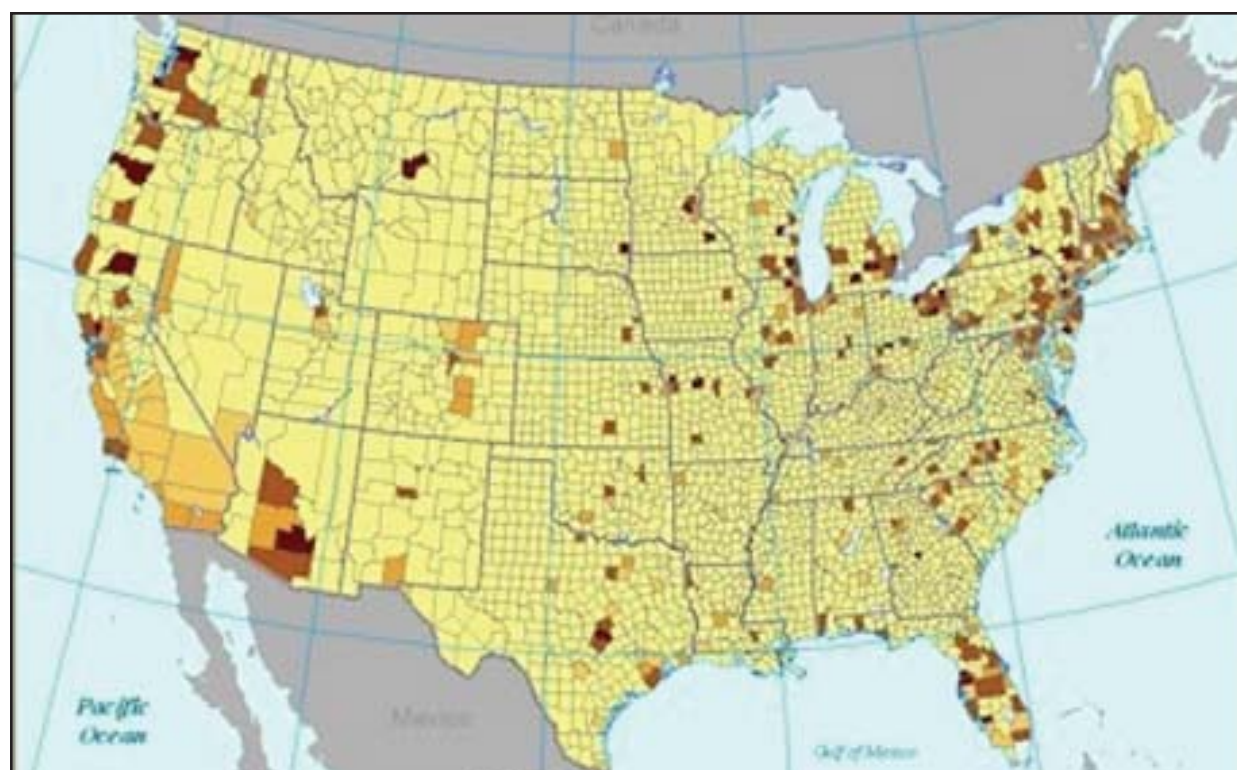
antibody levels associated with the progression of MS.<sup>15</sup> Thus, other candidate autoantigens need to be investigated.

The molecular mimicry theory has also been applied to Lyme arthritis, a chronic condition affecting about 10% of all Lyme patients.<sup>16</sup> Some researchers argue that Lyme arthritis is in fact a post-infectious autoimmune disease. Synovial samples from sufferers of this antibiotic-resistant form of Lyme disease do not test positive for *B. burgdorferi* DNA, suggesting that the disease persists even after spirochetal infection.<sup>17</sup>

One of the most widely accepted autoantigens in Lyme disease, following the molecular mimicry theory, is the



Normalized Count of Lyme (OSABD) Deaths by County (1998 over 1990 Census)



Normalized Count of MS Deaths by County (1998 over 1990 Census)

type of signaling molecule known as a cytokine.<sup>5</sup> Thus, if an LPS-lacking bacterium like *Borrelia* were at work in MS, one would expect to find low levels of IL-1 among patients. A review of the scientific literature shows that this is in fact the case.<sup>6,7</sup>

Interleukin-10 (IL-10), another cytokine from the same class of interleukin signaling molecules, inhibits *Borrelia*-induced endothelial inflammation.<sup>8</sup> Interferon-beta therapy in MS patients stimulates IL-10 production and has beneficial effects.<sup>9</sup> LPS can also induce endothelial inflammation, leaving open the possibility of LPS-containing Gram-negative bacterial etiological agents.

In addition, the plasminogen activation system and specifically tissue-plasminogen activator appear to be "turned on" in MS patients.<sup>10</sup> *B. burgdorferi* bacteria are plasmin-coated and activate plasminogen. *B. burgdorferi* can likewise degrade the extracellu-

The molecular mimicry theory provides a compromise between these two points. According to the molecular mimicry theory, MS is a post-infectious autoimmune disease resulting from an immune mix-up of a pathogenic antigen and a component of the myelin sheath. MS patients, some researchers believe, are infected by a pathogen whose antigen resembles a component in myelin. For some reason, myelin is degraded in MS patients.

Currently, researchers are investigating myelin basic protein (MBP) as the myelin target of this immune mix-up.<sup>12</sup> Proteolipid protein (PLP) and myelin oligodendrocyte glycoprotein (MOG) are also "candidate autoantigens."<sup>13</sup> However, several points complicate MBP's autoantigen status, including that elevated levels of anti-MBP antibodies do not appear to be specific to MS patients,<sup>14</sup> nor are anti-MBP or anti-MOG

human Lymphocyte Function Antigen-1 (hLFA1alpha), which contains a peptide similar to the *B. burgdorferi* outer surface protein A (OspA) from amino acids 165-173.<sup>18,19,20</sup> Thus, antibiotic-resistant Lyme arthritis may, like MS, be a result of an immune recognition error. However, Dr. Steven Phillips has pointed out that *B. burgdorferi* bacteria are very hard to detect and may still be present in Lyme arthritis patients.<sup>21,22</sup>

Thus, Lyme arthritis has yet to be unequivocally classified as either an autoimmune disease or a chronic infection.<sup>23</sup> MS faces similar classification difficulties. Until better detection methods are applied, elucidating the molecular mechanisms of "post-infectious" diseases will be very difficult. Further research must be performed to better understand the mechanisms of Lyme arthritis and its commonalities with MS. *pha*

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Letters to the Editor

The PHA is committed to researching and investigating Lyme Disease and other chronic illnesses in the United States. We have joined our forces with local and nation wide support group leaders. These groups include the chronic illnesses of Multiple Sclerosis, Lou Gherig's Disease (ALS), Lupus, Chronic Fatigue, Fibromyalgia, Heart Disease, Cancer and various other illnesses of unknown origins.

PHA seeks to bring information and awareness about these illnesses to the public attention. We seek to make sure that anyone struggling with these diseases has proper support emotionally, physically, spiritually and medically.

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Letters to the Editor

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Dear Editor,

I am writing in regards to an article that was recently published in Forbes magazine by the title of Lyme, Inc. Ticks aren't the only parasites living off patients in borreliosis-prone areas. The article was written by David Whelan.

Neuro-Lyme, (persistent, chronic, active Lyme disease) is a burgeoning epidemic. My psychiatric practice has been filled with the unfortunate but previously misdiagnosed victims of tick-borne diseases for at least the last 10 years.

There are literally hundreds of high quality, peer-reviewed, easily obtained, scientific articles credibly attesting to the devastating persistence of this living spirochete-caused neurological disease and its crippling effects on whole populations. However, instead of pursuing such research and presenting a balanced picture of the science, a Forbes magazine reporter has recently cited only the Infectious Diseases Society of America (IDSA), whose framing of the disease represents the most radically restrictive of all viewpoints in what is one of the more hotly-contested controversies in all of medicine.

For decades, physicians holding to IDSA's view of Lyme disease have turned away desperately ill patients by telling them they must be mentally unbalanced to imagine that they or their children are physically ill. These patients show up at my psychiatric practice crippled and in great pain, barely able to function. Only after receiving appropriate long-term antibiotic and immunity-enhancing treatments, usually far exceeding the IDSA guidelines, are their lives restored.

Alleged, inappropriate financial gain associated with some Lyme-treating physicians was alluded to in the Forbes reporter's poorly researched piece. IDSA authors, on the other hand, have documentable financial conflicts of interest that were never mentioned in this article. These include patents for a vaccine still under development in Europe and the US, financial interests in Lyme disease products such as test kits, and, most importantly, employment by the insurance companies that stand to lose money if the epidemic is acknowledged and paid for. The vested conflicts of interest of these authors are seldom revealed when they publish in their authoritative journals.

While these few exploitative yet influential academicians violate everything Hippocrates ever stood for, rank and file physicians stand by confused. In their impotency, they unknowingly are allowing this epidemic of tick-borne infections to grow exponentially.

Virginia T. Sherr, MD, DLFAPA

A Psychiatrist Saves a Life

Dear Editor,

This is a personal story that happened 3 years ago to a 51-year-old male family member. He is single and has a history of intractable migraines, depression, chronic prostatitis, UTI's, allergies, sinusitis, diverticulitis requiring removal of a

portion of bowel, chronic uveitis, back problems causing sciatica, knee surgeries, etc. He does not have a diagnosis of Lyme though I suspect that is the unifying feature of all his health problems.

In May of 2004 Brian collapsed at work where he was a computer trouble shooter. An ambulance was called and he was admitted through the ER totally incoherent and running a 101 temp. He was started on Rocephin and an IV anti-viral for possible encephalitis. He was put in restraints and was unable to indicate a contact phone number for over 12 hours. After about 24 hours, he was coming around, starting to recognize his parents. His fever was down and all tests including MRI, CT scan, and spinal tap and cultures came back normal. He was released from the hospital after 4 days with only one strange incident of his blood pressure dropping alarmingly. The final diagnosis--encephalitis from migraines. He was tested for Lyme and West Nile virus. All tests were negative.

At home, he was very weak and gradually began to lose a grip on reality. Within another 4 days, he was hallucinating, seeing people who weren't there, bugs, water, and all sorts of other bizarre things. My husband took him to the ER after an exhausting night trying to keep him in bed. This time they go to a different hospital because he had been seeing a neurologist for 7 years for his migraines who is affiliated with this hospital. The ER doc is

very concerned and suspects a medication reaction. We are concerned about the Welbutrin because he was on the highest dose. The records from his previous hospitalization had been sent to his neurologist. We believe that these records are what caused his neurologist to refuse to come to the hospital to see him or to admit him. The ER doc cannot admit without another doctor, so his hands are tied. He seemed genuinely sorry and angry. So, the mental hospital was called and admitted him for evaluation for medications.

Within 4 days, the psychiatrist called and told us that this was not psychiatric and that we needed to come get him. His condition continued to deteriorate. He was unable to answer basic questions like "Do you know what year it is?" He would try, saying, "Yes, hmm, it is 19. . . 19. . . 19. . ." and then just trail into nothing. He could not sign his name correctly or add 2 and 2. But, he tried to answer the questions. He wanted to communicate. The psychiatrist said that there was something going on and that there was nothing that they can do there. He wanted us to put him in a nursing home which we would find was no easy matter. He believed that Brian was dying because the deterioration

had been so rapid. Now, we already knew from our prior experience at two hospitals that there was no way we were going to be able to get him admitted. And if this was not mental then logically, it is physical and he needs a doctor. We told them that we could not come get him. We could not take care of him. His parents were 77 and 78 and in very poor health. I was already caring for a bedridden daughter. And we did not have the money to pay for a nursing home. We were totally in a quandary about what to do. We were frantically applying for social security, trying to get nursing home evaluations, and trying to get ready for my son's wedding that was in 2 weeks. We did not know what would happen if we declared him a ward of the state. No one was clear about what that would mean. We finally told the psychiatrist's assistant that we wanted him to refer Brian to a neurologist. He did not say, but I think that he knew this would be a difficult endeavor. He really just wanted us to come get him. We just couldn't.

After a couple more days of us trying to figure out something, anything, the psychiatrist sent Brian to the hospital via ambulance. He spent an

hour on the phone talking an internist into admitting him and a neurologist into evaluating him. We are eternally grateful to him for going out on a limb and spending that evening to help us. Within a couple of days, the neurologist had done more tests and concluded that it was depression and that he needs electric shock therapy. We were appalled and know that the mental hospital will not take him back. So, we really weren't too concerned that this would actually happen. It was never mentioned again. (Had they done this, it would have killed him.) His condition had deteriorated even further. He was in restraints and diapers. He was hardly eating at all. He did not recognize his family though it was difficult to tell that at times because he communicated and seemed to like watching baseball games. Once he asked my husband to take him with him and my husband said that he couldn't because he had to stay there and get better. Then Brian said, "Oh, that's OK, Frank is coming by and he will take me home." My husband is Frank.

Thankfully, the internist was not quite ready to give up. He knew that Brian's dad had cardiomyopathy and decided to run an echocardiogram. Brian was in heart failure. It had taken a month to get this diagnosis. But within 2 days of starting the heart meds, he was recognizing everyone, wanted out of the diapers and restraints, and wanted to feed himself. He came home from the hospi-

tal 4 days after starting the heart meds and gradually improved. He seemed like someone who had a stroke. He couldn't remember how to operate electronic things like the remote control, his camera, or his computer. But slowly these things have all come back. After 4 months, he was able to go back to work.

We think 3 things saved Brian's life--the psychiatrist who went the extra mile and correctly diagnosed a physical problem, the internist who kept thinking and trying, and his family because we just kept pushing for him to be admitted to a hospital not a nursing home where he would have undoubtedly died. Brian turned 54 this year. We had doubts that he would see this birthday and, most especially, that he would see it in his right mind able to understand that he was surrounded by those who love him.

Thank the Lord for doctors who think outside the box, for those who will keep trying when the case looks impossible, and for those who actually listen to their patients.

Karen Angotti

Strange Bedfellows

Dear Editor,

It has come to the attention of the Lyme disease community that the American Academy of Neurology has adopted Lyme treatment guidelines nearly verbatim of the much maligned IDSA Lyme treatment guidelines. One can only speculate why the AAN would adopt such similar guidelines now, when the IDSA guidelines are currently under investigation by the Connecticut Attorney General's office for possible anti-trust violations and refusal to incorporate contrary research into their guidelines. However, the picture becomes much clearer when one recognizes the fact that many of the same individuals responsible for adopting the IDSA guidelines apparently played a role in the adoption of the AAN guidelines. Is this an attempt to repair damage caused by the Connecticut Attorney General's office investigation? Their transparency and desperation is laughable. Unfortunately, it isn't a laughing matter to the multitudes that've become chronically ill because of their inadequate and exclusionary guidelines.

I also read with great interest on the AAN's website {www.aan.com} - the press release section- the following statement: "To develop the guideline, the authors analyzed all available scientific studies on the topic." All? Really? Does that include the two NIH funded studies showing long-term antibiotic efficacy, or Dr. Fallon's research at Columbia, or scores of other studies verifying long-term anti-biotic success? Perhaps, they didn't have access to the hundreds of thousands of Lyme-infected individuals nationwide who've resumed normal, pain-free lives because they were treated with long-term antibiotics? Perhaps, the phones weren't working properly at their St. Paul domicile and they were unable to call any of the fine ILADS doctor's who

"Letters to Ed."...cont'd p18



# A Mother's Nightmare, a Child's Torment

## When Lyme Disease is Misdiagnosed as Mental Illness

by Donna Benner

On Christmas day 1997 I took a 3 year old foster child into my home as the first step towards adopting him. I was 38 years old, an art teacher in the public schools and he would be my first and only son. His name was Nicholas. When I would talk to him he would smile back, staring at me with big brown eyes, but he couldn't talk to me. For reasons no one could figure out, he was unable to speak, he could only make funny sounds that appeared to be attempts to communicate.

I wasn't told a lot about his past. His mother, from a Lyme endemic part of Connecticut, suffered Bipolar disorder and had a drinking problem. His biological father was someone she had met in a bar one night, never to see again. Nick, at the tender age of three, had a long history of unprovoked violent rages and aggressive behaviors. As an infant he would scream and bang his head in his crib. In one foster home he attempted to strangle the family cat. At the age of two he would wake up in the middle of the night and run out of the house with such frequency that the family doctor instructed the foster mother to tie him to the bed while he slept for his own safety. He would bite and attack other children without warning on a daily basis. He had already spent two weeks in a psychiatric ward of St. Raphael's Hospital.

By March 1998, I was only working part time so that I could spend more time with him. I began taking him to the Yale Child Study Center in New Haven, Connecticut. After a few weeks of treatment I was told he suffered from severe Reactive Attachment Disorder (RAD) and that he would require intensive therapy with an expert in the field if he were to have any chance of overcoming his problems.

I was strongly advised not to finalize the adoption. I was told off the record that he was so violent, so angry, and his rages so dangerous, that he would end up in jail after killing someone, if he wasn't killed first. I was strongly

advised to place him in Yale's pediatric psychiatric ward. Instead, I took him home and adopted him.

The next two years was a blur of countless doctors and therapists and many different diagnoses-- Pervasive Developmental Disorder (PDD), ADHD, Oppositional Defiant Disorder (ODD), learning disabilities, Mental Retardation, Bipolar Disorder, Intermittent Explosive Disorder. I was always hopeful, but no one seemed to know what was wrong with him or how to begin to help him. Most professionals concluded that Yale was correct and that he was exhibiting behaviors consistent with RAD and children suffering from PDD.

In my heart I was certain that there had to be something physically wrong with him. He would erupt in a violent rage with very little warning or provocation. In these outbursts he would bang his head, bite his own arm, drawing blood, knock over chairs, tables, and other furniture, smash plates, and attack me or other people, pulling my hair, biting me, kicking me and throwing things at me. His face would turn red and he would often scream that he was hot. To keep everyone safe I had no choice but to physically restrain him. Going anywhere, even to the grocery store was a challenge, because he could erupt in violence at any time.

He was learning slowly how to speak in his pre-kindergarten and kindergarten classes, but he was becoming increasingly disruptive. He would, without warning, run out of the classroom and down the street. He was repeatedly expelled from daycares and from schools. The bishop at the church we attended asked us not to attend services.

In April 2000, he was diagnosed with early onset bipolar and thus began many hospitalizations. In six months he was hospitalized at St. Francis in Hartford,

Connecticut and Four Winds Hospital in New York five times. We seemed to be a regular at the ER. Both Four Winds Hospital and his out patient psychiatrist stated that he was the "worst" and "most difficult" of pediatric bipolar disorder that they had ever treated.

At this time, Nick had just celebrated his sixth birthday. A medicinal cocktail of Lithobid, Tegretol, Zyprexa and

After a stay in Westchester Medical Hospital, and then at White Plains, I was told that he had "seizure like" activity in his brain and the treating doctor told me that without high dosages of medication all his life, Nick "would be toast."

In the spring of 2003, the director of his school, a very kind and supportive woman, was trying to prepare me for the inevitable, that he would need institutional care and he would need it soon. There seemed to be no way around this grim truth.

In one last attempt to help him, we found our way to the office of Dr. Warren Levin. "Please," I told this kind doctor, "I will try anything you think might help him."

Dr Levin ordered some tests and I anxiously awaited the results. When the test results came in I was told Nick had Lyme disease and Babesiosis. I was so disappointed. Is that all? Once more,

I felt I had found another doctor who would be unable to help Nick.

We had both been tested for Lyme disease in the past and the results had been negative. This had been my last hope. Dr Levin insisted that this was significant and told me that I should make an appointment with a doctor named Charles Ray Jones in New Haven. With nothing to lose, Nick started on Zithromax and mepron.

Nick got worse before he got better. He always had sleep disruptions, but one night he couldn't sleep at all, and I spent the whole night, until 5 AM, trying to prevent him from jumping out a second story window, or from knocking over furniture.

Then a strange thing happened. It was obvious to both me and the director of his school that he seemed calmer, more able to focus. Nick seemed able to concentrate and the violent fits were much less frequent. We both agreed that the change in Nick had to be

linked to his treatment for Lyme disease.

At Dr Levin's insistence, I was tested and my results were positive for both Lyme and Babesiosis. I began to read whatever I could on the subject and was shocked to learn that Lyme disease could cause Bipolar and violent behaviors. Nick's psychiatrist was intrigued. Nick was no longer dismantling his waiting room. After several years of being medicated with high doses of four different psychiatric drugs, Nick was gradually able to cut back his medication until he was completely off all psychiatric drugs. Nick continued to improve and instead of being sent to an institution, he remained in school and was given an award for "most improved."

In the fall of 2004, Nick suffered a relapse into his old behaviors. He was expelled from school and spent 2 weeks in the psychiatric ward of St. Raphael's Hospital. Dr Jones tested him and he was positive for Lyme and Mycoplasma Fermentas. Once again, he responded to the antibiotic treatment prescribed by Dr Jones.

I was becoming increasingly anxious about where we were living--on two wooded acres next to protected wetlands in Fairfield County, Connecticut. Although I religiously had the yard sprayed for ticks, and had a 10 foot "buffer" of wood chips placed between our yard and the surrounding woods, herds of deer would venture into our yard all the time. A local company installed "mouse washing" boxes around the perimeter of our property, I had large trees cut down to open our yard to more sun, and I tucked Nick's pants into his Permethrin sprayed socks, but the nagging feeling in my stomach that we were not safe would not be still. I would gaze out at the natural splendor around me... it was so peaceful, so beautiful.

Over and over people used the same word to describe Nick --"miraculous." His violent fits, once an every day occurrence, were now non-existent. He was able to attend "Misdiagnosed"... *cont'd pg 10*

Then a strange thing happened. It was obvious to both me and the director of his school that he seemed calmer, more able to focus. Nick seemed able to concentrate and the violent fits were much less frequent. We both agreed that the change in Nick had to be linked to his treatment for Lyme disease.

Abilify seemed to help him a little. However, his rages continued and it was a rare day that I did not need to restrain him. I was always haunted by what the doctors at Yale had told me.

With in-home help from the state Department of Children and Families, and a highly specialized day school for severely autistic children willing to accept him, we struggled on.

Most parents look at their growing children with pride. I tried not to think about how fast he was growing or what I might have to do the day he became too big and too strong for me to physically restrain. I tried not to think about how, as I physically restrained him in one of his rages, that the only reason he wasn't beating my head in with a baseball bat was that I was still bigger and stronger. All kitchen knives were hidden away. He could be so sweet and loving one minute, only to change into an angry monster without warning.

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## Bridging the Gap



by Dr. Robert Bransfield, MD, DFAPA

The brain is the most complex organ and for its size and weight is the most complex structure in the known universe. Fully understanding the brain and its effect upon human behavior will be the last frontier in science.

When I was in medical school, the living brain was viewed as a mysterious "black box" that could be poorly visualized with skull x-rays, EEGs and pneumoencephalograms.

Since brain physiology and pathophysiology were so confusing, there was a large emphasis upon psychodynamic theories to explain the causes of mental illness. Many in medicine could not relate to these theories and closed their mind towards understanding psychiatry which resulted in a fragmentation of psychiatry from the rest of medicine. Residuals of this fragmentation persist today.

Although sophisticated research has demonstrated infectious diseases and immune reactions to these infections play a significant role in causing mental illnesses and other central nervous system diseases, it remains difficult for many to understand this connection. It is regrettable that

many immunology and infectious disease thought leaders have little training in or understanding of psychiatry and many psychiatrists have limited capability in infectious disease and immunology.

Since there is interaction between infections and immune system with the brain, we need the same level of interaction between infectious disease doctors, immunologists and psychiatrists.

The International Lyme and Associated Disease Society attempted to bridge this gap by including a broader range of expertise, including psychiatrists, on their guidelines com-

ing the extensive psychiatric literature.

The main consequence of inadequately treated tick-borne diseases are central nervous system symptoms (psychiatric, cognitive and neurological), not arthritis.

For unknown reasons, there has basically been a failure in some to advance beyond the original 1975 definition of Lyme arthritis. Since the Wormser, Shapiro, Halperin, et al. guidelines place a strong emphasis upon possible adverse effects of antimicrobial treatment with a weak emphasis upon possible adverse effects of under-treating tick-borne dis-

eases, the risk vs. benefit consideration is unfortunately skewed towards under treatment. This restricted view is contributing to an epidemic of mental illness that could otherwise be avoided or more effectively treated.

At the recent Lyme Induced Autism Foundation Conference, data was presented demonstrating a link between infections, tick-borne infections, including Lyme disease and autism spectrum disorders. It appears this is still another identified

harm to public health which is incurred by maintaining the status quo of restricted and fragmented views in medicine.

To move forward, the CDC, NIH, IDSA, AAN and others in healthcare need to join us in our efforts to bridge the gap between our respective fields. *pha*

More information and articles by Dr. Bransfield can be found at the following website: [www.mentalhealthandillness.com](http://www.mentalhealthandillness.com)

**“The main consequence of inadequately treated tick-borne diseases are central nervous system symptoms (psychiatric, cognitive and neurological), not arthritis.”**

mittee and considered the psychiatric literature which resulted in a more comprehensive and current conceptualization of tick-borne diseases.

Unfortunately the recent Wormser, Shapiro, Halperin, et al. guidelines for the Infectious Disease Society of America (IDSA) and American Academy of Neurology (AAN) perpetuated the fragmentation by creating Lyme disease guidelines without any psychiatrist on the committee or without consider-

## What are the Odds?

### Texas Ticks Causing Trouble

by Harriet Bishop

My GP doc, a neat young Aggie, smiled at me yesterday when he looked at my left arm, just above my wrist watch. A red bulls-eye appeared there, about the size of a nickel, with a tiny hole in my skin in the center, quite reddened around the edges, just beginning to fade in the area between the center hole and the red circle's edges.

"What are the odds?" he smiled, knowing that I was already being treated for chronic Lyme disease from the bite of an infectious tick in 1991.

"I dunno, but it looks classic to me," I replied, referring to the only definitive marker for an infectious tick bite, the well-known "bulls-eye."

How could this happen, here at Canyon Lake, Texas?

On Sunday evening we had a windstorm--70 mph was reported, and sure enough it blew down a branch 5 inches in diameter and about 12 feet long, branching out about seven feet wide. The huge heavy green leaves of our fig tree had caught the north wind like sails and brought the whole branch down, bending much of the tree down on our back lawn.

Two days later my husband and I sawed it free from the rest of the tree, and dragged it in three leafy pieces to the road, an area which happens to be where tick-infested deer daily enter our yard on their way to the creek below.

A week later, when lawn maintenance personnel and the trash collector had ignored it, I got out and reduced it in size hopefully to fit into our trash container by stripping off the drying leaves, and breaking the branches off shorter.

Though I was finally smart enough to wear gloves, the area from my wrists to my elbows sustained maybe a dozen skin breaks and scratches from the breaking twigs. The job took about an hour.

Afterward, I washed up thoroughly, and dotted the little skin breaks with Neosporin. You'd think that would be enough.

The next night I was awakened by frantic scratching in my sleep--a chigger bite on right wrist that drove me nuts for several more nights before it eased off, and I could turn my attention to the other little scratches that were healing.

Some of the spots had already healed, the tiny scabs having come off during baths...but on my left arm there were two scabs that did NOT come off...and those spots did not appear to be healing at all.

They were angry red, slightly larger than the size of a BB for a BB gun, with a tiny hole in the center. I remembered an earlier tick bite dating back to 1991 which had had a disastrous outcome when I had been re-infected with Lyme disease. Being extra careful I used sterile needle-nose tweezers to probe the red hole to see if I could extract anything.

If there was anything there, it was too small to see in the tiny drops of blood, but as I

rubbed the stain between my fingers, I felt something like a grain of sand. Too small for me to identify.... I touched up the two lesions with Neosporin and forgot about it....or tried to. I kept remembering that a dangerous infectious tick is often the size of a sesame seed, or the period at the end of sentence in a book. But, no, I hadn't found anything much in either of the lesions which lay about three inches above my wrist watch, and about two inches apart.

But on the one lesion closest to my wrist watch, the size of the red area increased over the next few days. Still, it didn't hurt, nor did it itch like a chigger, or anything at all. The redness reached the size of a nickel over the course of last weekend, and still thinking "Bulls-eye?", I noted on Monday that it was no longer getting larger.

The depth of the redness around the center was beginning to fade, so my husband and I thought we'd better record this with a photograph, as recommended on the website of the Texas Lyme Disease Association, [www.txlda.org](http://www.txlda.org), and [www.ticktexas.org](http://www.ticktexas.org).

We lay a ruler beside the red target, noting that it was between one-half inch and three-quarters of an inch in diameter, and took a digital snapshot of both the lesion and the ruler to record that it was about the size of a thumbnail.

On Tuesday I noted it was a little puffy in the circle area, raised a bit above the surrounding skin. The other lesion still had a bright red deep scab, but no tell-tale bulls-eye. OK -- two tick bites, one infectious and one not. Duh-- Finally coming to my senses about the needless delay in getting a doctor to look at it, I went right in on Wednesday.

The doctor examined lymph nodes in my armpit and found them apparently unaffected. After checking the protocols, he told me that because I am already taking a sufficient amount of daily antibiotics prescribed for Lyme disease, I would not have to take anything in addition. He felt sure the amount I was taking would protect me from developing acute Lyme disease.

Appropriate antibiotics are routinely prescribed for a person having a tell-tale bulls-eye rash from the bite of an infected tick. If the bulls-eye rash appears, the acute infection of Lyme disease has already been transmitted to the person.

Immediate treatment for the acute phase prevents the long-lasting painful effects of chronic Lyme disease which can develop when the acute phase is ignored and thus remains untreated.

Who needs a flu that never goes away? Check for ticks every single day if you have been outdoors! For the first 20 to 36 hours that a tick has been attached to the skin of a host (that's you), the tick is actively sucking up blood with an intake mechanism. During these hours (no one knows for sure just exactly how long)

*“Odds”...cont'd on pg 8*

## The Faith Factor... by Joan Vetter

### Fight the Good Fight



Everybody loves a winner. Whether it's Rocky Balboa or Lance Armstrong, the world is ready to cheer them on and happy to see them finish well.

As Christians we are told to fight the good fight of faith, but sometimes it looks like we're going down for the count. We all need those cheerleaders in our corner who are shouting, "You can make it - I believe in you." However, the dominant voice has to be God himself assuring us we can do all things through Christ.

Scripture clearly tells us that we are engaged in a fight. We are given promises in the book of Revelation to those who overcome. If there were no battles, what would we have to overcome? We are also told to endure hardness as a good soldier of Jesus Christ.

A key to winning any skirmish is persistence. How

quickly do we fold under pressure? How often do we believe the lie that we just can't make it? Jesus tells us the parable of a friend who comes at midnight knocking on our door. Well, let's be honest - who would be thrilled to hear even a close friend yelling, "Get up and open the door - I want three loaves of bread." I'm sure the answer would be similar to the one given in scripture, "Do not trouble me; the door is now shut, and my children are in bed - I can't rise and give it to you." Or in today's language, "Give me a break - why can't you just go to Wal Mart and buy it for yourself at this hour?" But in this parable Jesus is teaching us the value of persistence. In fact, he even states that persistence wins over friendship.

Often we look at strong-willed people in a negative way, but when our will is aligned with God's will this can be a real attribute. I once heard a man share about his strong-willed daughter. He was in the ministry and kept telling her they could not afford to send her to a certain college. This never fazed her. She just kept saying God will provide.

Suddenly large donations began to come into his ministry. However, there was always a stipulation - "this money is for your daughter's college tuition." By the time she was ready to go to college she was able to go to the college of her dreams.

The dictionary defines the word "persist" as "to persist in a state, enterprise, or undertaking in spite of counter influences, opposition, or discouragement." Thank God that Jesus set His face to go to Calvary. I'm sure He continually needed the power from His Father in Heaven to endure the humiliation, the disappointment in his friends who went to sleep when he needed them, the fear of pain, and the unknown. Because He persisted, we know that we now have a High Priest who can sympathize with our weaknesses, having been tempted in all points as we are. Therefore, let's allow the Word in Hebrews 6: 12 to work in our lives, "that each one of you show the same diligence to the full assurance of hope until the end, that you do not become sluggish, but imitate those who through faith and patience inherit the promises."

Press on!! *pha*



## Sitting on the Fence: Looking at Lyme Disease

by Johanna Lake

I recently attended a medical conference and the notes I took during a doctor's speech on Lyme disease contain the exclamations "Ha!" and "Right!" as if new information was delivered. It was not. After studying under a well-known Lyme disease treating physician, the doctor's speech supported more of medicine's narrow view that Lyme-is-a-simple-easy-to-treat illness (Camp A) position, than it supported the broader view that Lyme-is-a-complex hard-to-treat illness (Camp B) position, espoused by the International Lyme and Associated Diseases Society (ILADS).

Speaking to a packed conference room, the doctor dismissed wood ticks, "We don't worry about the bigger ticks [as carriers of Lyme disease.]" The doctor noted the common Lyme disease co-infections-- Babesia, Ehrlichia, and Bartonella, and explained the disease process of each, (more than the average doctor can do) but failed to point out: mainstream medicine knows that Ehrlichia and Anaplasmosis can be transmitted by ticks and mosquitoes.

Multiple symptoms of Lyme disease are hard to put together, the doctor told the audience, and patients often have explanations for various symptoms. A patient might attribute a swollen knee to an old football injury flaring up or tell the physician "It's just arthritis like my mother had." The doctor placed blame on patients for changing doctors, leaving records and tests behind, and noting current symptoms while forgetting to mention past symptoms. The doctor explained that Lyme disease's pattern of migrating pains further complicates "teasing out" the tick-borne illness.

What sounded like excuses for physicians missing Lyme disease diagnoses are actually hard-to-swallow truths for those suffering long-standing infection. For people like me, who vociferously declared the cause of their declining health to be Lyme disease, these truths are even harder to swallow. The doctor advised physicians in the room to consider Lyme disease when a patient presents symptoms that don't exactly fit the pattern of the most likely diagnosis. Two

examples given were Fibromyalgia with balance problems and weakness with memory impairment.

Already ticked off over wood ticks falling by the wayside, my level of irritation increased when the doctor attributed the *Acrodermatitis chronica atrophicans* (ACA) rash to forms of Lyme disease found only in Europe. ACA was described and reported in 1970 by Wisconsin dermatology professor Rudolph Scrimanti and if my neighbor had taken a picture of her father's classic ACA rash last year, I could prove this symptom of Lyme disease infection continues to decimate lives in Wisconsin, especially when misdiagnosed as Shingles or Reflex Sympathetic Dystrophy.

I wondered if the rest of this conference would be based on mainstream medicine's commonly-held beliefs about Lyme disease.

The answer was a resounding YES. He went on to describe how an immediate rash or swelling from a tick bite was a reaction to the tick saliva and not the beginning of Lyme disease. He insisted that ticks have to be attached at least twenty-four hours to transmit the illness and that if you found a tick that had been attached to you longer than twenty-four hours, you could ask a physician for the one-dose treatment, in case the tick carried Lyme disease. Was this doctor going to treat Lyme disease patients until they were well? Wouldn't a doctor spouting the twenty-four hour rule be spouting "easy-to-cure" three-week treatment next? That had been my experience.

I'd seen fence-sitting posture before in a Lyme-treating doctor:

The initial appointment my father and I had with an Infectious Disease doctor willing to treat my father's symptomatic, Centers for Disease Control (CDC) positive, neurological Lyme disease went well. The doctor and I agreed that a central line for antibiotics would be risky because my father suffers severe short-term memory loss. We thought he'd forget in minutes what a central line into his

heart was for, that he'd pick at a port or pull out a p.i.c.c. The doctor put Dad on an oral antibiotic, Cefuroxime (Ceftin), and planned to add another antibiotic to the treatment regimen a month later.

Dad's cognitive skills improved by the next month's visit and his memory and social skills showed significant improvement at the following month's appointment though Dad's Lyme-induced deafness left him out of the conversations his Lyme-treating doctor and I shared. At the end of the fourth or fifth visit the doctor told me Lyme disease can't be caused by anything other than the bite of a deer tick. I left his

"What doctor, I wondered, would not put a patient directly back on prescribed medication if a drug had been missed during treatment for tuberculosis or during cancer chemotherapy?"

office wondering why he felt he had to tell me this. Was he staking a position he knew I'd disagree with?

At the next appointment the doctor told me if his Lyme disease patients weren't making marked improvements after six to eight months, he believed they had recovered as much of their health as they could hope to recover. According to his timeline for Lyme patients (curiously equal to the outside limits doctors can push insurance to cover) those not responding to his prescribed treatment would be dismissed or sent on to specialists eager to confer diagnoses of syndromes and conditions whose origin or etiology could not possibly stem from Lyme disease.

Through the Lyme grapevine I learned Dad's doctor didn't treat for co-infections, didn't treat with Metronidazole (Flagyl) or Tinidazole (Tindamax), and used a one-size-fits-all approach to antibiotic therapy. I knew one of this doctor's dismissed patients had continued to improve after he began treatment under the wings of a committed Lyme doctor who doesn't ride the fence.

My father hadn't hit the eight-month wall and logistically there wasn't anyone else to treat my dad, so we continued to see the doctor each month even though every time I heard him referred to as an ILADS doctor, I'd cringe.

Two weeks after my dad was dismissed as a patient, I learned the marked improvement noted in month three of Dad's treatment occurred during combination antibiotic therapy that had been discontinued after one month. Nurses at my dad's assisted living facility stopped giving the second antibiotic the doctor had added and stopped reordering the medication from the pharmacy for reasons no one could explain. Dad's Lyme disease recovery had been stopped short.

I called the Lyme-treating doctor, struggling to control my anger over circumstances that had wasted months of my dad's life, whole days of driving for me, and hours of the doctor's time. Without making excuses for anyone, I told him what had happened to dad's medications. He told me the nursing staff had already called to let him know about the error. I asked him to resume Dad's treatment. He said no. He would not resume the combination antibiotic therapy my dad should have received for the previous seven months. In my mind's eye the doctor no longer rode the fence; he fell backwards into Infectious Disease oblivion, pulling my dad with him. What doctor, I wondered, would not put a patient directly back on prescribed medication if a drug had been missed during treatment for tuberculosis or during cancer chemotherapy?

Last winter, my Lyme-induced ear and balance problems drove me to seek out an Ear Nose and Throat (ENT) doctor reputed to be Lyme-friendly. In exactly seven days, the ENT's kind demeanor--"I had a friend with Lyme disease and we had to go to two different Infectious Disease doctors to get her treatment," changed to--"Lyme disease doesn't cause inner ear problems." The turn-about cemented my nascent Lyme-leery antennae in place.

In the last six years

Lyme disease slowly altered my trusting mentality. It took me far too long to understand the Infectious Disease doctor who treated my dad was a Burrascano wannabe who thought he had treatment for Lyme all figured out. He thought his treatment regimen would make him *the* Maverick in a field of mavericks.

Finding a doctor to treat my dad turned out to be a disaster but I learned something: What's said by a doctor in the doctor's office is usually what the doctor says in public. I'd thought of lending my support to the doctor who spoke through self-proclaimed Camp B lips. However, the Camp A message the doctor chose for the conference room audience that day gave me second thoughts:

Maybe that doctor does want to help people who have Lyme disease and the Power Point presentation was a well-meant attempt to change firmly entrenched, typical beliefs about the illness commonly held by mainstream physicians. If that was the goal, what beliefs had been challenged in the talk? Where was the new information they needed to hear? And if the doctor really believed every word said, should the doctor be considered Lyme-literate? On the other hand, if the talk was a sham and the doctor felt the need to act and speak one way before peers and planned to act and treat another way in clinic, could the doctor be trusted by members of either camp? I left the conference room wondering if my antennae had picked up the beginning of another Camp A victory.

Since the talk, I've re-examined my Lyme disease stance: Patients and their doctors have to share the same beliefs; you're either in the corral or you're out. There's room on the fence only for those who don't fully believe in the tenacity, mobility, and capriciousness of the beast we're trying to lasso. Much of what I believe to be true about Lyme hasn't been proven in studies, though anecdotal evidence grows every time I see a spreading bull's-eye rash under an attached wood tick. Important questions about Lyme disease transmission and treatment need to be answered but fence-sitting threatens every inch of ground the truth about Lyme has gained. *pha*

# THE HIDDEN EPIDEMIC

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# What Parents Need to Know About Alcohol and Drug Addiction

an Interview with John Flemming, M.D.

by Sue Vogan

A native of Mississippi and a graduate of the University of Mississippi Medical School, John Fleming, M.D., currently lives and practices family medicine in Minden, Louisiana. During his medical residency he trained at the drug and alcohol treatment unit at Navy Regional Medical Center, Long Beach, California, which was then a pioneer in chemical dependency treatment. That program influenced his medical practice, and also helped shape the way he and his wife, Cindy, raised their four addiction-free children.

Dr. Fleming, a board certified Family Physician, understands how critically important it is to protect kids from making poor decisions. In addition, his knowledge of attention-span disorders and depression adds a crucial dimension to his advice to parents.

Dr. John Fleming was recently notified that he had been selected as "Louisiana Family Doctor of the Year" for 2007 by the Louisiana Academy of Family Physicians. He will receive the honor on June 23rd at the annual convention. His name will also be submitted for the "American Family Doctor of the Year" for 2007 award that will be presented in the fall.

Dr. Fleming's particular interests are drug addiction, depression, ADD and chronic diseases. His book, *Preventing Addiction: What Parents Must Know To Immunize Their Kids Against Drug And Alcohol Addition*, is available at all fine book stores, Amazon or by visiting Dr. Fleming's website at [www.johncflemmingmd.com](http://www.johncflemmingmd.com)

**Dr. Fleming, please define addiction.**

Addiction can be defined as the persistent use of an ADDICTING substance despite its damaging effects on one's job, health or personal relationships. One can also expand this by adding that it occurs when addicting substances distort the normal feedback mechanism of the "reward center" of the brain, aka the Ventral Tegmental Area, which is mediated by the neurotransmitter, dopamine.

Of course one can be addicted to both legal and otherwise benign substances like beer, airplane glue or even tranquilizers and prescribed narcotic pain pills. On the other hand, some substances which are considered very addictive and of no medicinal value like methamphetamine or heroin are illegal to use from the start.

**When does addiction or the behavior that could lead to addiction begin?**

Addiction is a stepwise process. Though it follows the classic six steps listed below, for practical purposes it exists in three stages: experimentation, transition and completed addiction. Short of completed addiction, I don't think there is any way to know when addiction has taken place which is why early diagnosis is so problematic. Even at the final stage, the addict may so effectively hide his addiction (and personally deny it), that those around him are totally unaware of it. The only chance to prevent addiction exists in the experimentation stage and maybe in the transition stage if counseling and intensive monitoring---breathalyzer, home drug testing, etc are implemented.

A good example is that of a very close friend of mine when I was in my twenties and in medical school. He was a young pharmacist. We would occasionally go out and "paint the town" by

going to bars and getting intoxicated. We were both abusing alcohol to be sure and nobody could observe the two of us and predict who would have an addiction problem. As it turned out, my friend began drinking alcohol at a very young age and I began much later at 19. After going out and getting intoxicated, I would go home and go to bed. He would stay up the rest of the night and inject narcotics into his veins that he pilfered from his drug store. I was totally unaware of this until he was arrested. With time I gave up abusing alcohol for a rewarding family life. He has struggled with addiction since. I can relate several other similar experiences with others close to me in my life.

This is why it is not wise for parents to passively wait for "signs" of addiction. Kids may be working their way through the transition stage and into completed addiction and a parent may have no clue that they are addicted or even experimenting. Conversely parents should assume that their kids will experiment with alcohol and be tempted to experiment with drugs. Only then will they be in sync with what is actually happening in most cases. With the suggestion of ANY addictive substance experimentation, the alarm bells should go off and they should be loudest for the youngest kids based on the research in my book. If they parent is overly vigilant (as I have been at times) there is no harm. It sends a strong signal that you will not tolerate drug use or underage drinking.

**There are 6 classic steps to addiction you outline in your book, please elaborate on each:**

**Experimentation**

Virtually all kids will experiment with addicting substances in some way or at some point in their lives. The drug of choice 99% of the time will be alcohol. There is a tremendous overlap of tobacco, though its use among youth has dropped dramatically in recent years---a very good model for alcohol.

**Usage Increase**

Because the "point" of drinking or drugging is to get high, kids will want to participate more and more frequently as each experience is pleasurable. This is the "reward system" doing its job. God intended this reward system as an adaptive mechanism to encourage us to do things that improve our survival---eat, have sex, etc. Addicting substances pervert this process and do just the opposite, make us adapt toward destructive behaviors.

**Tolerance**

Drug addicts often comment that their first high was the best. Every use of drugs after that is done in order to regain that first experience. The reason is that the brain and other organs adapt to the effects of addicting drugs. Receptors in the brain "down regulate" such that more drugs are required to achieve the same effect. In the case of many drugs, especially alcohol, the liver creates much higher levels of enzymes to quickly metabolize the substance.

An example of this process is that of some alcoholics who are arrested while driving intoxicated have been found to have alcohol levels as high as 0.45 (legal limit is 0.08 in most states). The average non-alcoholic would be dead with that blood level, yet some, severe alcoholics can be conscious

enough to drive a car at that level!

Another example is that of heroin and methadone addicts (who are at highest risk of accidental death from overdose.) Typically they use higher and higher doses trying to achieve that fleeting euphoria, all the time increasing their tolerance levels. Then, for whatever reason, they take a break from using. Their physiological tolerance levels begin to drop. Then they use again starting with their last known dosage. Unfortunately the old dose is now too strong and they die because the entire brain is shut completely down including the brain stem which is designed to be the last to go as it controls basic bodily functions of life such as breathing and heart rate.

As a whole, addicts have a much higher tolerance level to all addicting substances in general. My anesthesia colleagues comment to me about sporadic cases of patients they have trouble putting to sleep for surgery because of their high tolerance levels to drugs which is found after the fact to be due to drug or heavy alcohol use. Even ER physicians see this phenomenon occasionally when they inject local anesthesia into a wound of an alcoholic patient in order to close a laceration. Their tolerance may be so high that the lidocaine local anesthesia doesn't even work.

**Physical dependency**

This is a poor prognostic sign of addiction. Physical dependency means that they body has so accommodated itself to drugs that it cannot function properly without constant dosing. Two examples of this are Delirium Tremens (DTs) from alcohol withdrawal which is

very dangerous and going "cold turkey" which is a term that refers to the extreme discomfort and "goose bump" effect that narcotic addicts undergo with withdrawal. Even the extreme anxiety of a "nicotine fit" is a type of physical dependency to tobacco. All addicting substances have some type of withdrawal syndrome due to physical dependence.

**Psychological dependency**

If it were not for psychological dependence, we could cure addiction. An addict can be easily weaned from drug dependency under the right conditions. But what cannot be removed from the brain of an addict is the infinite desire to achieve that first euphoria, again. If you can imagine not having eaten for 24 hours and sitting down to a table while others eat magnificent food before you and then extend that hunger sensation times 24x7, 365 days a year, you will begin to understand how powerful is the desire of psychological dependence. No wonder that less than 4% of addicts go into permanent remission and none are ever cured. Drugs have changed the brains of these people FOREVER!

**Addiction**

The addiction stage is the completion of the addiction process. It is at this stage that people around the addict begin to suspect that the victim is an addict. Though he may not behave abnormally or destructively at first, most people will recognize something is not right.

*"Addiction"...cont'd on pg 14*

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# MEDICAL PERSPECTIVES

## “Odds” ...cont'd from pg 5

enzymes are developing in the tick's midgut, preparing its infectious bacteria for injection into the host. If you remove a tick before this time has lapsed, you stand a good chance of avoiding infection even if the tick is a very sick one.

I wish I had suspected those spots the first day and removed the

almost invisible ticks before they dug so deep.....because even though a doctor has 'cleared' me, my left shoulder is now aching...and that has never, ever happened before. Is it merely the power of suggestion? ...or will I wake up groaning tomorrow and have trouble bending my wrist to read my watch? Stay tuned.... *pha*

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# Got Sleep? A Deeper Look at Sleep Apnea



by Angela Mrema, RCP, RRT

Everyone knows what sleep is because few of us get enough of it, but how many of us know about sleep apnea? Since we know what the word sleep means, we'll define the word apnea. Apnea is a Greek word that means "without breath". If we were to combine the words together, sleep apnea can be defined as sleep without breath. Of course at some point during the night, one does breathe, but when someone suffers from sleep apnea, they stop breathing many times during the night. This pause in breathing may last 10 seconds, 20 seconds, or

more. Some people experience this up to 30 times within one hour of sleep.

There are different types of sleep apnea. They are central, obstructive, and mixed. Central sleep apnea occurs when the brain forgets to send a message to the muscle to breathe. Obstructive sleep apnea is the most common. It is caused when the airway is blocked by the base of the tongue. During the day, the airway is open because the muscles at the base of the tongue keep it open. At night during sleep, these muscles relax causing the tongue base the collapse and obstruct the airway. The person is usually awakened by a loud snort or a choking sound. Sufferers of sleep apnea often do not know they have sleep apnea. It is usually the person that sleeps next to the sufferer or a family member that notices the symptoms first. They may notice that the person has long

pauses in breathing or may snore loudly, become quiet, then wake up with a snort. Mixed sleep apnea is a combination of central and obstructive sleep apnea.

Sleep apnea is a common disease that affects more than twelve million people in

Untreated sleep apnea has many affects on the body. A person who suffers from sleep apnea may feel sleepy during the day. This person is sleepy because they have had many waking episodes during the night and are unable to reap the benefits of deep sleep. They may never get to the REM (rapid eye movement) stage that is required for a person to feel rested. Sleep apnea may also increase the chance of high blood pressure, memory problems, weight gain, headaches, and impotency. Sleep apnea may also cause job impairment, due to lack of concentration and memory, and may be the cause of some motor vehicle accidents.

What are the risk factors for sleep apnea? Who is more likely to get it? Some risk factors for sleep apnea are: excessive weight gain (the

accumulation of extra fat on the sides of the upper airway cause it to become narrower when the muscles relax), age (loss of muscle mass is common as we age), being male (the male hormone causing structural changes in the upper airway), and other factors such as smoking, and family history (although it has not been proven that is linked genetically).

The good thing about sleep apnea is that it can be diagnosed and treated. So if you are someone you know has the signs or symptoms, consult your doctor about it. It's better to do something than nothing at all. *pha*

Sleep apnea may also increase the chance of high blood pressure, memory problems, weight gain, headaches, and impotency. Sleep apnea may also cause job impairment, due to lack of concentration and memory, and may be the cause of some motor vehicle accidents.

America. Even though it is common, many people go undiagnosed because they are unaware of the symptoms to look for, or may not have even heard about the problem.



## “Psychiatrists” ...cont'd from page 1

bite or develop the signature erythema migrans "bullseye" rash. As a result, many patients go untreated and develop psychiatric and/or neurological symptoms.

Lyme disease sometimes begins as a flu-like illness accompanied by fever, headache, sore throat and joint pain. After infection, patients may develop cardiac or early neurological problems including meningitis, encephalitis and cranial neuropathies.

Look for eyelid droop, facial weakness, numbness or pain, shoulder droop, sensory distortions or any other focal neurological signs. There may be a history of neck pain and stiffness or muscle twitching. Some patients may have arthritic symptoms in single or multiple joints. Most patients mention this to a psychiatrist only if directly asked.

At any time after a tick bite, patients may also exhibit cognitive symptoms such as memory and concentration impairments and word-finding difficulties, ADD/ ADHD-like symptoms, learning disabilities, OCD, crying spells, rages, depression/bipolar disorder, panic/anxiety disorders and psychoses - all may be caused or exacerbated by Lyme disease.

Disorders of the nervous system have been found in 15 - 40% of late-stage (tertiary) Lyme patients (Caliendo et al, Psychosomatics 1995;36:69-74).

When Lyme disease affects the brain, it is often referred to as Lyme neuroborreliosis or Lyme encephalopathy. Usually the patient is totally unaware of its presence. Neuroborreliosis can mimic virtually any type of encephalopathy or psychiatric disorder and is often compared to neurosyphilis. Both are caused by spirochetes, are multi-systemic,

and can affect a patient neurologically, producing cognitive dysfunction and organic psychiatric illness. Such symptoms may be dormant, only surfacing years later.

Dr. Brian Fallon, director of the Lyme Disease Research Program at Columbia University and principal investigator of the NIH-funded study of brain imaging and persistent Lyme disease cites five questions that imply warning signs of possible Lyme encephalopathy:

\*Are there markers of non-psychiatric disease such as erythema migrans rash, arthralgias or arthritis, myalgias, severe headaches, sound or light sensitivity, paresthesias, diffuse fasciculations, cardiac conduction defects, word finding problems, short-term memory loss, tremors, cranial neuropathies, and/or radicular or shooting pain?

\*Is this psychiatric disorder atypical or unusual? For example, does a panic attack last longer than the expected 1/2 hour? Or is it a first ever panic attack at age 50?

\*Is there poor or paradoxical response or excessive side effect sensitivity to medications that are expected to be helpful for particular psychiatric symptoms?

\*Is this new-onset disease without psychological precipitants such as new stressors or secondary gain?

\*Is there an absence of a personal history or family history of major psychiatric disturbances?

Negative answers to these questions do not rule out the presence of Lyme disease. But a "yes" to most of the ques-

tions, especially in a patient with an out-of doors lifestyle or a pet, demands further clinical assessment. Dr. Fallon recommends Western Blot serologic studies, lumbar puncture, neuropsychological testing, brain MRI and SPECT (single photon emission computerized tomography) scans. For more information, see [www.columbialyme.org](http://www.columbialyme.org).

Other helpful tests may include PCR for *Borrelia burgdorferi* in blood, serum, cerebrospinal fluid (CSF) and urine, and/or *Borrelia* antigen testing in urine and CSF. Because blood tests at the top three general medical laboratories in the nation fail to detect 35% of Lyme antibodies, ILADS recommends use of laboratories that specialize in Lyme and other tick-borne illnesses. Contact [www.lymediseaseassociation.org](http://www.lymediseaseassociation.org) for a listing of recommended labs. Blood tests should not be used to rule out Lyme disease when there is a strong clinical presentation. Dr. Robert Bransfield, a psychiatrist who specializes in infectious causes of neuropsychiatric illness, has developed a structured clinical interview to assess seronegative patients. See [www.mentalhealthandillness.com](http://www.mentalhealthandillness.com)

### What to Do?

Screen patients for Lyme symptoms, especially those with complicated or atypical presentations. Be suspicious of Lyme if a patient mentions cognitive changes, extreme fatigue, weight changes, headaches, fibromyalgia, a history of "mono," "spider bites," multiple sclerosis, explosive rages or sudden mood swings. To elicit data about cognitive problems ask broad questions such as, "How do you think your brain is functioning?" or "How many things can you handle at one time?"

Consider Lyme disease in children with behavioral changes, fatigue, school phobias, academic problems, learning disabilities, headaches, sore throats, GI complaints and/or migrating pains. In teens, Lyme disease may be complicated by drug abuse.

The Lyme spirochete is slow growing and can be difficult to treat, so be sure the patient is treated with appropriate antibiotics for at least two to four weeks beyond symptom resolution. Most individuals with Lyme disease respond to antibiotics, but the treatment course is highly patient specific. ILADS has published evidence-based guidelines for the diagnosis and treatment of Lyme and associated tick-borne diseases (Expert Rev Anti-Infect Ther 2004 ;2(Suppl):S1-S13). For more information, visit the ILADS website at [www.ilads.org](http://www.ilads.org).

### Some of the common symptoms of late-stage (tertiary) Lyme disease and other tick-borne coinfections:

- \* Profound fatigue
- \* Chills, sweats and skin flushes
- \* Night sweats
- \* Migrating arthralgias
- \* Muscle pains/twitching
- \* Sleep disturbances
- \* Severe headaches
- \* Shifting neurologic pains
- \* Tremors, shakiness
- \* Numbness, tingling sensations, pain often shifting and unusual in type
- \* Cranial nerve disturbance (Facial numbness, pain, tingling, paralysis, optic neuritis, trouble swallowing, distortion of smell or taste)

The more severe neurological symptoms or disorders associated with late-stage Lyme disease:

- \* Progressive dementias
- \* Seizure disorders
- \* Strokes
- \* ALS-like syndrome (similar to Lou Gehrig's Disease)
- \* Guillain-Barre-like syndrome
- \* Multiple sclerosis-like syndrome
- \* Parkinson's disease-like syndrome
- \* Other extrapyramidal disorders
- \* Visual disturbances or loss

Checklist of common cognitive impairments in Lyme disease (from Marian Rissenberg, Ph.D., clinical neuropsychologist)

Losses in fields of attention/executive functions such as inability to maintain divided or sustained attention, auditory and mental tracking and scanning, and memory retrieval can affect: Memory functions (lost items, missed appointments, retold stories), language functions (halting speech, disrupted participation in conversation), visual/spatial processing (inability to find things, tendency to get lost, disorganization, difficulty reading, especially for enjoyment), abstract reasoning (poor problem-solving/decision-making), and slowed processing speed (familiar tasks take longer, can't follow conversations well).

Most or all of these impairments, if caused by neuroborreliosis, may improve with proper antibiotics combined with other appropriate symptomatic treatments. *pha*

Edited by :  
Drs. Virginia T. Sherr and Debra J. Solomon, Psychiatrists

For More information about ILADS go to:  
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## “Misdiagnosed” ...cont'd from page 4

the local public school. This was something that I never dreamed could ever happen. Once again he was able to stop taking all psychiatric medication. It seemed like his bipolar symptoms had just disappeared. For the first time, he was actually learning to read. I thought life was close to perfect. In February 2006 Nick had a violent fit in which he tried to hit someone in the face with large stick. He had several more fits and panic attacks and he began running out of the classroom and down the street. The police had to be called to look for him. One day they found him after an extensive search-- on the railroad tracks with a train approaching. He was put back on psychiatric medication, but his condition only got worse. We were once again frequent guests in the ER.

Dr. Jones tested him and he was again positive for Lyme and Mycoplasma Fermentas. This time Nick did not respond immediately to the antibiotics. Soon Nick was being transported to hospitals handcuffed in the back of police cars. He was suspended from school, and then expelled, placed in a special school for children with psychiatric disorders, only to be expelled from that school, after he ran away and the police found him hiding in a swamp. He spent a week hospitalized at Notching Hospital and then another week in the adult psychiatric Unit of Danbury Hospital. He would spend days

at the ER only to go home when no pediatric bed could be located or no hospital would accept him.

Finally after 4 months of chaos, he was taken to the ER of Misstate Hospital in a police car and from there to Hall Brooke Hospital in Westport. The admitting doctor told me point blank not to expect him to be released. A child like Nick was far too dangerous, he was going to need long term institutional care.

The situation did not look hopeful for Nick. He was placed under 24 hour "constant observation " after he woke up in the middle of the night, ran into another patient's room and tried to strangle him as he slept. Sometimes the hospital had two staff members watching Nick at the same time. No words can ever describe how I would feel as a mother, when I would arrive at the hospital to visit, but would be told that I could not be allowed to see him because he was in restraints and was receiving shots of Zyprexa or Thorazine. I would be able to hear his screams. I can only imagine what he might be going through, but I was not allowed to touch, see or comfort him. Nick could never offer an explanation for his behavior.

Dr. Jones wanted to change Nick's antibiotics to see if that would help him, but the hospital refused to cooperate. I would download information about Lyme disease and mental illness but the hospital staff

remained unconvinced that the two conditions were at all connected. I related our past experiences in great detail, of how Nick had been extremely violent, how it seemed that he would never live outside of an institution, and how he had been miraculously cured by being treated for Lyme and its co-infections. No one would believe me. I understand that what I was saying sounded almost incredible. How could anyone believe that a different set of antibiotics could transform a child as sick as Nick into a different person? I believe in my heart that the doctors and staff working with Nick were kind and compassionate people and that they really wanted to help him. But I succeeded in convincing no one. The hospital continued trying different psychiatric drug combinations without success. And they continued to decline my suggestion to try the different antibiotic combination that Dr. Jones was suggesting.

I faced a terrible dilemma. If Nick remained in the hospital, it appeared that he might not be given the treatment that might help him. But even if I did manage to get him out of the hospital he was so violent and so strong at the age of 12 that he could have easily killed himself or someone else. It took several grown men to hold him down when he would go into an episode. And his episodes of violence were happening almost every day, usually several times a day. He

remained in the hospital for what turned out to be a long hot summer. The hospital did bring a Lyme Specialist in to see Nick, but she did not think that Nick had Lyme disease. Finally in the last week of September, the state informed me that the papers had been filed to have Nick admitted to a long term facility. I was told he could stay in that facility until he was 21, then we would have to find another placement. I was told that the state was trying to expedite this, as quite frankly, I was told that Nick had worn out the hospital staff. On the last Friday of September I began to pray that the treating psychiatrist would have a change of heart. On Monday he told me that he had changed Nick's antibiotics. By the end of the week, this doctor told me that "Nick was a different child and that it had to be the Lyme treatment. There was no other explanation for the change in his behaviors." I will always be grateful for the humility and courage this doctor showed.

Nick continued to improve. It took about two months to convince the State Department of Children and Families that Nick would not kill anyone if he was released. But by Christmas I received the only gift I really wanted. Nick was able to come home. He had been hospitalized for 6 long months.

I immediately sold my home on two acres next to the woods. It was a down market and I gladly reduced the price. I

only wanted to be out before spring. I moved to an area near downtown Danbury, a small city along the Connecticut and New York border. It is a very different type of neighborhood, but to tell you the truth, the day we moved out, I felt a sense of peace and the nagging feeling in my stomach was quiet.

I try to avoid thinking about how, if Nick were re-infected and were to once again exhibit extreme psychiatric behaviors, he could end up in a hospital, jail, or institution, or be denied treatment and spend the rest of his life locked up on physical and chemical restraints.

Sometimes I think about the other children who were in the hospitals with Nick. I often wonder how many of those children might test positive for Lyme or its co-infections and if they might be helped with treatment.

And that is why I am writing Nick's story.

It is July as I write this. Nick has been out of the hospital for 7 months. In our small back yard he looks for crickets and toads, he attends summer school, he really loves the rides at carnivals, and he has just started to notice pretty girls. He is a very different from the boy who smashed the furniture in his hospital room last summer.

pha

Donna Benner is an Art teacher in the public schools, Lyme patient and mother to Nicholas.

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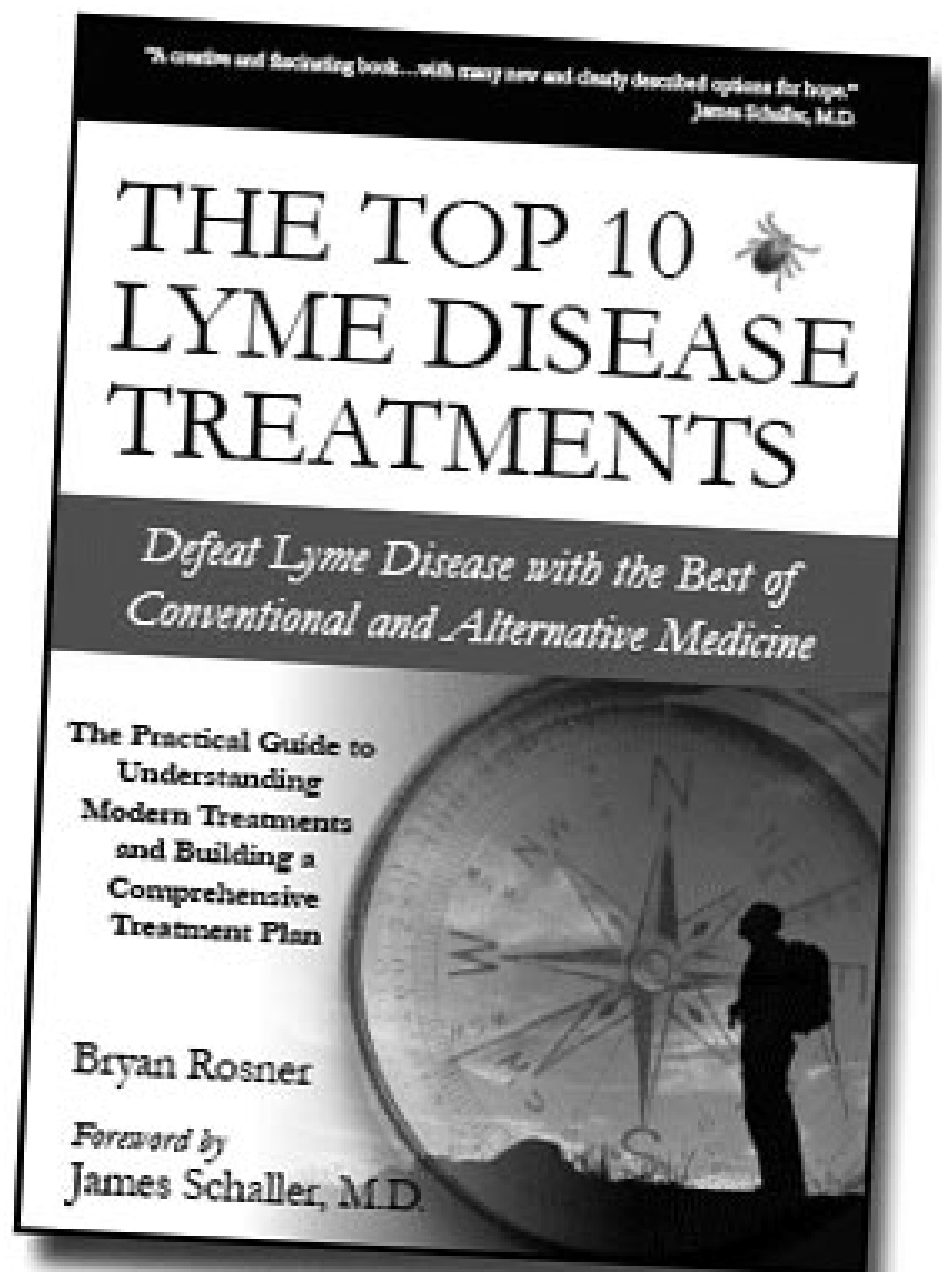
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### Greater Austin Area Lyme Council.

Teresa Jones  
tmomintexas2@yahoo.com

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Alexis Benkowski  
WA-Lyme-owner@yahoogroups.com

### WI / IL / MN Regional areas

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### Lyme Coalition of N. Wisconsin

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## WildCondor's World

## Lyme Disease Information & Links

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## Texas Lyme Disease Association



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## CALLING ALL TEXAS LYME PATIENTS AND CAREGIVERS!

STAND UP FOR LYME (SUFL) invites you to join our email list to receive news of advocacy activities and events promoting awareness of and solutions to issues faced by Texas patients.

To join the list, go to [www.standupforlyme.org](http://www.standupforlyme.org) and click the "Contact Us" link in the left hand side menu bar. Then have a look around the site to learn more about Lyme in Texas and the nation.

SUFL has been busy cultivating important state legislative supporters to develop a strategy which will lead to protection of our Lyme Specialists, and our work continues.

We are planning important future events for all to participate in. Please join the SUFL list for news and coming announcements with all the details!

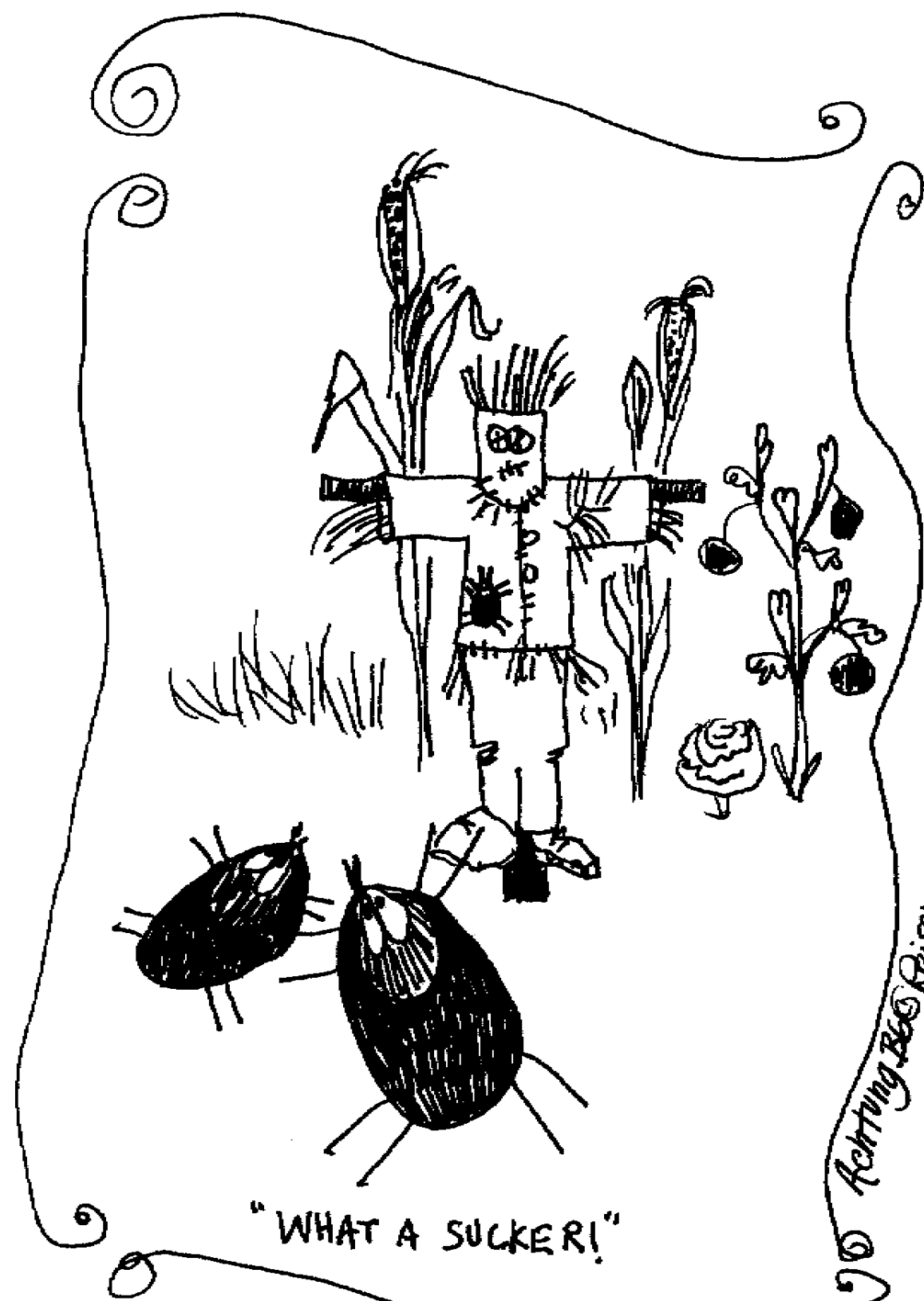
Working together we can make Texas a leadership state for quality care of those suffering from Lyme and associated vector-borne diseases.

Join us!

The STAND UP FOR LYME Team

[www.standupforlyme.org](http://www.standupforlyme.org)

## Ticktoons



by Terri Reiser



# Neuro-Lyme in the Courtroom is No Laughing Matter

by PJ Langhoff

As I sat on the witness stand in our latest family court trial (there have been 3), I listened to the uninformed opposing counsel attempt to bring into our post-divorce case, snippets of supposedly scientific information meant to illustrate to the judge and others present that I have a "mental illness", and that illness is caused by Lyme disease—an illness that he formerly claimed I didn't have either, until we paid an expert physician to testify that I did indeed, have Lyme, (bolstered by a long history of clinical symptoms, known tick exposure and positive blood tests) and the court has been told this numerous times but at least up until this trial, refused to accept it as fact.

Being a Lyme patient for more than 15 years, and having spent the previous 10 within family court due to post-divorce custody issues revolving around discrimination of a woman with a chronic illness, it was not exactly a real shocker to see opposing counsel attempting to use anything and everything at his disposal in order to try to win an argument. I laughed audibly when, after I testified that in 10 years not a single doctor had tested me for Lyme disease, I watched the

attorney smugly push a yellowed, ancient CBC, and ova and parasite stool test-result medical record under my nose, thinking that because the word "parasite" appeared on the document, that it was "proof" that I had indeed, been tested for Lyme, that my test result had been negative, that I lied about testing or couldn't remember that I had been tested, and that the test now before me would or could somehow impeach me as a witness.

What a very long way to go we have, I thought to myself, knowing that the attorney had absolutely no idea on God's green earth what he was looking at, and the fact that he had a mistaken belief that *Borrelia burgdorferi*, the spirochete which causes Lyme disease, could be found lurking within my cultured stool sample and/or there was a test sensitive enough to find it there, was preposterous to me at least. I wish-wouldn't that be great? Like a tapeworm, we could just poop Bb out at the end of its life-cycle and we could all be cured...I'd even sign up for an enema if it were possible in order to expedite the process.

This was, after all, the family court system, and the system itself is woefully imperfect. It has to be, in order for us to be in the mess our family has

been in for nearly a decade. So as I sit on the stand awaiting my cue to speak, my mind drifts slightly left of center, a tad out of focus from the conversation; in part, because I'm very fatigued, having eaten little the entire day and slept even less the night before. It's always stressful sitting on the stand having your life played out before you with every statement carefully recorded and closely scrutinized like so many microorganisms under a microscope. I sincerely know what the little buggers must feel like and it's most disconcerting.

For nearly 6 years, the question of "does she or doesn't she" (have a mental illness) has been the topic before the family courts. Never mind there is not a single shred of evidence ever saying that I suffered from any sort of mental dysfunction, and no witnesses, no psychiatric profile (I have 3) which says I have dysfunction or illness of any kind save for the physical symptoms of Lyme disease, and they did not include depression or any other mood affective disorder. But that's what false accusations will do to you—follow you like a big black cloud that just won't go away. Well okay, I did smash a telephone once in 2001 in a Lyme-affected, accelerated moment of utter frustration which bubbled over

and I needed to release it somehow and I dared to take it out on an inanimate object—some might call that Lyme rage. I was really angry at my ex-husband for trying to involve our son in our court hearing and the darned phone was full of static anyway. Some people drink or do drugs. I smashed a plastic phone—one unguarded moment in my entire life of (then) 40 years—and for that I am "mentally ill"? Yes I was exhibiting symptoms of neuropsychiatric Lyme, but they were mild and short-lived, and should never have been used against me to try to prove me unfit to parent my children.

In fact my neuro-Lyme symptoms never really were noticeable unless you consider the counselors thinking that I was "blocking" counseling sessions because I was so "hostile" and upset due to acute, undiagnosed neuro-Lyme symptoms, major surgery complications and the fact that I was forced to defend myself against false allegations of child abuse and the courts were trying to take away my children! Still I lost custody of my children—actually only one child, but I refused to let the social worker separate the two of them, so they both had to leave. Talk about heart-breaking for everyone—except my ex of course who no longer

had to pay child support or actively hide his income like he had been doing for 6 years.

I marvel in disdain at the misunderstood nature of this illness as I attempt to mentally block out the barely civil banter between the attorneys of both parties and the judge, who gets to determine who can say what and in what context. Lyme is a stealth pathogen which acquires perhaps 200,000 new victims each and every year in the United States alone and I was one of the "lucky" ones, (in 1992), the newest member of the Lyme statistics, involuntarily joining the "club" like someone who'd line up to have that enema I spoke about earlier. "Boy do I wish I could turn back time," I think to myself.

"Are you aware Ms. Langhoff, that IGeneX laboratory is the 'darling' laboratory of those who over diagnose Lyme disease (something, something)...." the attorney's voice trails off mid-sentence as he is interrupted by the judge, which startles me because he is so close in proximity and I was drifting off mentally for just a moment from lack of food and my typical afternoon fatigue and I wasn't paying attention. "That's enough counselor," barks the judge. A discussion followed where the judge let "Lyme in court" ...cont'd pg 16

## Sharing Our Stories: SOS

by Laura Zeller

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# Insane or Infected: The Allie Brinks Story



Several years ago, Allie Brinks was a dramatically different person than the one she is today. Locked up in a psychiatric ward, against her will, Allie's world had fallen completely apart. Cut off from her family and friends, and abandoned by the healthcare system, Allie Brinks was simply known as patient number 962 at the local psychiatric hospital.

Allie was a vibrant redhead, who loved her job as a wedding photographer. A single mother to Alan, her 4 year old son, Allie was a dynamo, always multi-tasking and a real go-getter. She ran her own photography business from her home, doing all her own print-making and spending many late nights bringing images to life in her darkroom studio. Allie's life was pretty normal and comfortable back then. Unfortunately, thanks to a tiny tick, her life did not stay normal and comfortable much longer.

The word summer usually garners up dreamy images of fun in the sun. We often think of green grass, lying in the sand at the beach, barbecues with friends and family,

and sipping lemonade under a backyard tree. Allie used to feel that way about summertime, but now, she has far different feelings and images about summer. "I really fear the warm weather now, because I know the ticks are everywhere." Allie remarks.

Allie's life took an alarming turn for the worse in the summer of 1999. A few days after photographing a wedding on a grassy lawn, Allie started feeling sick. She assumed she had the flu, and decided she better start sleeping more at night. The next day she awoke with a horrible sinus infection, stiff neck, fever, and what she described to me as "pain and tingling all over my body." Her family doctor prescribed a "Z-pack" which is 7 days of the macrolide antibiotic Zithromax®. Much to her relief, Allie's sinus infection and fever went away in 4 days and she felt much better and went on with her busy life.

Everything seemed to be perfectly normal until the autumn leaves began to fall in October. Allie's sinus infection returned, and with it, the aches and pains, fever and neck pain. She figured she had the flu again, one she figured she contracted from her young son or his play dates full of children's germs. She grew tired, and irritable, moody and increasingly anxious. She started sleeping all the time, and was eventually diagnosed with Chronic Fatigue Syndrome (CFS) and Fibromyalgia. She grew too exhausted to care for her little boy, so he had to go stay with his Aunt. Allie's life was chang-

ing for the worse, as her body weakened. Looking back, Allie remembers the exact date of what she calls "the beginning of the end" of her life.

One evening while she was trying to fold laundry, Allie was suddenly struck with a migraine headache, and felt tingling sensations down her arms and legs. "It was scary," Allie remarked as I interviewed her. "I never had a migraine in my life, and I felt numb all over my body. The light in the kitchen became so bright it shot right through me like a knife in my head." Allie collapsed onto the floor in pain. From that night on, Allie's life took an alarming turn for the worse. Her best friend Cora drove her to the emergency room. When Allie arrived at the ER, she became mentally and emotionally unstable. Allie started screaming, throwing objects at the nurses, and was full of rage. She quickly went from having a migraine to becoming a raving lunatic.

Allie's best friend Cora remembers the frightening transformation she witnessed that terrifying night. "I didn't know what to do to help her. She was screaming and crying and throwing things. The doctor gave her some tranquilizers, and it made her even worse. She went from my sweet best friend, to a crazy person, seemingly overnight." Cora explains. Allie then began threatening the hospital staff and smacking herself in the face. When the nurses tried to get an IV needle in Allie's arm, she went ballistic. "She tried to strangle one of the nurses, and then she started

choking herself with the IV tubing." Cora remembered. "It was just awful, and they had to sedate her and put restraints on her arms and legs. The police came in and she had to have a guard by her bed."

Allie was admitted to the mental health floor of the hospital against her will, as she was a danger to herself and those around her. Allie's behavior problems became the focus of her diagnosis. The doctors diagnosed her as a manic depressive, along with bipolar and anxiety disorder. Allie was paranoid of the medical staff, delusional (she believed her son was dying of cancer when he was healthy), and she had visual hallucinations. In addition to her multiple psychiatric diagnosis, Allie also had severe pain in her head, behind her eyes, and light sensitivity. She had blurry vision, and slurred her speech. Allie's psychotic behavior continued to worsen. The doctors offered no explanation for her sudden change other than it could have been hereditary.

Looking back, Allie remembers feeling very angry at everything and everyone, for no apparent reason. She remembers feeling very moody, irritable, and crying for no reason in the weeks leading up to her eventual breakdown. With the exception of Cora, Allie's friends and family took her outbursts and verbal abuse personally, and abandoned her.

What Allie did not realize was that a deer tick had bitten her earlier that summer. Unnoticed, the tick had infected Allie with Lyme disease,

babesiosis, and bartonella.

What began as a sinus infection was really an onslaught of dangerous bacteria that slowly caused Allie's devastating neurological condition. Lyme disease can cause neuropsychiatric illness, but psychiatrists are not routinely trained to diagnose and treat tick borne disease. Talk about a dangerous oversight!

Patients infected with Lyme and associated diseases can experience symptoms which include depression, memory loss, behavioral changes, rage (Lyme-rage), delirium, homicidal and suicidal thoughts. Lyme encephalitis (inflammation of the brain) can cause symptoms to develop including disorientation, panic attacks, confusion, irritability, and seizures.

Misdiagnosed and untreated for her tick borne diseases, Allie lay curled up in a fetal position on the floor of her locked room, crying in pain, and praying to God to let her die.

Allie was medicated with Tegretol® to control her seizures. She was also given Klonopin® to control her rage and anxiety, and Prozac® for depression. Instead of antibiotics to treat her Lyme disease, Allie was forced to take Lithium, Phenobarbital, and Xanax® to treat her behavioral problems. Allie's brain was full of a psychiatric drug cocktail to control her symptoms, not her illness.

Allie was locked up in the psychiatric hospital for over a year. Thanks to the mind-  
"Allie's Story" ...cont'd pg 14



# The Neuropsychological Evaluation and the Role of a Lyme-Literate Neuropsychologist

by Drs. Leo J. Shea III, Ph.D. and Judith G. Leventhal, Ph.D.

The neuropsychological problems commonly associated with Lyme disease and other tick-borne illnesses have a significant impact on learning, academic achievement, professional accomplishment and personal and family relationships. These problems may include difficulty with: 1) attention and concentration, 2) speed of information processing, 3) visual discrimination, 4) visual-spatial analysis, 5) learning and memory, 6) auditory processing and language expression, 7) planning and organization, 8) multitasking, 9) mood regulation and 10) behavioral control.

As a result of these problems, children with Lyme disease often have school-related difficulties and frequently perform below their innate intellectual ability. They may have difficulty sustaining attention, answering when called on in class, completing homework assignments and working within time constraints. In addition, because of frequent absences, they miss important learning and social opportunities. Our recent research has shown, for example, that mathematics and reading scores of children with Lyme disease are often significantly lower than their innate intellectual abilities.

Similarly adults with Lyme disease often experience difficulty performing job responsibilities, meeting deadlines, tracking conversations with colleagues, remembering critical information, multitasking, organizing projects and prioritizing tasks. At home, they may find that their physical symptoms, reduced stamina and neuropsychological problems interfere with their ability to accomplish the complex roles and tasks of daily family life.

## The Neuropsychological Evaluation

As defined by the National Academy of Neuropsychology, "The purpose of the neuropsychological examination is to assess the clinical relationship between the brain/central nervous system and cognitive/behavioral dysfunction, as well as to participate in differential diagnosis. It is a neurodiagnostic, consultative service and not a mental health evaluation or treatment service. The evaluation is performed by a qualified neuropsychologist who has undergone specialized education and intensive training in the clinical neurosciences, including the relationship between behavioral functioning and neuroanatomy, neurology and neurophysiology. Neuropsychological examinations are clinically indicated and medically necessary when patients display signs and symptoms of intellectual compromise and cognitive and/or neurobehavioral dysfunction that involve, but are not restricted to, memory deficits, language disorders, learning disorders, developmental disabilities, pervasive developmental disorders, impairment of organization and planning and

perceptual abnormalities." As indicated above, the neuropsychological evaluation is a medical procedure not a mental health procedure and thus, is covered under the medical benefits of insurance plans.

A neuropsychological evaluation delineates a pattern of existing strengths and weaknesses in cognitive, emotional and behavioral functioning. This information will clarify how strengths and weaknesses impact a person's ability to manage demands of academic, work, family and interpersonal life. Furthermore, cognitive weaknesses have a direct impact on self-confidence and self-esteem and can put an individual at risk for maladaptive behaviors resulting in disruptions of peer and family relationships.

An individual should be referred to a Lyme-literate neuropsychologist for evaluation to assess cognitive and behavioral functioning as soon as a Lyme/tick-borne disease (TBD) diagnosis is made. Having this information allows for a better understanding of cognitive strengths and weaknesses and provides the basis for treatment recommendations and educational and work accommodations. It also provides essential information to support disability applications.

Once history has been obtained and an extensive clinical interview has been completed, testing is initiated. Testing usually takes eight to twelve hours divided into three to four testing sessions over several days. The length of the testing sessions varies according to an individual's stamina and ability to concentrate. To maximize performance, it is important to monitor fluctuations in attention and concentration and physical and mental stamina and provide refresher breaks whenever necessary. An additional ten to fifteen hours of the neuropsychologist's time will be required to analyze the test data, prepare the final report and conduct the feedback session. The report consists of a review of medical, educational, family and vocational history, an extensive discussion of tests results, recommendations for treatment and evaluations by other specialists and academic and work accommodations. For example, an individual may require an audiological or neuro-optometric evaluation to assess sensory reductions. Identification of these sensory changes associated with Lyme disease is critical in maximizing functional performance.

The neuropsychological evaluation consists of a battery of standardized, age-normed tests that provide a profile of an individual's strengths and weaknesses across a variety of skill domains. These domains include:

1. Verbal and non-verbal conceptual and reasoning abilities
2. Visual discrimination
3. Visual-spatial skills
4. Visual-motor skills
5. Graphomotor skills
6. Fine motor skills
7. Sensori-motor skills
8. Attention and concentration
9. Memory
10. Information processing speed
11. Auditory processing
12. Oral and written communications skills

tion, individual and team sports and other extracurricular and recreational activities.

15. Use of technology assistive devices.

## Interventions

1. Cognitive Remediation: Cognitive Remediation is recommended for individuals who are affected by any neurological impairment, attention deficit disorder or illness compromising cognitive functioning. This

intervention is designed to help develop strategies to compensate for neurocognitive weaknesses with the goal of functional improvement. Such strategies allow an individual to maximize innate intellectual skills and to help restore self-confidence and self-esteem.

Cognitive remediation is provided by an experienced psychologist with expertise in the relationship between brain function and behavior in everyday life.

2. Individual Psychotherapy: Psychotherapy is often recommended to help an individual process the significant losses experienced as a result of the devastating effects of chronic Lyme disease. The medical problems associated with Lyme disease often necessitate absence at school or work, reduced interaction with peers and reduced ability to engage in sports, hobbies, extracurricular and recreational activities. In addition, psychotherapy may be necessary to address depression, anxiety, mood changes and emotional rages that are often seen in individuals with Lyme disease.

3. Family Therapy: The stress of Lyme disease disrupts all aspects of an individual's life and compromises interpersonal relationships. Disruptions in family relationships are common as individual family members attempt to address the demands of the disease. Family therapy can be helpful to address differing perspectives and to understand the impact of Lyme disease on family life. Moreover, the functional decline exacerbates the frustrations and burdens on family members. As is often the case, more than one family member may be suffering from Lyme disease and this adds additional stress to the already overly-burdened family structure. This makes family therapy all the more critical to help restore a sense of well-being in family life and to develop a sense of resilience in the face of challenging circumstances.

4. Consultation with School Officials and Academic Accommodations: Teachers and other school officials need to be aware of the undulating nature of Lyme disease. A child may appear to be functioning well one day or for part of the day and then may be so debilitated by an onset of Lyme symptoms that he/she will have to go to the nurse's office or leave school. Repeated tardiness and/or absences must be expected and allowed.

5. Consultation with Employers, Managers and Supervisors: Employers, management officials and supervisory staff need to be aware of the symptoms of Lyme disease and their impact on job performance. An employee may function efficiently one day or for part of the day and then may be so debilitated by Lyme symptoms that he/she will have to leave work early or take sick time. Repeated tardiness and/or absences must be expected and allowed. Accommodations will be necessary to assist the individual in meeting job responsibilities.

6. Consultation with Medical and Mental Health Specialists: The Lyme-literate neuropsychologist can assist medical and mental health professionals in understanding the neurocognitive, neurobehavioral and emotional manifestations of Lyme disease and provide assistance in addressing individual and family needs.

7. Re-Evaluation: A one-year neuropsychological re-evaluation is commonly recommended to assess treatment effectiveness, changes in neuropsychological strengths and weaknesses and to make any necessary revisions in the treatment plan

**Summary:** The neuropsychological evaluation provides the foundation for a program of interventions and accommodations that can lead to improvement in cognitive, behavioral and emotional functioning. These improvements can enhance academic achievement and work performance. They can also contribute to more satisfying family and social relationships, improvement in mood and behavior and increased self-confidence and self-esteem. *pha*

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13. Academic skills
14. Executive abilities (problem solving, planning, organizing and prioritizing)
15. Emotional factors
16. Behavioral factors
17. Interpersonal and family factors

The profile of relative strengths and weaknesses can be used by the neuropsychologist to determine the functional, academic and work accommodations that will maximize daily performance. Examples of recommended accommodations are:

1. Breaking tasks into smaller parts to make tasks more manageable.
2. Developing step-by step plans for organization of tasks.
3. Working on tasks at a slower pace to improve accuracy.
4. Developing multi-modal and hands-on learning tasks.
5. Employing repetition to improve recall.
6. Using cues to increase recognition of learned information.
7. Reduction in academic or work schedule.
8. Home tutoring.
9. Working from home.
10. Shortened assignments.
11. Provision for extended school or work absence.
12. Adjustments to school or work hours.
13. Time extensions for school or work assignments.
14. Allowance for reduced participation in physical educa-



## “Allie’s Story” ...cont’d from pg 12

numbing cocktail of psychiatric drugs she was given, she remembers very little detail of her hospitalization. "It's all a blur to me, I had no control over my own life, and I was like an animal in a cage. I couldn't see my son, and I was called an un-fit mother because I was crazy and locked in the loony bin. I just wanted to die." Allie remembers. "I had pain all over my body, my muscles and joints were swollen, my skin felt like I had sunburn and I had tingling and numbness all over." Allie continued. Despite her numerous physical examinations and her daily pain killers, the possibility of Lyme disease was never questioned. Instead, Allie was told her Fibromyalgia was flaring up, and that her psychosis was likely hereditary, even though nobody in her family was mentally ill.

Allie suffered needlessly for another 4 months before fate stepped in to help guide her towards the truth. Allie's friend Cora got bit by a tick while gardening, and began researching Lyme disease online. The more she read, the more she realized that her best friend Allie may have the same thing! Cora contacted me at wildcondor.com, and I referred her to research articles explaining neuropsychiatric Lyme disease. After several long e-mail conversations with Cora, she had enough information to investigate Allie's situation deeper. Cora visited Allie at the psychiatric hospital and asked her if she ever had any tick bites. Allie remembered her sinus infection a year and a half earlier, when her health began to deteriorate. After talking with Cora, and researching the medical information, it seemed

all too coincidental to Allie that this had all started after photographing a wedding on a rolling green lawn, in a tick infested area. "Everything just clicked..." Allie exclaimed. "...even with all the drugs in my system, I had a moment of lucidity and clearly connected the timing, and how I hadn't felt healthy since then. I didn't remember a tick bite, or a rash, but those ticks are so tiny, I could easily have never seen it." Allie said. She also used to walk her dog in the fields behind her house, so she could have been bitten and never noticed the ticks.

Acting as her mentor and health advocate, Cora met with the head of the psychiatric hospital, and presented the clinical picture, along with the Lyme and associated diseases information. A neurologist was called in to examine Allie, and he agreed to perform a spinal tap (spinal taps miss over 80% of Lyme cases) to determine if Allie had Lyme disease. He also ordered an ELISA test (also an unreliable test), both of which were negative, so they told Allie that she did not have Lyme. (Negative test results do not mean the patient does not have active infection!) Convinced the neurologist and hospital staff was wrong, Allie remained determined to get herself out of there and get a second opinion. After a long struggle, and a

myriad of legal woes, Allie was downgraded to an outpatient of the psychiatric hospital, pending consultation with a prominent Lyme literate MD.

Based on her clinical presentation, Allie's Lyme doctor had little doubt that she had late-stage neuroborreliosis. To help support her clinical diagnosis, Allie's LLMD ordered a SPECT scan, a brain MRI, neu-

Based on her clinical presentation, Allie's Lyme doctor had little doubt that she had late-stage neuroborreliosis. To help support her clinical diagnosis, Allie's LLMD ordered a SPECT scan, a brain MRI, neuropsychiatric testing, and a bounty of blood work. When the tests were completed, the results supported the clinical diagnosis fully. Allie was infected with Lyme disease, bartonella, babesiosis, and mycoplasma.

ropsychiatric testing, and a bounty of blood work.

When the tests were completed, the results supported the clinical diagnosis fully. Allie was infected with Lyme disease, bartonella, babesiosis, and mycoplasma. She had hypoperfusion on her brain SPECT scan which correlated to the areas of her brain that were damaged by Lyme disease. Allie's neuropsychiatric testing showed severe cognitive dysfunction. Allie needed aggressive antibiotic treatment, and her prognosis was hard to determine.

The link between Lyme disease and its effect on Allie's

brain was extremely complex in nature. The Lyme bacteria release poisonous neurotoxins into the brain of infected victims like Allie. The mixing of these toxins with brain chemicals caused her to become unstable. Some of her symptoms were extreme fatigue, crying spells, laughing fits, rages, depression, panic attacks, and dissociative episodes in which she was unaware

of her actions. Normally quiet and shy reserved persons have been known to go totally crazy, as Allie did, and become violent and hysterical. Most people (who are ignorant of the truth) describe Lyme disease patients as depressed because they are sick, as if they are bummed out and sad because they cannot do anything fun anymore. These people do

not realize that the brain of a Lyme patient is being attacked, and the immune system is being damaged by a complex array of tick borne pathogens. Personality changes can be a direct result of chemical changes occurring in the brain, and warrant an intense treatment protocol.

Allie received both IV and oral antibiotic treatment for her Lyme disease. She was treated for babesia with Mepron®, Zithromax®, and the herb Artemisia. Allie experienced strong Herxheimer reactions in the beginning of her treatment, which decreased in severity and time went on. On

treatment, Allie began to show signs of improvement almost immediately. Her panic attacks stopped abruptly, and her memory began to return. Allie gradually returned to herself again. Her joint swelling and pain disappeared. Her rages stopped, her mind felt clear and focused again. In time, Allie experienced a near full recovery thanks to the determination of her LLMD and her best friend's support.

It took 3 long years of treatment for Allie to regain her health, and return to work. She was reunited with her son Alan, and has since gotten married and is currently doing very well. Allie's story has a happy ending. Unfortunately, many other victims, just like Allie are at this moment locked up in a psychiatric hospital, or suffering psychiatric symptoms with no escape or relief. Many of these patients could possibly be infected with tick borne illness, and are being misdiagnosed and untreated. Psychiatrists should be trained to recognize the signs and complex symptoms of tick borne illnesses, especially in tick infested areas.

"My thoughts were filled with darkness, and now they are filled with hope." Allie reflects. "Something went terribly wrong that summer. I turned into somebody else, somebody I hope I never have to be again. The doctors should have been, and should be educated about what ticks can do to our brains. If Cora had not been bitten, researched Lyme, and gotten me out of there, who knows what would have happened to me and my son. The thought is too awful to imagine. I'm just thankful now for each day I have." *pha*

## “Addiction” ...cont’d from pg 7

Ultimately, behaviors will become more and more extreme and more and more characteristic of addiction. Typically, people will make excuses at the beginning of this stage by saying, "he can't be an addict or alcoholic because he can still...". You can fill in the blanks with any number of things like work, temporarily stop using, etc. They don't understand that only in the FINAL stages of addiction do people fit the classic picture---loss of job, homeless, failure of health, etc.

**In your book you write, "What we don't know can hurt our children" - what do you mean by this?**

I am referring to the "phase lag" mentioned in the book when kids experiment with alcohol or drugs, and parents are totally unaware. When kids are using regularly, they may be vaguely aware that they are "experimenting." When they are progressing toward addiction as demonstrated by such behaviors as binge drinking, DUIs and smoking pot, parents think they are just going through typical youthful "rite of passage." When kids are getting into real trouble including legal problems and are obviously fully addicted, parents begin to become con-

cerned. However, they look for signs---any signs that may reassure them that their parental intuition is incorrect. As soon as they get any kind of reassurance, usually from the kid's denials, they forget their concern and everything returns to status quo. We call this denial of the enablers.

Of course addicted kids are the biggest cons of all and are quite willing to lie to their parents. Unfortunately parents desperately want to believe their kids to get them off the hook, so much so that the real problem in their lives, addiction, goes unaddressed. Periodically, I hear young adults who are now addicts and who feel hopeless and become very angry with their parents for not "stepping up" and being strong and shutting down the lying and manipulation when they were in the addiction process. Trust me, kids will not appreciate permissive parents when they end up with such a lifelong problem. On the other hand they will greatly love and appreciate parents who have the courage to do the right thing and be authoritative.

**Drug addiction (including alcohol, prescription, OTC drugs) is incurable - how is it treated? What are the recovery rates?**

The first treatment that has shown any benefit is now over seventy years old---Alcoholics Anonymous. All major and credible treatment programs, free or expensive are based on the 12 steps of AA. There are programs that deviate from AA and the 12 steps, but they cannot show any improvement over the results of AA. Having said that, treatment programs are very closed about their success rates. I know this because I tried very hard while researching my book to find published data from credible programs. The most honest information I can find suggests that the best programs which are long term and expensive have less than 4% rate of prolonged or permanent remission. This usually occurs only after several admissions and relapses. I fear that now that drug treatment has now become a multi-billion dollar industry with stockholders and payrolls, insiders are not being forthcoming about the poor results. Instead, they carp about how insurance should do a better job to cover these expensive and sometimes luxurious programs.

The most illuminating information I found on this is from the National Institute on Drug Abuse. It took me a while to understand what their data was showing in the form of drug treatment response. Only

after I realized that their measure of success was simply a reduction in frequency and amount of drug use did I understand that treatment success in their view didn't even involve discontinuance of drug or alcohol use. That is a pretty low threshold of success in my opinion, but it appears to be the most realistic.

**What are the top three things that lead people to addiction?**

My answer to this is the mirror image of the "three walls of protection" that are outlined in my book. First and most importantly, AGE OF FIRST USE of any addicting substance is the most critical thing that leads to addiction. The earlier kids use drugs---mainly alcohol today, the more likely they will become addicted to some substance, period! Second, home lifestyle and attitudes about addicting substances have a strong impact. Your kids observe parental behavior and attitudes. They want to be like you, the parent, and want to enjoy novel and adult things. If you drink or drug in front of them, you are increasing their risk to do the same---and at an earlier age. If you insist on having alcohol in your home, then teach them that it is strictly for adults and hold them accountable for that. And, above all,

drink responsibly yourself. Third, lack of moral character is another important predecessor to addiction. Grooming your kids to know right from wrong while avoiding moral equivalences, teaching and enforcing honesty, and building good self-esteem are very important. I highly recommend that the family be involved in regular church or temple activities as well.

A fourth area that can lead to addiction that I must mention is that if kids are suffering from a biological depression (which is inherited), they may resort to drugs to feel better, thus self-medicating. So, addressing this issue with your family doctor and treating it timely may prevent addiction in an otherwise depressed youngster. Finally, kids with attention deficit disorder (ADD) may become frustrated and lack self-esteem due to this learning disability, even though they may be of normal (or above) intelligence. Studies suggest that not treating this disorder may lead to kids dropping out of school and resorting to drug abuse.

*In Public Health Alert next month, we'll continue the discussion with Dr. Fleming where he will address more on addiction, depression, and more.*

*pha*



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## “Lyme in the Courtroom” ...cont'd from pg 12

me off the hook as an "average person" who wouldn't be expected to second-guess lab results, and disallowed the opposing counsel's ability to utilize his so-called scientific "research" (a negatively spun news article) in a misguided attempt to make me and the lab who found my blood positive for Bb, look bad-as if I was supposed to know anything about any laboratory and its accreditations and abilities or dysfunctions if any were indeed publicly known as accurate.

And the next thing the attorney tried to do but didn't get away with, was an attempt to pull a recent, scathing article (David Whelan-Forbes March 2007, "Lyme Inc.") [1] into our court case, under the supposed argument that Lyme was an imaginary illness and that Lyme patients were doctor-seeking and doctors were preying on patients, and so forth and so on. Now Forbes was being heralded as the quintessential peer-reviewed medical journal and final word on the political aspects of an illness so wrongly represented by the media and its own researchers...and opposing counsel was calling me crazy-I think he had a lot of nerve trying to come off as an expert using an article that in my opinion, was obviously poorly researched and singularly one-sided. I squinted my eyes and studied the opposing counselor for a moment and reflected on his own eccentric nature (he had been attorney of record for nearly a decade and I had observed him throughout that time period) and how astonishingly fast he was to anger, as well as his lack of awareness of how he treated people. Perhaps this hot-headed, "try anything" counselor was suffering from a kind of mental disorder of his own. Who's to say that he wasn't? After all, some of the things I have seen him attempt over the years were nothing short of nuts in my opinion.

Nevertheless, the judge (finally, one who was not asleep on the bench), wouldn't let that nonsense into our trial either. Good thing, because we could have gone off for days on a tangent about the political aspects of a disease denied by many with patients ridiculed and called "crazy" by countless

more. And by the time I got through with answering questions about that, the entire courtroom would either think I was a profound genius for bantering on about aspects of medical research from haplotypes to epitopes-or else they would be convinced that I was completely mentally whacked with delusional thinking that I am some kind of a medical expert when I clearly had no credentials to "prove" otherwise (other than experience with the illness and years of medical research).

So when the topic of neurological Lyme disease was mentioned as this month's focus for this newspaper, I thought, "Ah, now there's a topic that could seriously use some heated discussion, and I am attempting to contribute to that with what I have observed and researched.

Since I have been a Lyme patient for so long, (and suffered complex neurological symptoms), I have run the gamut of this illness and there is very little that I haven't experienced, so I would have to call myself a hands-on "expert" by virtue of personal experience. I have also spoken to, or interviewed probably several thousand Lyme patients, written much on the topic, and had the privilege of working with several top physicians in their field who know a thing or two about tick-borne illness. And the bottom line that we collectively know is that neurological Lyme exists and it is devastating and sometimes deadly.

*Borrelia* spirochetes have the ability to travel to every organ system in the body, and that includes the brain, where it has a special affinity. Once there, it can produce subtle to severe psychiatric disorders.[3] Physicians who treat patients with Lyme disease must be concerned about neuropsychiatric symptoms, which can take months to years to emerge, if they do at all. Prompt diagnosis and effective treatment are necessary in order to avoid debilitating symptoms and sometimes, irreversible mental illness associated with this brain infection.

Up to 40% of Lyme patients will develop neurologic involvement in either their peripheral or central nervous system (CNS). Dissemination

of the spirochete into the CNS can, and often does, occur within the first few weeks after skin infection.[3] Early signs of CNS involvement include encephalitis, meningitis, cranial neuritis, and radiculoneuropathies (irritation at the nerve root level). Later, encephalomyelitis and encephalopathy may occur. Many psychiatric reactions have been associated with Lyme disease, including panic attacks, major depression, anorexia nervosa, paranoia, dementia, schizophrenia, bipolar disorder and obsessive-compulsive disorder. The rate of depression among Lyme patients ranges across studies from 26-66%[3] In addition, symptoms of neuro-Lyme mimic attention deficit hyperactivity disorder (ADHD) and multiple sclerosis.[4] I have seen both of my children as well as myself and my ex-husband exhibit many of these symptoms at least on a short-lived basis for me, so I'd say the rate in this family is 100%.

It is well-known that Lyme causes cognitive dysfunction in adults, but little is known about the long-term effects in pediatric Lyme patients. Children with Lyme disease have significantly more cognitive and psychiatric problems and present with behavioral changes, declining school performance, forgetfulness, headaches and fatigue. Lyme disease in children may present with long-term disturbances, affecting them socially and academically.[5,6] I have seen this occur in both of my children, who were diagnosed as having Lyme disease but due to our court drama, have never been successfully treated. Both exhibit all of the symptoms above (except one did not decline academically), and both have clear signs of mood disturbances and difficulty tolerating frustration-at times displaying classic symptoms of Lyme "rage". My daughter defines herself as "bi-polar".

I know about the cognitive impairment aspects of neuro-Lyme, having experienced many of them myself. And the scope of my symptoms over the years literally do fill a textbook, as my medical records stack (what I could collect), stands nearly two feet tall.

The depression I felt was mild to moderate and I was acutely aware that it was caused by my illness-luckily it reared its ugly head just after I was finally diagnosed. IV medications took care of that aspect, along with the cognitive impairments and other neuropathies.

I think one of the most difficult aspects of neuropsychiatric Lyme disease is the difficulty that patients have proving that their disease is real, and the willingness of social workers, counselors, courts, family members and friends to so quickly label patients "mentally ill", which carries a horribly negative stigma, if they display the slightest lack of clear-thinking or impulse control. Granted some people are so horribly affected by Lyme that they become delusional and psychotic or demented and even dangerous to the point of hurting themselves or others, and these people deserve the most compassion and best care medical science has to offer. In fact, I know of several mothers of Lyme children who have been through their children's multiple suicide attempts, which is simply a heartbreaking tragedy because these patients cannot get treatment in a political quagmire which denies Lyme exists, especially neurological Lyme. Meanwhile the only pediatric Lyme specialist in this country, Dr. Charles Ray Jones is being crucified in medical board proceedings for being willing to treat and cure thousands of these patients using a standard of care not dissimilar to the status quo for Lyme treatment-relying on his decades of clinical expertise and medical training-and with great success, when no one else will touch these patients. The defense attorney Elliott Pollock was reported as saying that Dr. Jones' case was about "a non-custodial father - attempting to use the Connecticut system when the Nevada system did not help him to obtain custody of his children. even to the point of accusing his former spouse of mental illness." [8] Gee, I know just a little bit about false accusations of mental illness...

Finally, psychiatrists who see patients whether in an endemic region or not, should at least consider the possibility

of Lyme disease in the differential diagnosis, especially in psychiatric disorders having atypical presentations.[3] And just because an illness has connotations of mental illness does not automatically mean that a patient is affected mentally in an adverse manner, even if they display other neurological symptoms as well (hear that, ex and opposing counsel?) In my case, although I can openly laugh at the ridiculous antics of the attorney-who-is-out-to-get-me (Lyme paranoia or just plain observation?) within the family court system; in truth, neuropsychiatric Lyme disease in the courtroom is no laughing matter.

pha

### End Notes

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## National Program Empowers Citizens to Raise Awareness on the Dangers of Lyme Disease

### Turn the Corner Foundation

Lyme disease is falsely viewed as an illness that mostly affects the northeast United States (US). However, what many people do not realize is that Lyme disease has been diagnosed by physicians on every single continent. Unfortunately, most programs that address Lyme disease are located in the northeast US due to the concentration of the disease in this area, leaving those that suffer from this dreadful illness who live outside of the northeast US without the resources and education they deserve. Turn the Corner Foundation (TTC) has heard the voices of the many who

have demanded better treatment for Lyme disease nationally. To speak to this urgent call to action, TTC has created a groundbreaking grassroots program that spreads Lyme disease education around the country community by community.

TTC is pleased to announce its newest national strategy in the war against Lyme disease: The Lyme Educational Awareness Development Series (LEADS). LEADS empowers people to become LEADERS by hosting their own educational event in their home while raising funds for research initiatives on Lyme disease to find a cure. The mission of LEADS is to empower ordinary people to make an

extraordinary difference in the lives of others by educating as many people as possible on Lyme disease and raising people's awareness on the need to fund research designed to find a cure.

The LEADS program educates people on everything from how to check for ticks on your body and remove them to how prevalent the disease has become around the world. The components of LEADS that contribute to its success are an educational piece that teaches people about the realities of Lyme disease through printed materials, a video, a presentation and a question and answer session. There is also a fundraising component that

contributes to research and education projects for the community and health care professionals approved and funded by TTC which address Lyme disease.

LEADERS receive a tool kit that has easy to follow, step by step instructions for creating an educational event on Lyme disease in your home. You can choose to have a more intimate event and have a small group of your close friends over for the program and use only a few tips suggested in the tool kit or you can take your event to the highest level you desire and use all of the resources with which you have been provided. The tool kit is designed to suit all types and

sizes of events; so no matter what style of event you have in mind, you will find the entire process from start to finish fun, simple and professional. Components of the tool kit include:

- \* Getting Started: Planning Your Educational Event
- \* Health Care Professional Involvement: Securing a Health Care Professional in Your Community to Support Your Event
- \* Public Relations: Getting the Word Out About Your Event
- \* Fundraising: Securing Donations at Your Event
- \* Event Logistics: Managing "Awareness" ...cont'd p 17



# The Top Ten Lyme Disease Treatments

A Review of Bryan Rosner's Latest Work

by Marjorie Tietjen

Chronic Lyme patients are unique. Usually it is not just the Lyme spirochete they are left to deal with but those who are chronically ill often harbor several, if not many pathogens. This creates a situation where symptoms can affect every part of the body and there is no way to be sure which pathogen is causing what symptom. With the many allopathic and natural treatments we are bombarded with, especially for Lyme patients with cognitive problems, it is difficult to effectively decide where to begin. What treatments are most effective? How should they be combined? What are our most affordable options, where we as patients have more control?

Many times I have just thrown up my hands in defeat and decided not to deal with any of these questions. Because antibiotics alone seemed to be working for me, the rest was just too complicated to sort out. However, at some point we may not have access to antibiotics for the use with chronic Lyme. Another consideration is that antibiotics don't always remain effective forever, and for some people they just don't seem to work. These drugs can also build up in your system and cause toxic side effects.

This is where Bryan Rosner's book "The Ten Top Lyme Disease Treatments" comes into play. The author has created a practical resource that is organized and easy to understand and implement. Being a Lyme patient himself, he has done much research and experimentation. He offers information gleaned from his experience and the experience of others.

Antibiotics alone have not been the complete answer for curing or effectively controlling Lyme disease. Most people will come to the same conclusion concerning natural treatments. The Lyme disease germ, *Borrelia burgdorferi*, is a very smart organism. It is able to evade the immune system, antibiotics and current available testing.

Bryan Rosner's solution is to offer us valuable information concerning both allopathic and natural medicine and how to use them together to form a comprehensive treatment plan. He emphasizes 5 core treatment protocols and other supportive treatments. He suggests that antibiotics be rotated and used for fairly short periods of time. The author warns us that treating Lyme disease and the co-infections is more of a

marathon event as opposed to a sprint. If we approach the treatment of Lyme with this in mind, it will help us to avoid discouragement.

On page 293 of Rosner's book he says, "Because Lyme disease is caused by a bacterial infection, the core of a Lyme disease treatment protocol is comprised of antibacterial therapies. The most effective antibacterial therapies are pharmaceutical and non pharmaceutical antibiotics, the Marshall Protocol, and Rife Machine therapy. At all times during the recovery process, at least one of these three therapies should be in use."

Bryan believes that Rife machine therapy should be the foundation of an antibacterial treatment and tells us why. He discusses the Rife Machine in this book but for those who want a more comprehensive understanding of this type of electro medicine, one should read his first book "Lyme Disease and Rife Machines."

The book stresses that we need to strengthen the immune system through diet, eliminating exposures to toxic and allergic substances, detoxification, electro medicine and herbs. He also points out that there is no magic remedy and that patients must become proactive and take the time to adjust their priorities.

Rosner does an excellent job making sure the patient understands what can and cannot be expected from the various holistic and allopathic treatments. Many of us are aware of the raging Lyme wars (disagreement on the testing and treatment of Lyme disease) that are keeping patients from getting proper treatment. Here is what Rosner has to say about that. "The debate has recently reached a boiling point, involving the passions, fears, biases, personal experiences --- and let us not forget, financial interests --- of those involved. Amidst the inferno, it has been largely forgotten that the goal of health care is not to establish exclusive, single-minded medical truths, but instead, to utilize all available medical treatments that cure disease --- regardless of which paradigm they belong to."

There is so much practical information and so many helpful resources listed in this book that I could go on and on but I am sure you would rather read the book. I highly recommend "The Top Ten Lyme Disease Treatments" to anyone who wants to better understand the realities of treating Lyme disease and what it takes to get well.

# Promoting Lyme Disease Prevention In The Schools



by Maggie May Sabota

As Miss Cumberland County, I am passionately committed to spreading the word about effective ways to prevent the contraction of Lyme Disease. This is because I have seen the devastation caused by the disease first hand. Both my mother and my brother Luke contracted Lyme Disease. With antibiotic treatment, Luke recovered, although he was unable to play soccer his Freshman year as planned. Unfortunately, my mother was found to have an antibiotic resistant form of the disease. She has suffered from headaches, shooting pains, dizziness, severe joint pain and swelling and chronic neurological problems for 13 years. Her hands and feet frequently go numb and she has problems with concentration and short-term memory. Since the age of six, I have watched her struggle with pain and disability so severe that at times she uses a walker or wheelchair to get around.

Since being crowned, I have had numerous appearances throughout my county and the state of New Jersey. Recently I have chosen to place an emphasis on teaching elementary age children about Lyme. This spring, I gave pre-

sentations at several local elementary schools. As a future educator, I am aware that it is always best to emphasize a few main points to students rather than bombarding them with too many details. In each presentation I used colorful charts to help emphasize four main points: 1) Protect 2) Do Tick Checks 3) Remove Ticks Properly 4) Call the Doctor. I also taught them the importance of applying tick repellent and wearing long sleeves and pants when you are in tick infested areas. The students also learned about making their own tick removal kit, containing a small vial with a label, tweezers and antiseptic. The Lyme Disease Foundation ([www.lyme.org](http://www.lyme.org)) has materials and coloring pages emphasizing these steps, which I gave to the students. This foundation, as well as the Lyme Disease Association ([www.lymediseaseassociation.org](http://www.lymediseaseassociation.org)) provided me with informative pamphlets for the children to take home to their parents as well. I was thrilled to find that there are many resources available to teach children how to protect themselves. One such helpful tool is a book called "No Time For Lyme" written and illustrated by Sarah DeMar, a woman who contracted Lyme Disease as a child. The book, available

in PDF format from the Lyme Disease Foundation website, provides age appropriate information about what it is like to have Lyme Disease. Also at each of my school visits, I made sure to stop and visit the school nurse and the librarian. I talked to them about the different resources there are available for Lyme Disease Prevention and also about ways to incorporate them into the school curriculum. Looking back on my presentations, I was astonished at the number of children who told me that they had found ticks on themselves, and at the amount of students who knew someone with Lyme Disease. I am continually reminded of how prevalent this disease is, and how important it is to teach children prevention tips at a young age. My crown has afforded me valuable opportunities to teach children how to prevent this potentially devastating disease. I am surprised at the insightful questions being asked by young children about Lyme Disease. Questions range from, "Can my dog get Lyme Disease?" to "Can you die from Lyme Disease?" However, my favorite non-Lyme Disease related question so far has been, "Do you sleep in your crown?" *pha*

## Awareness

the Day of Your Event

\* Close Out: Reporting Back to Turn the Corner Foundation after Your Event

One of the highlights of this program is that if a town raises enough funds at their event, they can send a physician from their community to study with a Lyme-literate

physician through TTC or secure funding for a local physician to participate in one of TTC's groundbreaking Lyme disease research programs. This extension of the program allows for the education first presented in your home to last a lifetime in your community through your local physician's

Lyme-literate practice. Most of all, TTC believes that through this program, community members and health care professionals who have not had the opportunity to learn about Lyme disease will be able to receive an education previously unavailable to them, empowering them to protect themselves,

their families and their community from Lyme disease. *pha*

To become a LEADER, please contact Ken Grosso by phone at 646.278.6737 or by email at [ken@poweredbyprofessionals.com](mailto:ken@poweredbyprofessionals.com)





# For Those Who Fought a Valiant Fight

## Dr. Edward McNeil



Dear Friends,

It is with deep sorrow that I write this to you; as I have lost one of the best friends I've ever had. Dr. Edward L. McNeil, known to his friends as "Dr. Ted" or "Teddy", lost his battle against *Borrelia* (Lyme disease) and *Babesia* infections on the afternoon of Wednesday July 11, 2007.

To know him was to love him; that's my perspective. And when you read these few amazing things about him, know that they're only a very few of the many, and see why it's so easy to love him and why this unique man will be so sorely missed.

I remember the day I met him, he was entertaining everyone with his songs and lyrics. He had many close

friends in "the Lyme community", and those who knew him and those he touched, will find this a sad time indeed.

Photo: wildernetwork.org

Edward L. McNeil, known to his friends as "Dr. Ted" or "Teddy"

Read the article by Dr. Ted "*Personality, Pathogens and Parasites*" <http://lymeblog.com/modules.php?name=News&file=article&id=374>

Learn more about Dr. Ted visit his web site: <http://www.wildernetwork.org/drted.html>

Learn more about Dr Ted's extensive medical career here: <http://www.wildernetwork.org/drtedCV.html>

He was clever, quick and entertaining with his lyrics and rhymes and songs. He adored his son and three daughters. And had a great love of horses and of the arts. He loved to sculpt wood and made beautiful carvings of ballerinas and lovers among others. He was multi-instrumental and loved to play the bagpipes and other instruments and was on an album called (I think it was...), "In the Limelight".

Before he got too sick,

we'd chat most days... and if you have one, you know how good it is to have a friend who understands because they're fabulous and so sick at the same time; they've been just where you're going and help you get through; never fatigued of friendship, always themselves and never having to apologise for it! Never guilty or obliged... Always uplifted... with a story or a "silly" or a song. And he had a big laugh; I'd call him just to hear it. And a sparkling, infectious smile you'd travel three thousand miles to see.

But that was his "Teddy-bear side", he also had a much more serious side; after all he was a doctor. And not just a regular old family doctor, but an incredible emergency room doctor, an airborne emergency doctor, and a surgeon in England and New York! He wrote the text, "Airborne Care of the Ill and Injured", which is based on his experiences of multiple international medical air rescues and was the first medical text of its kind.

Dr. Ted also conceived of a safe form of basic life support or Cardiopulmonary Resuscitation which is quite popular in Japan and the far East and catching on in Western Medicine as an alternative to the "Heimlich Maneuver" for

choking and drowning; I liked to call it the "Teddy Technique". A great lover of flying, at age fourteen he got his glider license and at sixteen Teddy, "saviour of the western world", was in training for the Fleet Air Arm of the Royal Navy. He enjoyed flying for many years and he also enjoyed being on the water; many of his friends will remember how he liked to sign some of his notes, "the ancient mariner".

Dr. Ted was a philanthropic volunteer; a humanitarian. Throughout his life he was a volunteer at the Bedford VFD, a member of the Advisory Committee to the Microbiology Department of Bowen Research and Training Institute in Florida, Medical Advisor for the American Red Cross, Honorary Medical Officer for the Bedford Police Department and he was involved in starting the first ever Neighbourhood Watch system for Bedford Village, he was advisor to many Volunteer Ambulance Corps, Medical Director of Corporate Angels Network, Medical Director of World Aid, Medical Advisor to Flying Doctors of Africa, and a member of the Aviation Safety Committee for Aerospace Medical Association, among various other volunteer activities.

In lieu of flowers: Teddy would be pleased if you'd keep and enjoy any flowers intended for him, as well as a wee nip of your favorite spirit in a toast to his memory.

Dr. Ted believed that every human needs to be aware of the dangers of the tick-borne diseases because not only is diagnosis often delayed and no treatment recommended if you're not cured on the first try, but also there are no services available for those who continue to suffer symptoms.

Dr. Ted was an advocate and volunteer for sufferers of the tick-borne diseases, often helping children get to the doctor. Dr. Ted co-founded and was vice-president of WILDER Network, Inc. a non-profit organization dedicated to furthering awareness of tick-borne diseases on an international level, as well as offering support for individual sufferers. Please carry on advocacy and volunteer efforts in his memory. Support WILDER Network, Dr. Ted's favorite non-profit or yours; volunteer, spread the word.

Lauren Leigh  
President  
Co-Founder  
WILDER Network, Inc.

## Gardasil, the HPV Vaccine, Kills Three

by *The Judicial Watch*

WASHINGTON, DC --

Judicial Watch, the public interest group that investigates and prosecutes government corruption, today released documents obtained from the U.S. Food and Drug Administration (FDA) under the provisions of the Freedom of Information Act, detailing 1,637 reports of adverse reactions to the vaccination for human papillomavirus (HPV), Gardasil. Three deaths were related to the vaccine. One physician's assistant reported that a female patient "died of a blood clot three hours after getting the Gardasil vaccine." Two other reports, on girls 12 and 19, reported deaths relating to heart problems and/or blood clotting.

As of May 11, 2007, the 1,637 adverse vaccination reactions reported to the FDA via the Vaccine Adverse Event Reporting System (VAERS) included 371 serious reactions. Of the 42 women who received the vaccine while pregnant, 18 experienced side effects ranging from spontaneous abortion to fetal abnormalities.

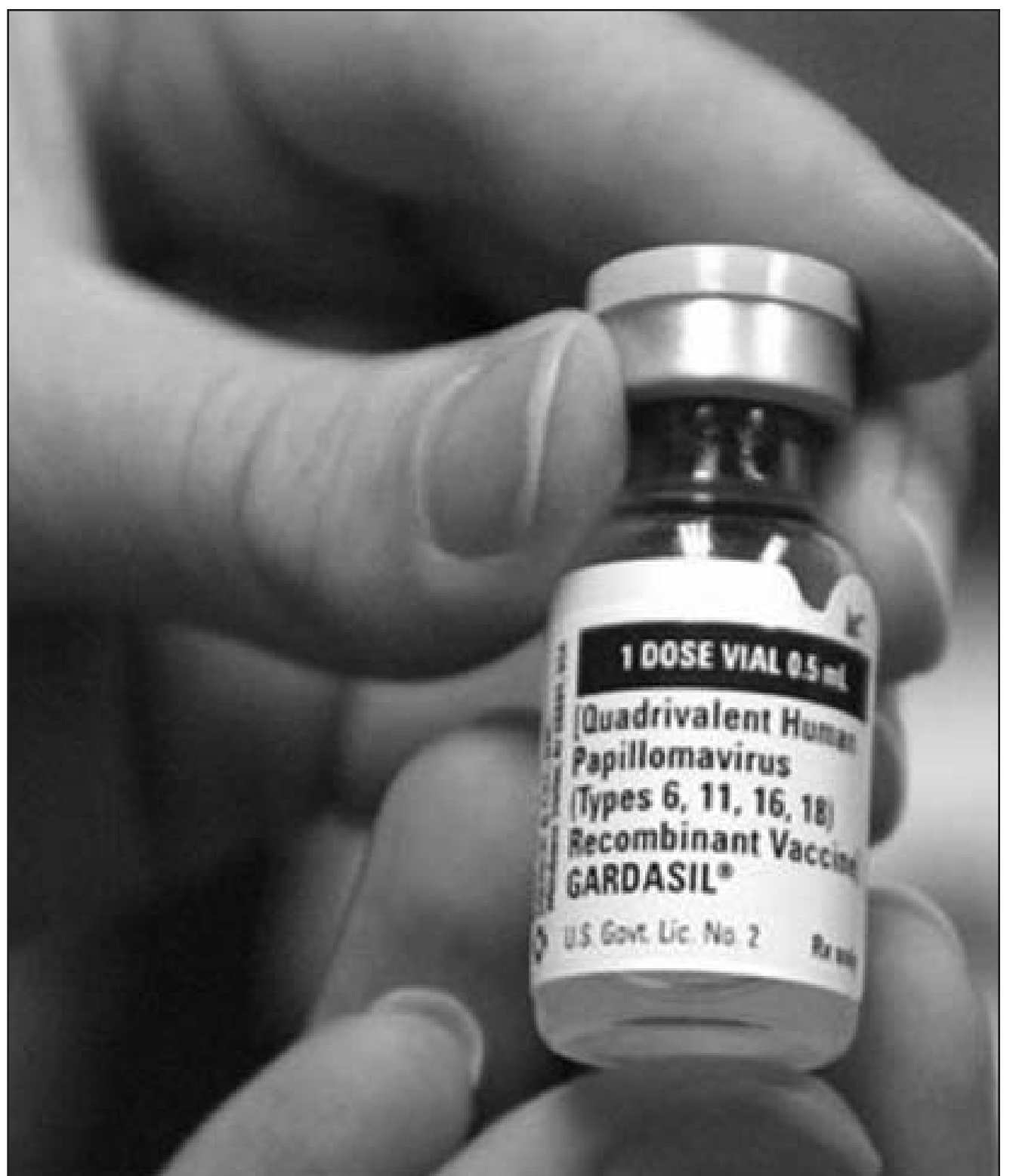
Side effects published by Merck & Co. warn the public about potential pain, fever,

nausea, dizziness and itching after receiving the vaccine. Indeed, 77% of the adverse reactions reported are typical side effects to vaccinations. But other more serious side effects reported include paralysis, Bells Palsy, Guillain-Barre Syndrome, and seizures.

"The FDA adverse event reports on the HPV vaccine read like a catalog of horrors," stated Judicial Watch President Tom Fitton. "Any state or local government now beset by Merck's lobbying campaigns to mandate this HPV vaccine for young girls ought to take a look at these adverse health reports. It looks as if an unproven vaccine with dangerous side effects is being pushed as a miracle drug."

Judicial Watch filed its request on May 9, 2007, and received the adverse event reports from the FDA on May 15, 2007. Judicial Watch has posted the adverse event reports on their Internet site at: <http://www.Judicial Watch.org>.

A recent study, published in the *New England Journal of Medicine*, also questioned the general effectiveness of Gardasil.



## "Letters to the Editor" ...cont'd from pg 3

work on the front lines of this disease with numerous success stories? Perhaps, an AT&T tech support person is needed or a good Optometrist to assist them? Or, perhaps a good attorney to fact-check "all" of their available scientific studies?

I'm sure the 20,000 or so neurologists that make up the Academy will be thrilled to

learn that their board has now embroiled them in supporting guidelines which are currently under legal investigation.

Never would I have deemed it possible that a group of medical people would work so vigorously and with such malice against a group of desperately ill people. But, here it is. Despite the true ulterior

motives of these individuals, the collective effect of their actions is to deny wellness to a huge segment of Lyme disease sufferers.

It seems the IDSA and the AAN truly misunderstand the Lyme disease community. When families see their loved one's suffering with unremitting pain and debilitation they seek

a cure. If that cure or improvement entails long-term anti-biotic treatment they will seek this course of action. When stodgy, narrow-minded medical societies attempt to deny this treatment, families push back. The IDSA and the AAN can get the International Amalgamated Society of Ear Wax Removers to endorse their guidelines. It

matters not. They cannot deny the existence of scores of people who've gotten their lives back from long-term anti-biotic use.

Sincerely,  
Mike Nickel  
WI. Lyme disease Groups



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