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From IDSA to ILADS: A Journey Toward Reconciliation

by *Scott Forsgren*

Many patients with chronic Lyme disease have had the experience of meeting doctors who did not believe that our illnesses were real. Many have been told that our conditions are manifestations of our mind. We have been denied adequate care as the result of the IDSA (Infectious Disease Society of America - the most influential organization related to infectious disease in the United States) Guidelines. We often migrate towards doctors that hold a broader perspective, the ILADS (International Lyme and Associated Diseases Society) perspective, on our disease. As a result, over time many of us recover.

Dr. Sam Shor, MD, FACP is an internist in Reston, VA had a practice with a focus on the treatment of Chronic Fatigue Syndrome (CFS). His journey later introduced him to the significant overlap between CFS and chronic Lyme disease and he began to think outside the box, way outside the box in the eyes of many. Dr. Shor's journey is one of hope. It is a journey that requires courage and a willingness to do what is right for suffering patients. It is a journey which we often wish more medical profession-

als would take. Dr. Shor's journey is a journey from IDSA to ILADS.

Trained in primary care and internal medicine, Dr. Shor completed his residency in 1985 at George Washington University. He has been in private practice in Virginia since that time. Shortly after he started practicing, he became interested in people with a chronic fatiguing illness of unclear origin which subsequently became known as Chronic Fatigue Syndrome. In the late '80s, Dr. Shor referred several of his patients to the National Institutes of Health (NIH). In the '80s and '90s, he took part in a number of NIH symposiums in Bethesda, MD and continued to solidify his interest in the illness. He later became a member of IACFS, the International Association for Chronic Fatigue Syndrome.

Dr. Shor's patients were suffering with a myriad of complex symptoms which included sleep disorders, Fibromyalgia pain, dysautonomias (changes in the autonomic nervous system that result in fatigue, lightheadedness, dizziness, rapid or slow heart rate, and problems with blood pressure), and cognitive impairments. He observed a consistent pattern and was convinced



Dr. Sam Shor, MD, FACP believes that chronic Lyme disease is a very real condition and has had clinical success in treating difficult patient cases with ILADS approaches

that this complex illness was not only very real but that there had to be a common theme which resulted in patients presenting as they were.

In an attempt to do his due diligence after having been intellectually challenged by the complex presentation of many

of his patients, Dr. Shor published an article in 2003 titled "Pathogenesis of Chronic Fatigue Syndrome, A Multisystem Hypothesis" in the Journal of Chronic Fatigue Syndrome. In the article, Dr. Shor attempted to explain the "IDSA to ILADS" ...cont'd pg 2

Ginsu Knives & Psychiatric Lyme Disease: Cutting Through the Misinformation

by *PJ Langhoff*

Psychoses, hallucinations, dementia, delusions, paranoia, rage, aggression, suicidal thinking, anxiety attacks, ADD, ADHD, OCD ? words that would make any patient, physician, family member or researcher recoil when reading about the possibility that Lyme disease can cause one or more of these or other psychiatric issues. Anecdotally speaking, psychiatric issues, and in particular those connected with tick-borne infectious diseases, are something that is rarely, if ever, discussed. The topic has been largely overlooked until the recent mainstream media coverage of a Lyme-suffering chimpanzee named Travis that attacked its Connecticut owner and a friend. This startling story was quickly followed up by a March 9, 2009 human tragedy where an Edwardsville,

Illinois man went on a shooting spree, killing a southern Illinois pastor during Sunday services.

The firestorm of debate over whether Lyme disease could be responsible for psychiatric issues including homicide quickly ensued. One Yahoo news release indicated that according to Yale University Lyme disease specialist Dr. Eugene Shapiro, the disease does not cause someone to commit this kind of an attack. But in reading that statement, the first question that came to my mind as a Lyme patient, was "where is the scientific data to suggest that it does not cause this kind of behavior?" As I said in my latest book on Lyme disease, *The Baker's Dozen & the Lunatic Fringe: Has Junk Science Shifted the Lyme Disease Paradigm?* (Amazon.com) "An absence of proof is not proof of absence."

Over a few days, I performed a short review of an assortment of peer-reviewed articles, abstracts, and several published resource books lying on my shelf; all pertaining to neuropathies, psychiatric issues, and Lyme disease. While many publications referred to psychiatric manifestations of Lyme disease, the common theme in most of them was that *Borrelia burgdorferi*, the spirochete that causes Lyme disease (a close relative of Syphilis), does cause psychiatric problems such as mood disorders, paranoia, depression, OCD, ADD, ADHD, hallucinations, cognitive problems and at times, dementia. Typically however, these "syndromes" were described by academic publishers as "mild". That description certainly felt curious, if not dismissive, to me.

The first book I wrote

in my *It's All In Your Head* series on Lyme disease (Patient Stories From the Front Lines), revealed stories about neuropsychiatric Lyme disease. When I was researching patient stories for use in the second book in the series, *Around the World in 80 Lyme Patient Stories*, one of the most common symptoms reported by Lyme patients and their families, was a symptom called "Lyme rage". Indeed, the book series, which was released in January 2008, is dedicated to two patients who took their own lives specifically as a consequence of having Lyme disease. There have been reports that Lyme rage is "uncommon" or that it is an "atypical" presentation of Lyme-induced brain infection. What I found, which is not yet backed by clinical trials or lengthy scientific studies, is that most Lyme patients who "Lyme Rage" ...cont'd pg 7

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“IDSA to ILADS” ...cont'd from pg 1

best understanding of the symptom complex and the process of CFS known at the time.

Soon after the article was published, Dr. Shor became aware of Lyme disease and the potential that Lyme disease could present with a very similar set of symptoms. Prior to that time, Dr. Shor was adhering to the IDSA Guidelines which he notes were fairly strict and remain fairly strict even today. As a generalist, his perspective at that time was that the IDSA doctors were the specialists in infectious disease and he deferred to their guidance when treating conditions such as Lyme disease.

As Dr. Shor learned more about Lyme disease, in an attempt to pursue his due diligence, he went to his first ILADS conference in 2004. He states that he was "struck and dumb-founded" by the similarities of the issues that were presented by the ILADS doctors. He found that there was a significant overlap between what he had been observing for over a decade in the world of Chronic Fatigue Syndrome and what ILADS doctors had been observing in the world of Lyme disease.

At this point, Dr. Shor felt that there had to be a commonality between these two disorders. He was exposed to the difficulty in diagnosing Lyme disease. He also became aware of the adverse impact on the immune system that the Lyme disease infection has.

Dr. Shor and others in the field of Lyme disease recognize that "Lyme disease" is characterized by more than just an infection with *Borrelia burgdorferi*. He notes that *Borrelia burgdorferi* is the punitive agent involved in Lyme disease proper but that there are other agents involved such as *Babesia*, *Bartonella*, and others.

Dr. Shor learned that *Borrelia* has the capacity to evade the immune system in many ways. First, it can rapidly change its outer protein coat. It is this outer protein coat which serves as a signal to the immune system to create antibodies. If there is not a sus-

tained stimulus in order to mount an immune response, the body cannot properly generate antibodies. *Borrelia* can become an immune neutral cyst form when it senses that it is in a toxic environment, such as in the presence of antibiotics. *Borrelia* adversely impacts the health of the immune system as it has been shown to lower a particular type of NK (natural killer) cell called CD57.

All of this information made Dr. Shor realize that he was likely dealing with a phenomenon that was "minimally similar to if not actually responsible for" what he had been characterizing as Chronic Fatigue Syndrome. He further believed that the difficulty in testing for, and making a diagnosis of, Lyme disease perpetuated the problem of characterizing CFS.

CFS by definition is a diagnosis of exclusion. There is no laboratory marker for the syndrome. The diagnosis is characterized by a fatiguing illness of six months or longer with a reduction in functional capacity of 50% or more of one's level of functioning prior to becoming ill. Other causes must be ruled out. In this setting, if Lyme disease is so difficult to diagnose,

it is by definition difficult to rule out. The classic presentation of CFS is that a person gets a flu-like illness and has not been well since. In many cases of CFS, there may actually be a viral cause which initiates the process but often, that flu-like illness may very well have been Lyme and related infections. These may serve as the onset of the phenomenon that leaves many patients quite disabled.

Given that Dr. Shor had developed an interest in CFS and that so few people in the medical community have interest or expertise in the illness, he felt obligated personally to learn as much as possible about all ramifications of the symptom complex known as CFS. He became very familiar with the management of dysautonomias and even gets referrals from cardiologists. He became familiar with the management



Dr. Shor presents the IDSA vs. ILADS debate at a Congressional Briefing.

of Fibromyalgia and sleep disorders by the virtue of the fact that he was seeing these issues so commonly and repeatedly. He became an expert in each of these areas to help those that were so disabled. When Dr. Shor, via his association with ILADS, became aware of the potential cause of patients' suffering, it gave him a whole new perspective from which he could offer patients hope and an improved outcome.

Dr. Shor continued to assimilate all of the information that he was, at that time, just beginning to understand. In 2006, he published an article titled "Lyme Disease presenting as Chronic Fatigue Syndrome". Dr. Shor wanted to further solidify the validity of his approach on a daily basis. He generated a 30 question questionnaire that was a subset of Dr. Joe Burrascano MD's larger Lyme questionnaire. The intent was to extract questions that would give a broad sense of a patient's clinical status and allow the patient to grade how they felt at any point in time. The questionnaire was used over time as the patient was being treated and could be evaluated to determine whether or not outcomes were changing.

Soon after the ILADS meeting, Dr. Shor took select patients from his CFS population and started to investigate

their cases with his newfound insight. When there was enough evidence to suggest that the patient may actually have Lyme disease, he began treating them. Dr. Shor needed more supportive evidence himself to substantiate the perceptions that he had at the time. When he started to observe the results, they strongly supported his earlier impressions and moved his work to the next level. He was "flabbergasted not only by the gestalt in clinical improvement" but that the numbers were substantiating his clinical impressions.

One of Dr. Shor's patients was a 42 year-old lawyer that had carried the diagnosis of CFS and was on disability and out of work for over two years. The patient was intent on going back to work but had fatigue, cognitive impairment, and difficulty sleeping along with many other symptoms. He fulfilled the international case definition of CFS but after exploring his case with new-found insight, Dr. Shor felt that he actually had Lyme disease.

Dr. Shor put together an ILADS-approved protocol and started treatment. Recognizing that treatment is a process that takes time, over the next 12-15 months, the patient improved so much that he is today back at

Confidently, 50% or more of my CFS patients may have Lyme disease as the underlying cause of their illness.

Exploring complementary medicine has to be a part of the approach for many patients or they simply may not get well.

"IDSA to ILADS"... cont'd pg 9

Public Health Alert

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 nationwide support group leaders. These groups include the chronic illnesses of Multiple Sclerosis, Lou Gehrig'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's attention. We seek to make sure that anyone struggling with these diseases has proper support emotionally, physically, spiritually and medically.

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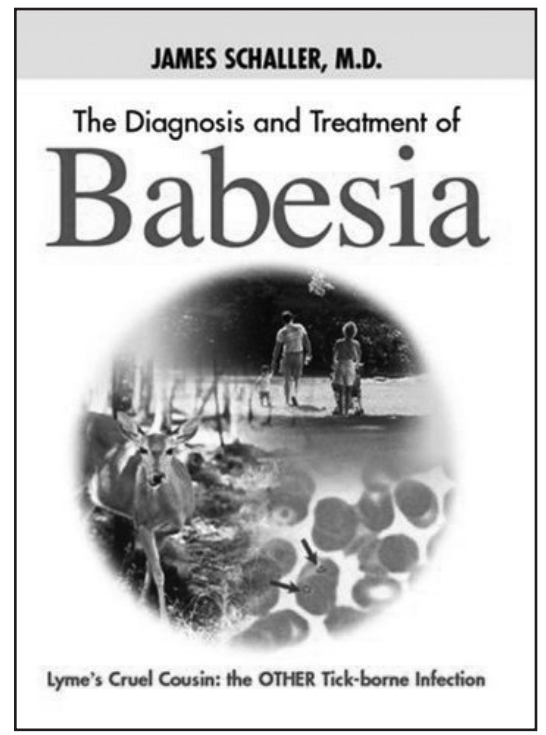
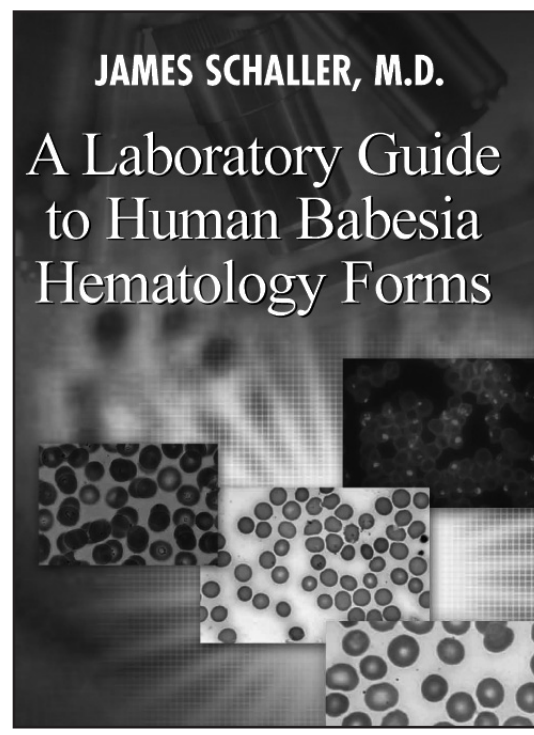
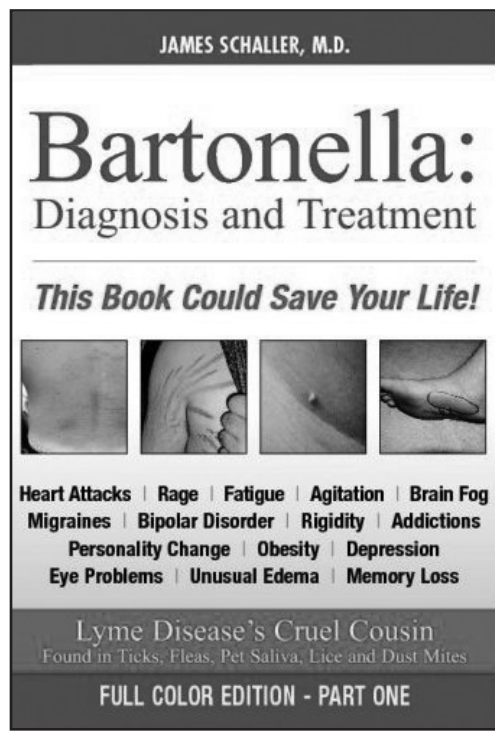
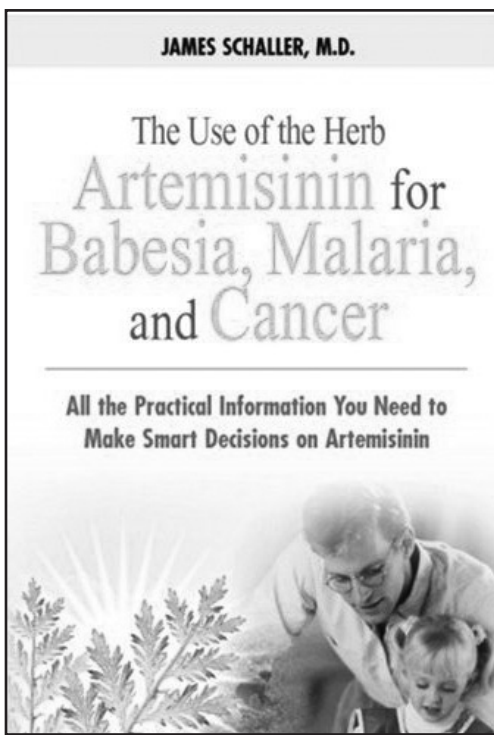
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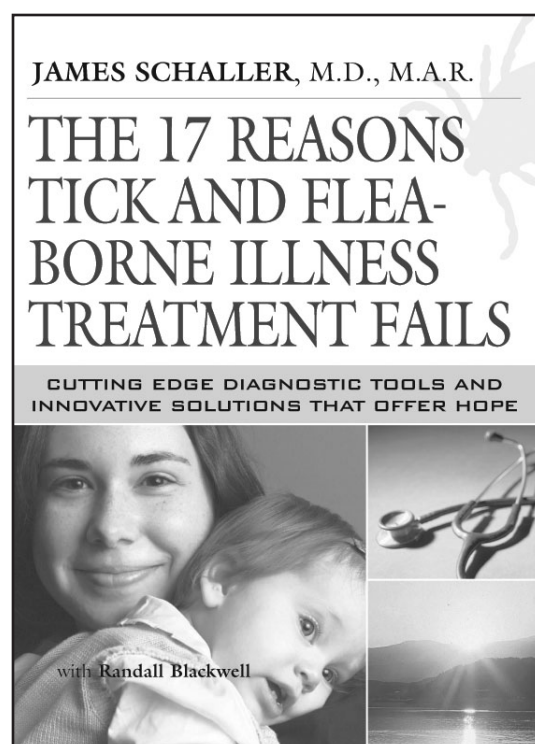
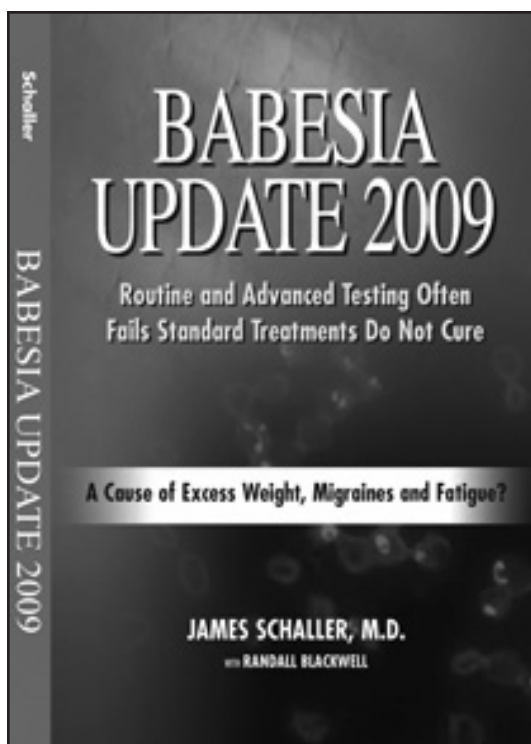
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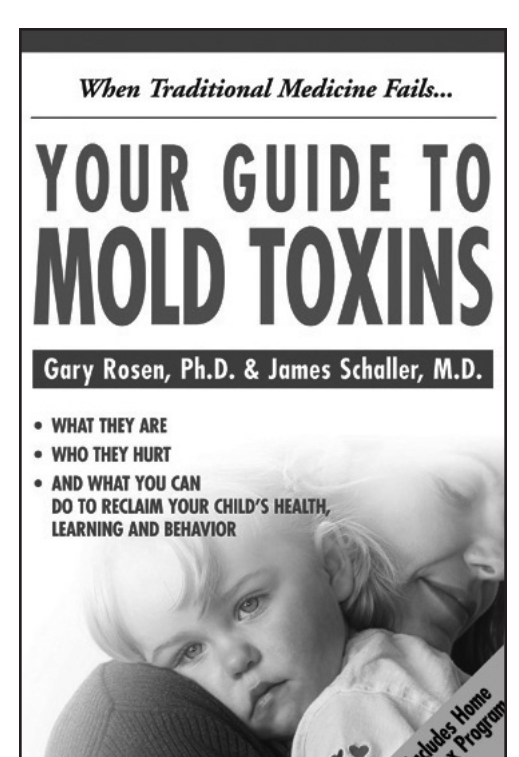
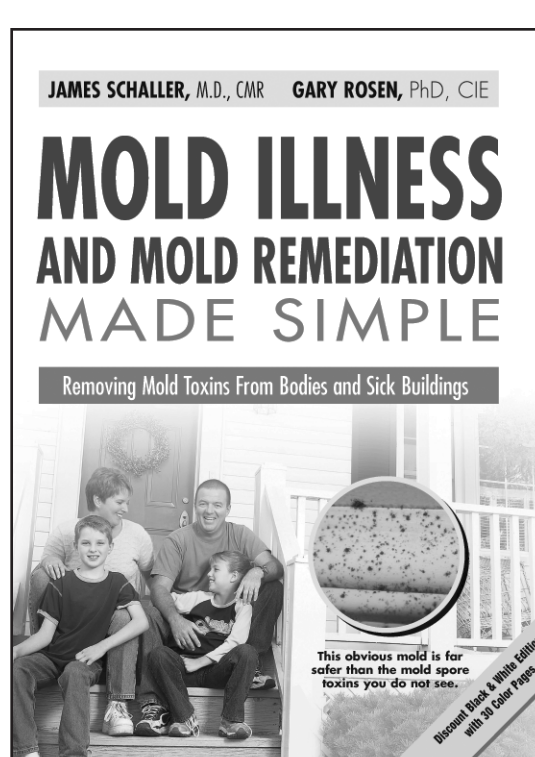
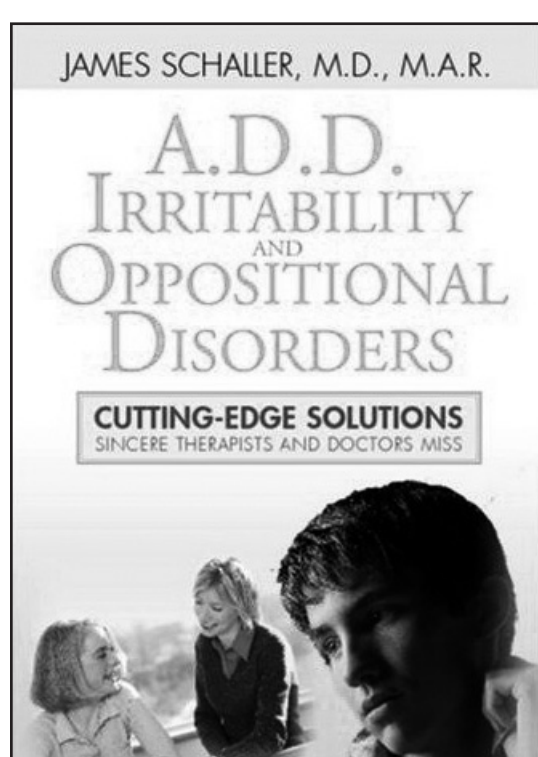
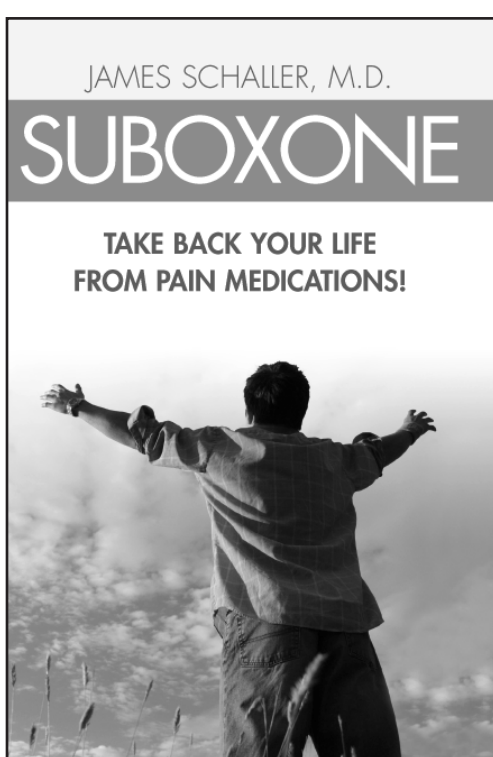
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Strength in Weakness



by Linnette R. Mullin

Filled with various trials, the past year has made me weaker. You read right. Weaker. But that's a good thing. God's word says, "When I am weak, then I am strong." and "...His strength is made perfect in weakness." Yes, I've become weaker through my trials, and yet my trust in God is stronger. I realize more with each passing day that I am nothing and He is everything. I'm learning that life is meaningless...unless you know Christ and realize that HE is what matters in life, as well as in death.

Just before Christmas break of 2008, I enjoyed a few days of incredible joy. God showed me during those days what it means to have the joy of the Lord as my strength. I felt invincible and I thought at the time that God must have been preparing me for the days ahead. I didn't miss my mark. The following two weeks were some of the most trying of the year and, quite honestly, I battled with depression.

Three times an infected emotional wound was ripped open by loved ones who just don't understand how sick I am simply because I look healthy.

They can't see what goes on under my skin and have no idea how debilitating this disease is. Accused of not wanting to go to church, not wanting to help my extended family when they need me, not taking care of my house, my husband, and my kids like I should, etc, I reached a point of near devastation.

I know that I'm not alone. All chronically ill people suffer such traumas to some extent. It's enough to make me wish at times that I had cancer instead of Lyme disease. Then, maybe people would take my illness seriously.

It's not that I want pity. I just want to be understood and believed. When I say, "I can't," I don't need people to make me feel guilty over something I cannot control. I do a good enough job of that myself. Yet, because I look healthy, I'm made to feel like a liar - always having to justify my actions or decisions to one person or another. That hurts...especially when it comes from the people I love the most.

What most people don't get is that this illness is deadly. If left untreated, it will either kill you slowly in a torturous manner, or it will kill you quickly in an agonizing way. My husband's college professor dropped dead from a fast growing Lyme-induced brain tumor. A lady in the Lyme community died at the age of 41 - her heart stopped in her sleep. Two Missouri girls who went to camp together both returned with Lyme infected tick bites. One of them suffers with Lyme today while the other died within a year - her organs were attacked and shut down one-by-one.

This is a serious illness and it needs to be taken seri-

ously by those who love us. I don't know how many times I've come close to death, but I can tell you there have been many times I felt as if I were on its doorstep...times when others were waiting for news of my death.

But, apparently, God has a purpose in keeping me alive. And, if for no other reason, I want to live for my boys. Who will understand what they go through? Who would take their illness seriously better than me? So, until God calls me home, I will live to get them the help they need in hope of healing them from this terrible disease ravaging their bodies. They are gifted boys and I want them to be able to use their abilities to glorify the Lord. And if that's my only purpose in life, then that gives me reason to live.

As I reflect back to the two weeks of Christmas break 2008, I think of all that took place: the accusations of not doing my duty by the Lord or my loved ones; betrayal and rejection by a special family member; my husband being ridiculed for standing by me and the boys rather than leaving us; taking care of kids with stomach flu, respiratory influenza, and pneumonia; going through a power outage with the boys all running fevers; contracting influenza myself; losing my laptop with all my writing and pictures on it to a malicious virus; and my husband losing his job. Happy New Year, right?

I'm reminded, however, that Jesus was despised and rejected by men. His own people - family and friends - were the first to mock, reject, even betray Him. He was a man of sorrows and acquainted with

grief. If anyone ever knew about physical, mental, and emotional pain and anguish, it was Jesus. He knows. Jesus Christ knows!

When the pain becomes too much to bear, Jesus understands. He holds me. He cries with me. He prays for me. He loves me through it every time. He is my friend who sticks closer than a brother. And that's what gets me through it all.

He gives me the strength to endure, the hope to see beyond what I can see, the faith to believe that with God all things are possible and that all things WILL be made beautiful in its time. He is my rock and my fortress, my very present help in every kind of trouble. He is my comforter and sustainer. He is my promise-keeper.

There is no one who knows me and understands what I go through more than Jesus. There is no one who pleads to the Father on my behalf more than He. How can I not find joy and strength in that?

I admit that I was glad to see 2008 become history. And honestly, I didn't look forward to 2009. But, I found comfort and strength in knowing that no matter where life takes me, Jesus Christ goes with me - carrying me, holding me, and providing for all my needs. And when I can't see the way, I pray He will always give me faith to believe in what I cannot see.

Entering the New Year, I made no resolutions. I prayed.

And, I continue to pray - for God's mercy on me and my family; for the faith and the wisdom we need to live each day; that He would continue to provide for our needs; and that,

somehow, we will be able to shine as His light to the world around us no matter what trials He gives us to endure.

It is also my prayer that you will be blessed with a solid, unwavering faith in the Lord Jesus Christ; that you will learn more of His loving-kindness through the trials you face each day; that you will be a shining light in the midst of the dark world you live in.

I pray that even in the midst of our suffering, we will work together to shatter the grip of disbelief that holds captive the world around us. *pha*

About the Author:

Linnette R Mullin is a freelance writer and publicist who enjoys writing fiction, as well. She has written articles for In Touch Magazine with Charles Stanley and The Write Connection for Heart of America Christian Writer's Network (HACWN) in Kansas City, Missouri. An active member of HACWN, she was chosen "Cheerleader of the Year" for 2008 and won "Article of the Year" for her non-fiction article, God's Healing Promise, at their annual conference.

Linnette ministers through her on-line support group for chronically ill people and their loved ones called "LymeLife: Living with Chronic Illness." You may visit her and her links at www.LinnetteMullin.com.

Linnette currently resides in Belton, Missouri with her husband, John, and their four awesome boys. Linnette and her sons are currently being treated for Lyme disease.

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extends our deepest & heart felt sympathies to the family and congregation of First Baptist Church of Maryville, Illinois in the tragic loss of Pastor Fred Winters.



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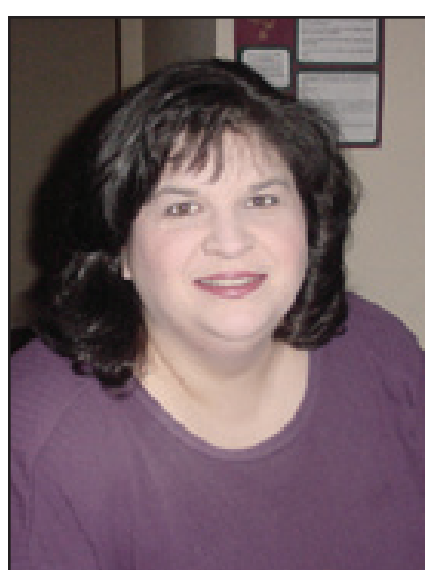
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IDSA at the Helm: Crimes Against Humanity?



by Dawn Irons

"Unless we put medical freedom into the Constitution, **the time will come when medicine will organize into an undercover dictatorship to restrict the art of healing to one class of men and deny equal privileges to others:** The Constitution of this Republic should make a special privilege for medical freedom as well as religious freedom."

Dr. Benjamin Rush, signer of the Declaration of Independence.

One might wonder how Dr. Benjamin Rush, one of our Founding Fathers in America, could have known over 230 years ago the unfortunate drama that would play out before us today. The medical controversy, and dare I say tyranny, that he described then seems almost prophetic in retrospect.

My pastor is forever reminding people that, "Time proves all things." And this is certainly the case where the ideas of Benjamin Rush are concerned. The "undercover dictatorship" who is attempting to restrict the healing arts to their exclusive medical society at the expense of denying equal privilege to other researchers and practicing physicians has absolutely proven true over time.

The Infectious Disease Society of America (IDSA) has proven to be so exclusively territorial over the treatment and diagnosis of Lyme disease that they have been brought before the Attorney General of Connecticut Richard Blumenthal on charges of anti-

trust violations. In layman's terms, anti-trust violations are the attempts of one group (IDSA) to shut down their competitors for the sake of financial gain.

The competitor in this medical tug-of-war is the International Lyme and Associated Disease Society (ILADS). This group also has a set of treatment guidelines which is the target of IDSA's crushing blow of medical treatment dictatorship.

AG Blumenthal, through process of investigation of IDSA, discovered numerous financial conflicts of interest and the authors of the treatment guidelines were ordered to be sidelined, in a manner of speaking, while an independent mediator would be appointed to oversee the IDSA while they reviewed the guidelines to see if these conflicts of interests helped shape the treatment recommendations.

The Controversy

The bitter conflict between IDSA and ILADS has to do with long term antibiotic treatment for Lyme disease. The two medical societies could not have a more polar opposite approach to the treatment of Lyme disease.

No one disputes the fact that if Lyme disease is caught early and treatment administered immediately, it can be easily cured with a standard course of antibiotics.

The problem lies in the dilemma of catching it early. The ILADS doctors who are the physicians who are actually treating this disease in the trenches, as opposed to the IDSA doctors who primarily do academic research, have reported that fewer than 50% of the patients testing positive for Lyme disease have presented with the typical bulls-eye rash. It is very possible to have a rash, on the scalp for instance, that is never visibly seen.

IDSA, on the other hand, insist that the bulls-eye rash is seen in over 80% of patients with Lyme disease. But these academic doctors do not treat patients on a daily basis.



The Consequences

When the doctors who are entrusted with medical care are engaged in bitter battles over their treatment guidelines, it is the patients who are at risk and suffer.

The vast majority of Lyme patients are finding themselves having to travel out of state in order to get medical treatment for their Lyme dis-



Pastor Fred Winters of First Baptist Church Maryville, Illinois was gunned down and killed by a man suffering from Chronic Late-Stage Lyme disease. The church requests for further prayers for the family of Pastor Winters and also for Terry Joe Sedlacek and his family and friends.

ease. If one's symptoms do not resolve in the IDSA's recommended 14-28 days of antibiotic treatment, many are left with

little options for continued treatment.

Insurance companies are using the IDSA guidelines as a basis for denying further treatment to Lyme patients since they report that Lyme is easily diagnosed and cured in 28 days or less. The insurance companies are clearly choosing the cheaper option because the ILADS guidelines are also recognized and accepted into the national clearinghouse of treatment guidelines for Lyme disease. But IDSA's guidelines are shorter and cheaper...and have fewer positive outcomes.

Many Lyme patients, after trying the IDSA protocol and finding no relief in the treatment, are refused longer treatments and are left to find doctors who would consider treating with the ILADS guidelines.

Can Lyme Disease Cause Mental Illness?

Make no mistake, Lyme disease, if left undiagnosed or undertreated, will affect the brain to varying degrees.

Terry Joe Sedlacek was a member of the Saint Louis Lyme disease support group. This group knows and understands the conflicts of the IDSA vs. ILADS debate over treatment protocols. Sedlacek was suffering the consequences of an insurance company who

would not cover further treatment. The support group is now working on a fund raiser to help with Sedlacek's further treatment. Their website states, "Terry Joe Sedlacek has been suffering from Lyme Disease and its co-infection Ehrlichiosis for the past several years. He nearly lost his life to this disease five years ago and battles the effects daily. His medications and doctor visits are cost-



Terry Joe Sedlacek, CLD patient, was treated by IDSA standards that should have cured him. Recent tests showed his Lyme and co-infections are active and he has left temporal lobe brain damage as well due to ineffective short term IDSA treatments that offered no curative value for his late-stage of the disease.

ly. New test results revealed the return of this disease and left temporal lobe damage. He will "IDSA Crimes"... cont'd pg 14

Lyme & Mental Illness: A Mother's Personal Story

Dear Editor:

When I adopted my son at the age of three, he had already been in psychiatric hospitals for violent behavior. I was told by Yale doctors when he was only four that they had no doubt when he got older he would kill someone and they pressured me to put him a psychiatric facility.

My son had been placed in highly specialized schools, and all the experts at these schools could not help him. He had been expelled from one school after another.

I took him to countless doctors and psychiatrists. He had been on many different meds (including several years on a cocktail of Lithobid, Tegretol, Abilify and Zyprexa) and many different diet and behavior plans.

One of these doctors was the author of the book *The Bipolar Child*, Dimitri Papolos. Dr. Papolos said that my son

Nick was one of the most severe cases of pediatric bipolar he had ever seen. Nick had made the rounds of many hospitals such as Hall Brooke, Four Winds, Natchaug, St. Francis, Danbury, St Raphael's, White Plains, and Westchester. Some of these places he had been in 3 or more times.

None of these facilities had been able to help him. I couldn't even begin to count ER visits. The ER staffs at the Danbury Hospital know me by name. The treating psychiatrist at Four Winds Hospital told me that Nick was the worst case of pediatric bipolar she had ever seen, they could not help him and after 6 admissions they said they would never take Nick back.

The last time he was in Danbury Hospital, he was taken there handcuffed in the back of a police car because he tried to kill someone with a knife. Although a child, he was placed

in the adult unit and the social worker at Danbury Hospital tried for 3 weeks to find a pediatric placement but could not find a single place that was willing to take him and the social worker told me he was looking everywhere in the continental U.S.

I was told many times that Nick needed to be institutionalized. And I knew that meant for life. This would be a life of daily physical and chemical restraints. Nothing and nobody seemed to be able to help this child. Nothing could stop his homicidal and suicidal rage... that is, until one brave doctor took the time and made the real diagnosis: Lyme disease.

And after a long and winding, Nick is a completely different child.

Can Lyme cause mental illness and violent behavior? YES.

There is absolutely NO

other explanation for what happened to my son. ALL of his symptoms were psychiatric in nature. Nothing else can account for the complete transformation in his life.

Anyone anywhere who doubts that Lyme disease can cause mental illness and violent behavior, including homicidal rages, send them to me. There is absolutely, positively NO other explanation at all for the complete change in my son.

The treating psychiatrist at Hall Brooke said it himself (until he was pressured by superiors to "shut up"), "It has to be the Lyme treatment, there is no other possible explanation for the change in Nick."

I have no medical background at all, I studied painting, drawing and art. I cannot begin to explain what happened to my son in any medical terms. I am just the witness to what did happen.

Now is he unique? ...Of

course not. I suspect that there are many people out there who suffer from some degree of mental illness and/or Lyme rage and hide it. Many do not even speak about it in their own Lyme communities because of the stigma attached to it and because they are afraid of being outcasts.

I am hoping that if someone is embarrassed by the label of mental illness and doesn't want Lyme disease to be linked to psychiatric illnesses or violent behavior only because it might reflect badly on them personally-I ask them to reconsider their position.

We need to be telling the world the truth about this illness. And the truth is that it can cause mental illness, violent behavior and, yes, sometimes extreme violent behavior.

Donna Benner, Art Teacher Mother to 15-year-old Nicholas, a great young man.

New Treatment Provides Dramatic Results



by Tina J. Garcia

A woman painfully hobbles into the clinic, barely able to stand at the front desk. She scribbles her name on the sign-in sheet and makes her way to the nearest available seat. The overwhelming fatigue causes her to drop heavily into the chair. She braces her head in her hand and closes her dazed and weary eyes. The eyes that used to draw compliments for their beautiful luster and sparkling allure now reflect years of sleepless nights, episodes of wracking pain and a loss of enthusiasm for life. Makeup hardly helps, so she doesn't even bother to use it anymore. Besides, her arms are so tired and weak that it takes too much effort for her to apply the mascara. Once shiny and full of body, her hair has thinned and looks dry and brittle. She combs her hair before going to her doctor's appointments, but she doesn't have the energy to style it, as she had before becoming debilitated from Lyme disease and co-infections.

Borrelia burgdorferi, the bacterium that causes Lyme disease, invades the body in a stealthy way. As it burrows into the brain, muscles, tendons, ligaments and nerves, it causes more and more damage that manifests as various complaints throughout the body. At first, you may think you're just tired from doing too much or stressed out from work and family duties. It's easy to dismiss these common, everyday complaints during the first few weeks and months that you experience them. However, when you notice tingling and numbness in your arms, hands

and feet, you begin to think it might be more than just a stressful job or too much to do around the house. Then when you can't sort the papers on your desk, make accounting mistakes and forget what you are doing and where you are going, you know that something else is definitely wrong. Add painful, swollen joints that hurt with every step and you're ready to seek a medical diagnosis.

This is when the Lyme Odyssey begins. To the detriment of patients and treating physicians alike, it's rare to get an immediate diagnosis of this insidious infection which robs a person of their physical and emotional well-being. It usually takes many different medical encounters before a doctor finally determines the underlying cause of these diverse symptoms - co-infections and Lyme Borreliosis Complex (LBC), which is a late-stage diseased state. By this time, the bacterial load has the upper hand and is destroying the physical body. The patient's immune system has already mounted a valiant attack, but has either been defeated or is stuck in "overdrive" by the time treatment is finally administered.

In this difficult situation, the patients and the treating physicians are behind the eight ball. Patients are desperately looking to the doctor to cure them so they can regain their pre-infection abilities and return to their previously productive lifestyle. Patients maintain a high standard for their treating physicians and hold them accountable, whether or not the treatment results in being cured.

Lyme-treating doctors are seeing an increase in patients presenting with these similar symptoms. The goal of these physicians is to restore their patients' health, which is not an easy task. In their spare time, physicians read medical literature and books and consult

with colleagues in search of better ways to treat their ailing patients. They are on a continual quest to keep abreast of new developments and discoveries with regard to *Borrelia*, *Bartonella*, *Ehrlichia*, *Babesia*, *Mycoplasma* and viruses, all co-infections that may be complicating their patients' health. Treating late-stage Lyme Borreliosis Complex and the other infections that accompany it, is a learning process. Studying the diseases and gaining experience in the clinical setting provides a critical understanding of the many complexities involved in treating such a complicated mix of infections. It takes fortitude

Envita Natural Medical Centers of America (also in Scottsdale) and David Korn, D.O., M.D.(H), D.D.S., Medical Director at Envita and LongLife Medical, Dr. Korn's private practice in Mesa. The result of these discussions is the application of a novel treatment protocol administered by Dr. Korn, who in addition to his osteopathic license is also a homeopathic physician licensed in Arizona. The combination treatment is currently providing great improvement and relief to Lyme disease patients. Drs. Korn and Prato are grateful to and acknowledge Dr. Fry for sharing his insight and knowledge about the destruction of biofilms.

The new treatment protocol begins with the insertion of a port-catheter by an interventional radiologist for administration of intravenous therapy. The therapy is given in the doctor's office once per week for nine weeks, give or take a week or two. It begins with a three-hour IV with an agent that destroys the biofilm surrounding the bacteria. This makes the previously-sequestered bacteria vulnerable to antimicrobial therapy. Immediately following the first IV, Azithromycin antibiotic is administered, also intravenously. This second IV takes approximately two hours. This

is done in one day and the patient goes home. The patient returns to the office the next day and receives an IV mineral supplement, absent magnesium.

Dr. Fry explains that the reason magnesium needs to be withheld from the mineral supplement is due to the fact that magnesium aids the bacteria in the development of the biofilm.

Therefore, after destroying the biofilm and the bacteria, it is not logical to provide magnesium, which will only help create more biofilm. Dr. Fry has also found that Lyme disease patients more often than not have an overabundance of magnesium. However, he recommends monitoring the

patient's magnesium level during treatment.

The doctors are reporting dramatic improvement in patients, such as the woman described above who was so sick prior to treatment. After three weeks of the combination therapy, this woman bounced into the clinic with renewed enthusiasm, reclaiming herself as the vibrant person she was before becoming so ill! After only three weeks, her energy level had increased substantially, enabling her to apply her makeup and fix her hair again. As a chronic LBC patient, I can relate to the importance of regaining previous function and a return to one's previous self. I feel very comfortable after speaking with Drs. Fry and Korn and look forward to receiving this treatment protocol in the future, also.

The doctors are not claiming this treatment to be a cure for every patient, but one treatment for approximately nine weeks sure beats several weeks or months of antibiotic therapy three times a day. The staff at Envita and LongLife Medical are available to answer questions you may have about this promising new treatment. Please note that Dr. Korn is the only physician mentioned in this article who is licensed to administer and who is administering this particular treatment. Dr. Fry's information is provided for questions only; he does not provide this particular treatment protocol. For your convenience, phone numbers and websites are provided below.

Dr. Dino Prato & Dr. David Korn
Envita Natural Medical Centers of America
www.envita.com
866-830-4576
602-569-4144

Dr. David Korn
LongLife Medical
www.longlife-medical.com
480-354-6700

Dr. Stephen Fry
Fry Laboratories
www.frylabs.com
866-927-8075

Dr. Stephen Fry
Airpark Medical Center
www.airparkmed.com
480-991-4555

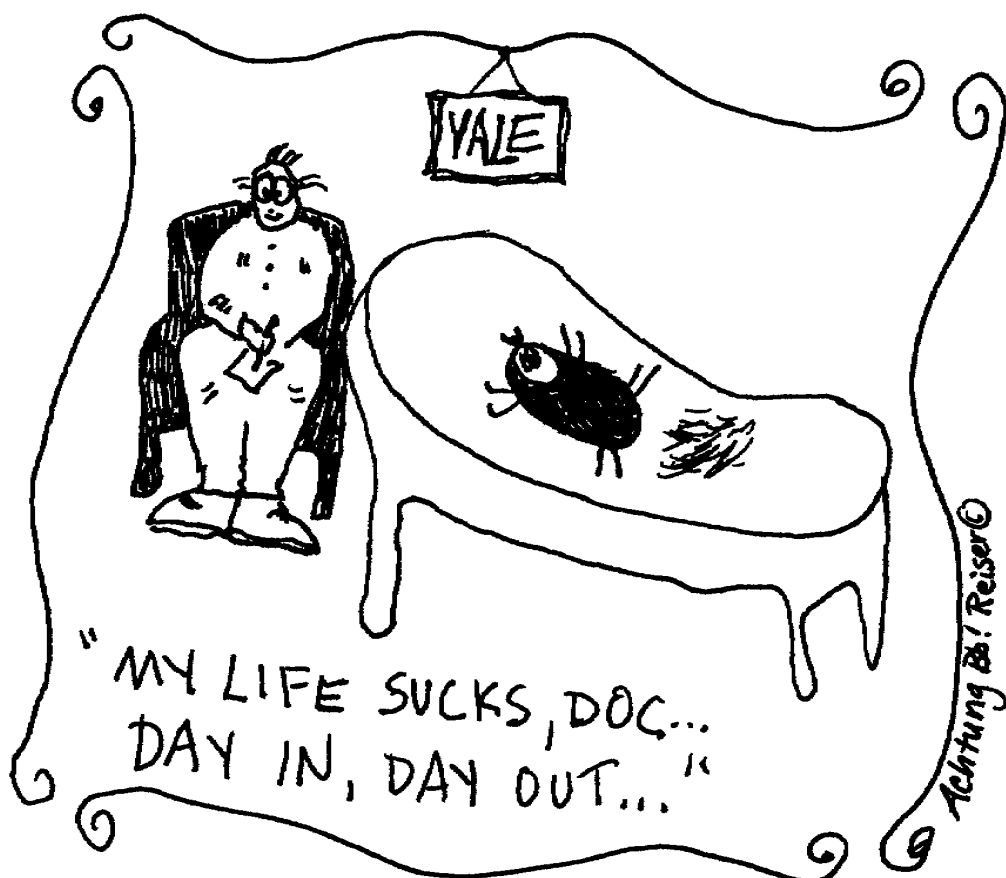
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“... it's rare to get an immediate diagnosis of this insidious infection, which robs a person of their physical and emotional well-being. It usually takes many different medical encounters before a doctor finally determines the underlying cause of these diverse symptoms - co-infections and Lyme Borreliosis Complex (LBC), which is a late-stage diseased state.”

and a willingness to try different treatments on an individual basis to see which ones will be most effective.

Recent developments in research on *Borrelia burgdorferi* biofilms has been a catalyst for three Lyme-treating physicians in Arizona to collaborate for the benefit of their patients. Microbiologist Stephen Fry, M.D. of Fry Laboratories in Scottsdale, has contemplated the use of certain agents that destroy biofilms which surround and protect bacteria and cause remissions and relapses in chronic infections. In 2008, Dr. Fry began discussing research on this subject with Dino Prato, N.M.D., owner of

Ticktoons



by Terri Reiser

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Scientific Evidence for "Lyme Rage"

by Kris Newby
www.undertheskin.com blog

In light of the tragic shooting in Illinois, we'd like weigh in on the issue of whether the shooter's case of late-stage Lyme disease could have caused violent behavior. First, during our four years of research for the film, UNDER OUR SKIN, we interviewed a number of patients who had bouts of "Lyme Rage" before appropriate treatment. While it doesn't seem that common, it does seem possible. In addition, many of the physicians we interviewed, specifically the ones who treat a large number of Lyme patients, acknowledge that they have had patients with Lyme Rage. And finally, there are over 100 peer-reviewed medical journal articles linking tick-borne diseases to mental symptoms and quite a few that document Lyme-induced rages. For your convenience, I've cited some of these articles at the bottom of this post.

In this morning's press, the IDSA and CDC came out with guns blazing, denying the possibility of Lyme Rage.

Dr. Gary Wormser, the lead author of the controversial Infectious Disease Society of America (IDSA) Lyme guidelines, said, on WebMD:

"I don't know of any convincing evidence that Lyme disease can cause violence or psychosis."

Paul Mead, a medical epidemiologist with the CDC, said in an article by Roger Schlueter of the News-Democrat:

"So the spirochete certainly can, in the lab, attach to nerve cells, and it certainly causes acute inflammation of nervous tissue," Mead said.

"But whether that would cause psychiatric illness is, as far as I know, impossible to say."

While I personally find their Lyme-denialism baffling, I encourage those of you interested in the science to read the peer-reviewed journal articles listed below, and decide for yourself.

The News-Democrat also cites the Prague study, which says:

"In 2002, a study at the Prague Psychiatric Center involving 1,900 people found that people with psychiatric illness had about a 30 percent increased incidence of Lyme disease antibodies in their blood compared to other study participants."

Isn't it worth keeping our minds open to the emerging evidence that the Lyme bacteria - a neurologically invasive spirochete just like syphilis - could be the root cause of a myriad of psychiatric disorders that are currently considered incurable? How costly to our society and inhumane to medicate and lock up thousands of supposedly mentally ill people, when they may have a treatable bacterial infection.

Lyme-Induced Psychiatric Disorders

Peer-Reviewed Literature from Around the World:

Lyme disease: a neuropsychiatric illness by Fallon, BA; Niels, JA. *American Journal of Psychiatry*. 1994 Nov; 151(11):1571-83.

"A broad range of psychiatric reactions have been associated with Lyme disease including paranoia, dementia, schizophrenia, bipolar disorder, panic attacks, major depression,

anorexia nervosa, and obsessive-compulsive disorder."

Late-stage neuropsychiatric Lyme borreliosis Differential diagnosis and treatment by Fallon BA, Schwartzberg M, Bransfield R, Zimmerman B, Scotti A, Weber CA, Liebowitz MR. *Psychosomatics*. 1995 May-Jun;36(3):295-300.

"Although dermatologic, articular, cardiac, ophthalmologic, and neurologic manifestations are well known, it is less well known that psychiatric disorders may also arise. Depression, panic attacks, schizophrenia-like psychotic state, bipolar disorder, and dementia have been attributed to Lyme borreliosis."

Functional brain imaging and neuropsychological testing in Lyme disease by Fallon BA, Das S, Plutchok JJ, Tager F, Liegner K, Van Heertum R. *Clinical Infectious Diseases*. 1997 Jul;25 Suppl 1:S57-63. Review.

"Patients with Lyme disease may experience short-term memory loss, severe depression, panic attacks, unrelenting anxiety, impulsivity, paranoia, obsessive compulsive disorder, personality changes marked by irritability and mood swings, and rarely, manic episodes or psychotic states."

The underdiagnosis of neuropsychiatric Lyme disease in children and adults by Fallon BA, Kochevar JM, Gaito A, Niels JA. *Psychiatric Clinics of North America*. 1998 Sep;21(3):693-703, viii.

"In addition to the disorders listed by Kohler and Omasitis, Lyme disease appears to be capable of causing syndromes that manifest as person-

ality change, depersonalization, mania, hallucinations, (auditory, visual, and olfactory), paranoia, cataonia with stupor and mutism, somatization disorder, obsessive compulsive disorder, violent outbursts, panic attacks and disorientation."

The neuropsychiatric manifestations of Lyme borreliosis by Fallon BA, Niels JA, Burrascano JJ, Liegner K, DelBene D, Liebowitz MR. *Psychiatry Quarterly*. 1992 Spring;63(1):95-117. Review.

"Lyme disease is aptly called the "new great imitator," and it can imitate psychiatric disorders no less than medical ones. Psychiatrists working in endemic areas are well advised, then, to keep Lyme disease in mind as part of their differential diagnosis for a broad range of disorders including, for instance, panic attacks, somatization disorder, depression, and dementia."

A 25-year-old woman with hallucinations, hypersexuality, nightmares, and a rash by Stein SL, Solvason HB, Biggart E, Spiegel D. *American Journal of Psychiatry*. 1996 Apr; 153(4):545-51.

"The [Lyme] patient expressed a delusional belief that she was controlled by an attractive popular male former high school teacher who had put a curse on her family before her birth and was now sexually obsessed with her."

Lyme borreliosis in neurology and psychiatry. Germany: Neurologische Klinik mit Poliklinik, Universität Freiburg. Kohler J. *Fortschr Med*. 1990 Apr 10;108(10):191-3, 197.

"Involvements of the Central Nervous System are

expressed not so much in focal deficits, as in diffuse psychopathological disorders... The clinical symptomatology may be dominated by severe psychiatric syndromes."

Higher prevalence of antibodies to Borrelia burgdorferi in psychiatric patients than in healthy subjects.

Czechoslovakia: Prague Psychiatric Center. T. Hajek. hajek@pcp.lf3.cuni.cz
Hájek T, Pasková B, Janovská D, Bahbouch R, Hájek P, Libiger J, Höschl C. *American Journal of Psychiatry*. 2002 Feb;159(2):297-301.

"These findings support the hypothesis that there is an association between Borrelia burgdorferi infection and psychiatric morbidity. In countries where this infection is endemic, a proportion of psychiatric inpatients may be suffering from neuropathogenic effects of Borrelia burgdorferi."

Poland: **Klinika Psychiatrii**, Biaymstoku. Rudnik I, Konarzewska B, Zajkowska J, Juchnowicz D, Markowski T, Pancewicz SA. *Pol Merkur Lekarski*. 2004 Apr;16(94):328-31.

"Mental state examinations and psychometric testing revealed in majority of the patients, mainly in those who suffered from neuroborreliosis and erythema migrans evidence of various psychiatric symptomatology. The range of psychiatric presentations included: mild cognitive deficits, organic mood disorders, mild dementias, depressive and anxiety episodes with non organic etiology."

pha

"Lyme Rage" ... cont'd from pg 1

have had the illness for several months to many years have experienced at least one episode of Lyme rage, if not many more frequently in number.

To describe the sudden emergence of this overwhelming rage is to say it is similar to turning on a light switch. Just as quickly as it manifests, it ceases entirely to exist. The sudden flare-up and intensity of this bizarre brain dysfunction can be described as a kind of seizure or malfunction (having experienced these myself). The triggers of Lyme rage are very small, and can be anything that feels irritating to the sufferer. The incidents can be as simple as a verbal attack against a party, or more aggressive, physical contact-sport like activities such as throwing objects, hitting, kicking, or punching inanimate objects like walls or furniture. It can even encompass road rage or physical abuse, according to some patients (fortunately, not in me). In those moments where the control center of a Lyme-infected brain ceases to function and momentarily "stop" untoward behavior from happening, the patient is often barely aware of the intensity of their aggression, let alone able to control it meaningfully. It is within this moment that I and many others have found ourselves caught by the Lyme bug. For myself, it

has been one symptom that required due diligence to control when I was at my sickest, which was years ago. The best method of avoidance is to avoid even minor irritations, and certainly any stressful situations or individuals. A Lyme patient can become quickly overwhelmed and this can lead to episodes of unintentional rage. Patients describe the episodes as "coming from out of left field."

Another aspect of brain infection is that at times the patient is aware of their own activities, but for some reason they feel like an unwitting participant, as if observing their own activity with complete apathy or indifference. I'll call this "Lyme-induced indifference", or LII, just to provide a label. Just for the record, there is no history of mental illness in my family, despite the best efforts on three occasions over years, for psychiatric and other experts to determine whether or not I had mental illness through rigorous and extensive psychiatric testing. Fortunately, I was always declared quite sane, so I

cannot be accused of having previous or existing mental illness. Despite those declarations, an example of LII came about years ago when I was feeling particularly irritable (Lyme causes brain inflammation with intense headaches -

When the inflamed brain or central nervous system (CNS) is in the middle of an attack of meningitis or encephalitis, the pain can be intractable, and even "standard" pain medications can have no effect. This kind of pain, when endured over a period of time, can certainly make someone feel "crazy" - crazy out of their mind with pain.

think PMS x 1,000). I was about to eat an apple and decided to cut it into slices. I opened the cutlery drawer and removed a new Ginsu® knife.

Wondering if it was as sharp as it was advertised to be,

without pausing for a moment to think about the consequences of the action, I drew the knife across my left arm, three times in quick succession. Mind you, under normal circumstances, no person would do such a thing. But on that day, under those

conditions and with severe brain inflammation, my startling and unanticipated behavior left no other explanation except that I was aware of what I was doing physically, but the filter in my brain that normally says "that's probably a bad idea" was momentarily and entirely absent, only to return immediately upon completion of the behavior, shaking me back to reality. Some might call this a momentary lapse of reason.

Good fortune was on my side as I had not put much pressure upon the knife, and so the cuts were reduced to deep scratches. They could have been far worse.

The incident frightened and embarrassed me. "What is wrong with me?" is a question many Lyme patients ask themselves on a nearly daily basis and, that day, I was first in line. Both of my children, who have

documented exposure to Borrelia burgdorferi, have experienced episodes of Lyme rage and depression. And sadly, one child spent three days under observation in a psychiatric unit due to serious threats and homicidal and suicidal postings on the internet, depressive essays, artwork that was violent, and photographic stills that would make any parent question their child's sanity or intent.

I tell you these episodes because I never shared this with a physician in a clinical setting for fear of myself or my children being labeled "crazy" - a term which does not describe us on any given day. And I am willing to bet that most patients don't share their more intimate, dysfunctional details with members of the medical profession, either. Naturally, we worry that our doctor may jump to a conclusion that a patient exhibiting this kind of behavior is "depressed", or worse, certifiable. Further, I know many Lyme patients who have thought of killing themselves, spoken openly about it, and tragically a few who have been successful at it. Were those patients "crazy?" My guess is no, or only momentarily due to brain inflammation. Family members can attest that "this kind of behavior" never

"Lyme Rage" ...cont'd pg 13

What Psychiatrists Should Know about Lyme Disease

Edited by *ILADS Psychiatrists*
Drs. Virginia T. Sherr and
Debra J. Solomon

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 loss ("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

(OCD), sleep disorders, attention deficit/hyperactivity disorder, (ADD/ADHD)-like syndrome, 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 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 encephalopa-

thy:

- ❖ 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 questions, 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.columbialy-me.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 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

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
"Psychiatrists" ...cont'd pg 9

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“Psychiatrists” ...cont’d from pg 8

gia, 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.

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) See Category below.

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 scan-

ning, 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)
- ❖ 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*



International Lyme & Associated Disease Society

ILADS is a group of forward-thinking doctors who understand the complexities of Lyme disease and are pioneering a new standard of care to ensure all patients have access to care.

www.ilads.org
contact@ilads.org

ILADS offers physician training programs

“IDSA to ILADS” ... cont’d from pg 2

work full-time. Dr. Shor notes that the process was a gradual one and that those patients with chronic Lyme disease generally do not improve overnight. Using the questionnaire that Dr. Shor had created, clear evidence of patient improvement was seen every 4-8 weeks at his regular visits and overall sense of well-being improved. Today, the patient is off all antibiotics and continues to work full-time with an herbal protocol.

A second patient was a 16 year-old high school student that had been home-schooled because she could no longer tolerate the normal rigors of a student schedule. Initially, she was diagnosed with CFS and Fibromyalgia, but she also fit the paradigm for chronic Lyme disease. Dr. Shor started treating the patient with antibiotics and within three months, she was back to school full-time. In fact, she felt so well that she stopped the antibiotics but she quickly got worse and her symptoms score significantly raised. She was put back on antimicrobials and within three months, she was again back to a state of good health.

The experiences that Dr. Shor was having with his own patients were supportive evidence that what he was doing and what was being recommended by ILADS was in fact "valid and appropriate". Dr. Shor recognized, however, that publishing case reports would not be enough to convince the larger medical community of his findings. He knew that there had to be a more randomized, controlled approach to studying the matter further.

Dr. Shor has written a

proposal currently being evaluated by the NIH which would substantiate what he has been seeing in his private practice. He has created a protocol that randomizes patients into either an active or placebo-controlled group of three months of Omnicef and Biaxin. In order to enroll, the patient must have been symptomatic for less than five years, have a negative Lyme ELISA, have criteria for both CFS as well as having supportive evidence through other means, such as IGeneX or low CD57, to suggest that the patient may have Lyme disease.

Different metrics will be used to evaluate clinical changes to see if the patients show a clinically-significant improvement. The study will attempt to show whether or not Lyme disease treatment can improve many of the symptoms that patients with "CFS" experience.

Dr. Shor's patients recently convinced Congressman Frank Wolf to put together an open town meeting on the topic discussed in this

article. Dr. Shor was one of three speakers. The other two were from local county health departments. They expected thirty people to attend this event and in fact, over 400 people attended in an indication of the profound interest that the community has on this topic. Members of the audience approached Dr. Shor and asked him to speak at a Congressional hearing with Andy Wilson from *Under Our Skin* and Pam Weintraub, author of *Cure Unknown*. The goal was to make Lyme disease a priority for Congress to pro-

vide funding for research as well as to deal with the "unfortunate, restrictive approaches that the IDSA is placing on the whole area".

In asking Dr. Shor if he had attempted to become a member of the new IDSA panel tasked with revisiting their current Clinical Practice Guidelines on Lyme disease, Dr. Shor shared that he, like numerous other ILADS members that had applied, was disqualified by the IDSA for "seeing too much Lyme disease". Unfortunately, any practitioner that makes over \$10,000 per year from the treatment of Lyme disease was automatically excluded from the new IDSA panel according to Dr. Shor. This excludes clinicians with the most experience in treating the disease.

Dr. Shor suspects that anyone that fits this paradigm sees enough Lyme patients that the IDSA believes the practitioner has a perspective that is inconsistent with its own or if the practitioner is seeing that many patients with Lyme disease, they must have conflicts of interest and likely want to generate their own income by making a frequent diagnosis of Lyme disease.

Dr. Shor points out that the reality is quite the contrary. In his case, the interest evolved because of the need. The word started getting out that there was someone that could help. The end result was a growth in his practice which ultimately became a volume difficult to manage. Dr. Shor notes that his practice is not "churning people out to make money" but rather that he is working with very complex illnesses in people where many are quite disabled.

According to Dr. Shor, to improve the quality of life is the goal of medicine. Fortunately, in its evolution, he has tapped into a multiphasic, multi-system approach that takes the entire person into consideration and has been able to evolve a paradigm that has worked for the majority of the patients that he sees.

Dr. Shor has journeyed from IDSA to ILADS. This is a journey that so many of us with chronic Lyme disease wish that other doctors would be brave enough to take. It is a journey that has helped many people in his practice. However, it is a journey that the larger medical community as a whole must take in order to meet the needs of so many patients that are struggling to find adequate medical care.



When Dr. Shor first started to explore this perspective he noted that he initially had a negative perspective on chronic Lyme disease. The more that Dr. Shor did his due diligence in an academic and intellectual way, keeping in mind doing no harm but looking for ways to help people, the more confident he became in his belief that chronic Lyme disease is an important area that needs to be "further explored and openly understood".

Dr. Shor holds a hope that we will have reconciliation within the medical community for the betterment of a large segment of the population that "heretofore has gone undiagnosed due to the lack of insight or the direct antagonistic perspective on the topic." He hopes that "the powers that be,

who are putting out roadblocks, can ultimately have reconciliation so that we as a society can move forward and benefit from it."

Here's to your health.... *pha*
[See Q&A with Dr. Shor pg 11]

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About Dr. Shor

Dr. Sam Shor, MD, FACP practices Internal Medicine in Reston, VA. His practice provides care for patients dealing with CFS, Fibromyalgia, and chronic Lyme disease. Dr. Shor is an Associate Clinical Professor at George Washington University.

Dr. Shor is a member of ILADS which can be found on the internet at <http://www.ilads.org>. For patients interested in working with Dr. Shor, his office can be reached at 703.709.1119 or via his web site at <http://www.intmednova.com>.

For additional information on Lyme disease medical policy issues, visit the Lyme Policy Wonk at:

<http://tinyurl.com/lymepolicywonk>

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Military Lyme Support is an online source of information and emotional support. This site is for Military Members, Veterans, and their family members who suffer from Lyme and other vector-borne diseases. Members are stationed in the United States and abroad.

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Q&A with Dr. Sam Shor, MD, FACP

by Scott Forsgren

What percentage of the previously diagnosed CFS patients that you see may actually be dealing with chronic Lyme disease?

Confidently, 50% or more of my CFS patients may have Lyme disease as the underlying cause of their illness.

What is your preferred treatment for Borrelia?

In my study, I am using Omnicef and Biaxin. This was a combination that Dan Cameron, MD had used in a paper to show statistically significant improvement in chronic Lyme disease. I find this combination to be high on my list, though it depends on a number of different issues. I consider whether or not a particular co-infection may need to be addressed. For example, if the patient has Ehrlichia, then I lean more towards Doxycycline.

Which co-infection would you say causes your patients most severe symptoms?

Either Babesia or Bartonella. Both can be very profound. Profound neuropathic pain is identified with Bartonella. Profound fatigue, profuse sweating, and headaches are indications of Babesia.

In terms of difficulty in treating, Bartonella is more difficult. Babesia usually responds to treatment with a macrolide, Mepron, and artemisinin. It may require high doses and require treatment for protracted periods of times. Babesia is easier to track as the majority of people have some sweating and this is an easy symptom to track in patients and adjust treatment. Following Bartonella is more difficult.

What do you find to be the most successful treatment approach for Bartonella?

I use a macrolide and Mycobutin (Rifabutin). Sulfadiazine can be useful but generally are not nearly as effective. I don't like using quinolones due

to problems such as myalgias, arthralgias, and tendonitis which may be experienced with Levaquin. These are generally an independent action of the drug and do not signify a die-off reaction.

With Babesia, when you notice that the sweats are gone and stop treatment, do you believe that the organisms are fully eradicated?

No. I believe that certainly Borrelia and likely Babesia and Bartonella and likely other co-infections cannot be totally eradicated. The goal is to get people to a state of remission. When the diagnosis is made, I tell patients that the goal is to get them to a level of functionality and quality of life that they feel is normal and that does not require antibiotics to sustain. We recognize that the goal represents remission, not cure.

With cure, you do not expect any recurrence of symptoms unless there is a re-exposure. With remission, you can have recurrence even without re-exposure. When a person is in remission, I will then convert the patient to an herbal program for a period of time. Best case, the patient goes off the herbs and the remission is sustained. In some cases, the patient will experience an increase in symptoms when moving from antibiotics to herbal treatment but as the herbs take hold, they normalize. Some people may transition too early and require going back to antibiotic therapy.

What laboratories do you find the most helpful in providing you with information to appropriately diagnose and treat your patients?

I have used a number of labs. I use LabCorp to do the first phase testing. They are the lab that does the CD57. Most of their technology is acceptable though we have to recognize that their Western Blot is far from ideal. Their IgM Western Blot only looks at 2 of 5 Borrelia-specific bands and IgG only 3.

Most insurance companies are more likely to cover testing from LabCorp. If you are able to make a diagnosis

from their tests, you can avoid the more expensive testing. If I have clinical suspicion and only partial validation from LabCorp, then I will use IGeneX.

I do preliminary co-infection testing through LabCorp. They are very good at picking up Babesia duncani. I have gotten lots of positives and I am on the East coast. It is definitely found here on the East coast.

If I need more solid grounding on co-infections, I will use IGeneX. Most commonly, I use their IgM and IgG Western Blot for Borrelia. If there is clinical suspicion of a co-infection, such as if a patient has sweats and shortness of breath along with fatigue and headaches, the patient has Babesia until proven otherwise. If a patient has cognitive disturbances, neuropathic pain, and joint pain, Bartonella is likely.

The C6 peptide test can be helpful. When it is positive, it is quite useful, but it is not that sensitive. When it is positive, it is a prognosticator much like CD57 but when it is negative, this does not mean that one can rule out Borrelia as a possible cause of illness. When the test is positive, it is quite helpful, but it is not sensitive enough to rule out the disease when the result is negative.

I generally will treat people in cases where clinical symptoms point to one of the common infections regardless of lab results. Lab testing is expensive and insurance is not covering many of the tests that are done. With the economy in its current state, doctors have to be critical as to which tests are ordered. You have to really know that you will use the data. I ask myself the question, "Am I going to change the decision that I make based on the lab result? If the result is negative, am I going to treat anyway?" If the answer is yes, then I don't order the test.

Do you find the CD57 test to be of value in gauging treatment progress or progression of disease?

Yes, with a major qualifier. I do feel that CD57 is a useful marker in the majority of patients. If CD57 is below 40, then that is a good indicator of

the activity of the disease. One can then use this information to help direct the decision making process with respect to intervention or treatment. I generally use the concept that Joe Burrascano, MD has defined. If CD57 has been shown to be low and you can get it back above 120, generally this is associated with an improved sense of well-being, improved health, and decreased risk for recurrence of symptoms.

This is not an absolute, however, and the major qualifier is that in those people who clinically have Lyme but CD57 is well within the normal range or even high, these patients generally have co-infections and most often, Babesia. In some cases, treatment of co-infections will result in a drop in CD57. It may be the case that when you are treating one co-infection which may have somehow been suppressing the activity of the Borrelia, Borrelia may then move into a more active state and CD57 may drop. This can be difficult to sift through. If CD57 is elevated and the patient is presenting with many of the symptoms, they likely have co-infections such as Babesia or Bartonella.

Do you believe that autoimmunity plays a significant role in the persistence of symptoms? If so, how do you treat patients when their own bodies begin to turn on themselves?

Autoimmunity in my view is only a secondary phenomenon. We know that autoimmune markers are very often elevated, though in low levels and in a non-specific presentation. ANA markers may be elevated but the majority of people have a normal SED rate which indicates that there is not a profound systemic inflammatory process underway.

With the insights that I have, my view is that it is a combination of several things. First, the fact that Borrelia, and possibly other co-infections, bore into cells of many different types and in the process, there is a remnant destruction of cells which provides an antigenic stimulus for the body to respond to itself. It is the body's own cells that are being

destroyed on a microscopic level. Thus the body's attempt to clear what it now perceives as foreign is the autoimmune response. It is an immune response to self that is being generated by the infection that is exposing the body to cells or chemicals that would otherwise not be present.

We know that in the majority of Western Blots, it is more commonly the IgM that is positive in people with chronic Lyme disease, not IgG as in most other infections. Generally, IgM is the antibody response seen in an acute phase of an infection that goes away and is later followed with IgG response which occurs after the IgM response and is sustained in order to impart immunity to whatever it is that the body is responding to.

In Borrelia, this is not what happens. The immune system struggles to clear the Lyme infection. It only intermittently perceives its presence due to a number of mechanisms that Borrelia has acquired which allow it to hide from the immune system. If enough of the infectious agent is present and the immune system is exposed to enough of the protein coat of the organism and the immune system is healthy enough to perceive its presence, the body generates the acute or IgM response. The organism has evolved mechanisms to hide and thus the immune system perceives that the infection has been cleared when in actuality has not.

There is a cyclic pattern where the body perceives and later does not perceive the presence of the infection. This cyclic recognition causes the immune system to remain in a hyperactive state in attempt to clear the infection. Many markers which represent this "revved up" immune system are often found in patients with Chronic Fatigue Syndrome. If you extrapolate my perception that the majority of CFS cases are actually Lyme disease, this would fit the paradigm that the body is constantly trying to clear this infection.

Unfortunately, since the immune system is in a "revved up" state, it is generating antibodies to things that it should not be and thus it is not uncommon

"Q&A" ...cont'd pg 14

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Lyme is a Brain Disease



by Virginia T. Sherr

Lyme borreliosis is a brain disease as well as a multi-systemic disease caused by spirochetal bacteria.* Quite frankly, it is an infection that has been burdened with a thousand inaccurate medical diagnoses. The manner in which the current pandemic of tertiary Lyme disease, neuroborreliosis, has usually been handled--either angrily dismissed or strangely misdiagnosed--throughout the 30 years following its "discovery," has blemished the historic excellence of modern American Medicine.

After all the years, neuroborreliosis is still actually considered rare by a majority of physicians, most of whom are spirochetally naive. Officially tallied patients (the numbers showing a dip down to 19,804 cases in 2004 after flawed reporting styles were instituted), when combined with uncounted cases may approach upward of an annual quarter million new borreliosis infections in the USA alone. And Lyme infections have been verified as present on all but one continent, globally. The disease

is more often than not accompanied by several of a half-dozen or so of the other serious tick-borne co-infections that currently have been identified.

Losses of acuity in the human brain's visual cortex have been observed as early as 6 hours following the toxic bite of an infected tick. Lyme may persist after too brief a period of treatment or if there has been no treatment, and may result in chronic infections whereupon Lyme borreliosis becomes a potential cause of every symptom in medical and psychiatric lexicons. It is the "Great Imitator" of this Millennium, spirochetal paresis (neuro-syphilis) having been its precursor and its model.

Chronic or persistent Lyme disease--neuroborreliosis--seldom is identified by the symptoms of its most frequent form--subacute encephalitis--an infected/inflamed brain as well as an infected nervous system. However, this is the form in which it most commonly exists. Unfortunately, the syndrome that is falsely considered typical--a bull's eye rash, fever, positive Elisa test, and/or a swollen large joint--occurs in fewer than half of proven cases. Instead, Lyme borreliosis confirms itself in subtle to profound neuro-psychiatric symptoms, such as overriding confusion, loss of organizational skills, decreased concentration, memory loss, mood disorders, irritability, and unprovoked rages--to mention just a few. These symptoms can be very obvious to an experienced professional practicing in a Lyme-endemic area. However, cerebral-behavioral symptoms of neuro-Lyme remain invisible to

those whose diagnoses are solely based on old-fashioned concepts limited only to the aforesaid doctor-viewed rashes, swollen knees with positive Elisa blood tests.

Blood tests completed by local labs most frequently show false negatives due to general laboratories' inadequate understanding of proper diagnostic technique and choices of poor quality spirochetal samples on which to base tests. Of course, insurance companies prefer their negative tests. As mentioned, Lyme can rapidly go from Stage One (Early borreliosis) to Late (Tertiary) Stage disease following attachment of an infected deer tick's or other vector's bite so that quick and competent treatment are of the greatest importance. Later, accurate findings by sophisticated laboratories may be helpful, especially if Late Stage symptoms appear many years after the infection.

Over the years, I have been asked to create a compendium of my published and unpublished works on the subject of Borrelia's neuropsychiatric epidemic. These literary contributions advocate for correction of medical neglect--the usually inadequate, sometimes cruel, diagnostic and treatment neglect experienced by victims of chronic Lyme borreliosis and its co-infections. I also have had articles published in an effort to attract attention from Organized Medicine--attention badly needed on behalf of a nearly invisible but serious epidemic that is more significant by far than anything this country has experienced since the Spanish Flu of 1918, the causative spirochete being less

immediately deadly than was the virus of that epidemic, but deadly, nonetheless, cerebrally.

Sadly, Organized Medicine has mostly ignored or deserted the field of neuro-Lyme's immense proportions. The American public rapidly is becoming jaundiced toward doctors' lack of up-dated knowledge of spirochetal science and, having read the latest (indeed copious) peer-reviewed recent literature for themselves, are turning to other disciplines--even to veterinarians for accurate medical advice on the subject of Lyme disease and its co-infections. Veterinarians are more up to date on the diagnosis and treatment of human Lyme than the "Diagnose-and-treat-by-the-old-Guidelines" types of powerful but passé Academic physicians who cling to outdated medical dogma.

I have written about the rampant epidemiology of neuro-Lyme disease and its potent co-infections (especially the red cell parasite that causes babesiosis) and the fact that these are being systematically ignored, minimized, or distorted by this nation's overseeing healthcare agencies.

Astoundingly, there are agencies that, in ignorance or arrogance, may actively persecute the victims of such borrelial, pan-systematic illness, traumatizing parents and children as well as their treating physicians. There are those in authority who sponsor the official separation of children from parents whose only sin is that they persist in seeking help for their ailing children. Tragically, those authorities are empowered to permanently remove sick or partially healed young

ones from their devoted families.

To their everlasting shame, medical authorities have stood by while innocent mothers have been sent to jail for insisting that their children were ill and again have stood by while the parent's belief was verified by the death of their sick child while under state "care." The rights of patients and their treating physicians have been trampled by governmental and insurance agencies in ways reminiscent of the era when AIDs was trivialized and its victims spurned as "psychosomatic." Today's infected millions worldwide show how wrong they were. The phenomenon of that epidemic is being repeated with the spread of Lyme borreliosis. My writing is an effort to illuminate this dark and now vast expanse of medicine and to inspire activism and compassion for those patients who are suffering in agony while having to hear caretakers say, "I don't know what you are worried about--you look just fine--maybe you are just depressed." Or as one unknowing, dismissive and flippant doctor joked to a frightened patient who came to him for treatment and reassurance, "Well, we all have to die of something, sometime." *pha*

*Alan G. Barbour, MD: "These tick-borne infections are notable for multiphasic antigenic variation through DNA recombinations in the case of relapsing fever, the occurrence of chronic arthritis in the case of Lyme disease, and invasion of and persistence in the brain in the case of both diseases." www.ucihs.uci.edu/microbio/

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“Lyme Rage” ... cont'd from pg 7

occurred in their loved one before tick-borne infection. Were they likely suffering from severe brain inflammation and/or chemical imbalance due to infection, neurotoxins or other effects of Lyme on the sensitive brain and nervous system? You bet.

When the inflamed brain or central nervous system (CNS) is in the middle of an attack of meningitis or encephalitis, the pain can be intractable, and even "standard" pain medications can have no effect. This kind of pain, when endured over a period of time, can certainly make someone feel "crazy" - crazy out of their mind with pain; especially when there is no relief, or worse, no credence from doctors, scientists, or family members. And I contend that these people are not the minority of chronically infected Lyme patients. Read the stories in books 1 and 2 of my series, and see how common these symptoms are in Lyme patients all over the world. Various symptoms of brain dysfunction occur all too frequently within the population, whether those patients are diagnosed with tick-borne illness or not.

Similar types of dysfunction have been documented to occur due to Syphilis infections, a close spirochetal cousin of *Borrelia*. Secondary, or co-infections by other organisms such as *bartonella*, *babesia*, or *mycoplasma* that occur in the body or are introduced at the time of Lyme infection through tick or other insect bite or transmission route, can magnify existing or cause new psychiatric symptoms on their own.

Unfortunately, medical science has not kept pace with emerging infections, as I outlined in my newest book, *The Baker's Dozen*. Evidence reveals: "...direct patient experience is rapidly overruling clinical research, and one reason why infectious disease doctors and treating physicians need to listen to the patients, the voices of those doing the practical 'field work.' Academicians and physicians, your 'anecdotes' have a lot to teach you, and we are asking for you to listen."1 Nevertheless, academic scientists are the first to point the finger at patients, and disassociate Lyme disease as a cause for "socially unpalatable" symptoms, the existence of which these scientists appear to be at least peripherally, if not openly, aware.

An interesting comment from an Infectious Disease Society of America (IDSA) clinical practice guidelines author Dr. Steere and his associates, had this to say about whether patients were inventing their symptoms. From a 1992 peer-reviewed article in *Neurology*, Lyme encephalopathy was recognized as a common late manifestation in patients who were affected by sleep, mood or memory. The conclusion of this study was a hypothesis that "...Lyme encephalopathy is caused by CNS dysfunction and cannot be explained as a psychological response to chronic illness."2

Another article referred to "chronic" Lyme disease and indicated that two of the three

stages of Lyme "potentially" involve the CNS; stage 2 causes cranial neuritis, meningitis or radiculoneuritis. The third stage was referred to as "chronic neuroborreliosis", and it included parenchymal involvement (the functional part of an organ, including the brain). The article said that in the infection's tertiary stage, symptoms could mimic many illnesses such as MS, viral encephalitis, brain tumors, vasculitis, viral encephalitis, myelopathy, and psychiatric illness.³

In *The Baker's Dozen* book, under a chapter titled *A Restrictive Approach to Treatment*, I discuss research evidence that reveals there may indeed be a causative link between infectious diseases and psychiatric manifestations. Quoted from a patent we read the following: "...Behavioral symptoms have previously been associated with certain infectious diseases. Specific examples of bacteria that may cause psychological symptoms are the causative agents of syphilis... and... Lyme disease, *Borrelia burgdorferi*.... The association of certain gastrointestinal illnesses with neurological and psychological symptoms is also recognized, as in d-lactic acidosis.... In spite of the recognized association between bacteria and neurological and psychological symptoms in certain conditions, the possibility that the vast majority of mental illnesses [sic] symptoms are caused by a bacterial infection of the intestinal tract is a paradigm shift."1,4 Strong words to be sure, and a point of view for physicians and researchers to consider carefully.

Later on in the text of this same patent we learn the following: "The pathogenic proliferation of microbes in the gut can at least partially cause deleterious mental symptoms and syndromes of many disorders, including at least some forms of Attention Deficit/Hyperactivity Disorder (ADHD), Autistic Disorder, Childhood Disintegrative Disorder, Conduct Disorder, Oppositional Defiant Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Anxiety Disorder, Mood Disorders including Major Depressive Disorders, Bipolar Disorder (I and II), Psychotic Disorders including Schizophreniform, Schizoaffective Disorder, Schizophrenia (all types), and Psychotic Disorder Not Otherwise Specified. The common etiology of these mental symptoms and syndromes makes possible a common therapeutic and preventative concept, embodied in the present invention."4

Lyme patients have long had to endure claims by a handful of scientists who are considered experts in infectious diseases that Lyme symptoms are perhaps not as severe as patients are reporting. Nevertheless, my new book *The*

Baker's Dozen is packed full of research that illustrates that Lyme disease spirochetal infections persist within the human body, even after antibiotic treatment. Further, that these infections require longer antibiotic treatments than what current IDSA guidelines recommend. And the acknowledgement by some of the IDSA guidelines authors and their associates in earlier published research, grants and patents, of the chronic, persistent and poten-

A Lyme patient can become quickly overwhelmed and this can lead to episodes of unintentional rage. Patients describe the episodes as "coming from out of left field."

tially severe or deadly nature of Lyme disease, along with its myriad of manifestations, is explored extensively within my book. I also examine the potential conflicts of interest, and other affiliations and relationships of many individuals who are quick within the media, and perhaps within medical guidelines to discount Lyme patients, and their symptoms; psychiatric or otherwise.

One statement made during a physician continuing education video course that I cited within my book was made by IDSA 2000 guidelines author Dr. Benjamin Luft, where he said with regard to antibiotic treatment of Lyme disease, "Duration of therapy is based on the severity of infection and the patient's response to treatment."1 This does not seem to reflect current guidelines recommendations on treatment duration. Indeed, in another resource, under a heading titled Late infection, stage 3 (persistent infection), we find that "two to three years after infection" is when patient symptoms become more noticeable. "CNS symptoms may be quite variable..." The book describes that this is determined by location of lesions and whether or not there appear symptoms such as "...chronic progressive encephalomyelitis, cerebellitis, spastic paraparesis, ataxia, transverse myelopathy, cranial nerve palsies, and mental disturbances." Last, the publication indicates that the organisms "...may persist in the CNS despite antibiotic therapy."5 As I stated previously, it says that treatment is dependent upon stage, and localization. The text says that treatment failure "is possible, and resumption of therapy may become necessary. The duration depends on the disappearance of symptoms."5 Again, I have not found these same sentiments within the 2006 IDSA guidelines for Lyme disease, a document that insurance companies are quick to cite in order to deny benefit coverage for Lyme patients.

Deciphering the truth about a rapidly emerging epidemic such as Lyme disease may be difficult, especially when the dissemination of sci-

entific information appears to lag far behind the clinical experience. In addition, patients and their physicians must question the validity of claims made by a handful of infectious disease experts and their associates when we look closely at the available research evidence. At times, the current experts appear to contradict their own published research and spout conjecture rather than scientific fact. When the information supplied to the media does not reconcile with their own research or the patient experience, then something is amiss. Indeed, science-based medicine is useful in many ways to test validity of hypotheses, but what happens when this kind of analysis is outpaced by the infections present within the general population? The patients whom these experts are not privileged to see within a clinical practice setting are revealing a very different experience than the scientific one currently promoted.

And what happens to patients if the same experts who dictate current information to the media, to the Centers for Disease Control (CDC), or through clinical practice guidelines that might dismiss various aspects of an illness, are motivated by private or federal research funding acquisitions, societal agendas, patent interests, or other potential conflicts of interest - including when they act as paid consultants to the insurance, legal, or pharmaceutical industries? Indeed, these very questions are explored throughout the book *The Baker's Dozen*, and the information compiled there may surprise everyone. For example, in the 2006 IDSA guidelines for Lyme disease, the antibiotic doxycycline is promoted as a useful treatment for Lyme infections but is contraindicated for prophylactic treatment encompassing the first 72 hours of tick exposure. However, in my book I printed a statement from a grant issued to Dr. Gary Wormser that states the following comment that appears to refute the guidelines statement about doxycycline's usefulness, and underscores the importance of its implementation in prophylactic treatment: "...the medication must be obtained within 72 hours of tick removal for the treatment to be effective."6

I don't know about you, but as a Lyme sufferer who had to wait nearly 13 years before a physician was willing to provide my family with an accurate diagnosis of Lyme disease, due in part to physician ignorance or the inaccessibility of practical scientific information my physician could use in a real-time clinical setting, I can't afford to wait out the debate. Imagine waiting more than a decade to obtain life-saving, necessary treatment due to not being diagnosed with an illness I knew we had at onset, which could have easily been treated and halted at tick exposure.

Something about the IDSA guidelines, the dismissive-sounding statements being broadcast to the media and the entire Lyme disease paradigm,

appears highly suspect to me. Might I recommend you run, do not walk, to get a copy of my latest book, *The Baker's Dozen & the Lunatic Fringe: Has Junk Science Shifted the Lyme Disease Paradigm?* Because it is only when we closely examine the published research by this handful of highly respected, powerful individuals who apparently hold the purse-strings of information censorship, will we find exactly who, or what, may be keeping Lyme patients ill and their physicians' hands tied. And like that which I saw my own child post on the Internet over two years - warnings of potentially homicidal or suicidal intentions-- and having learned of suicides that friends have successfully and tragically achieved, I don't need a scientific finding nor an infectious disease expert to tell me that Lyme disease can cause psychiatric behaviors as severe as a shooting incident. I'm the mother of a child who could very well have had that potential just a few short years ago. I absolutely believe it is possible, despite the absence of scientific "evidence."
pha

About the Author:

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“IDSA Crimes”... cont'd from pg 5

begin a new and hopeful treatment in July; most of the expense of these treatments will not be covered by insurance.”

There is nothing that I find more disgusting than the mainstream media who have been reporting this case and ignorantly state that the “murderer is using “Lyme disease” as an excuse for his defense. All the while they are quoting only one side of the treatment debate when they interview doctors about what Lyme disease is and what it does to the human body.

The IDSA doctors who are being interviewed are the very same doctors that the Connecticut AG Blumenthal have found to be riddled with financial conflicts of interest regarding their treatment protocols. This only adds to the dictatorial behavior of IDSA trying to silence the competition and using the media as a means of censoring the ILADS doctors by not interviewing them.

The frequency of Lyme disease in the headline news over the last 2 months has been an eye opener. First their was Travis the Chimp who nearly killed a Connecticut woman while being treated for Lyme disease. IDSA doctors tried to spin that story by saying that unequivocally Lyme disease does not cause rages or violent

behaviors. They blamed the incident on the medication the chimp had been taking.

Any respectable Lyme treating physician knows about the Jarisch-Herxheimer (herx for short) reaction that often occurs when the antibiotic kills off the bacteria and the die-off starts to release toxins into the body.

A herx reaction causes many symptoms that range from a worsening of all Lyme symptoms temporarily, agitation and mood swings, to severe pain. These are all a sign the treatment is working and killing the bacteria. Many doctors have tips for coping with the temporary herx reaction that will pass as the antibiotics do their job. Maybe Travis the chimp was having a herx reaction because the treatments were working at killing the Lyme bacteria, not causing him to go “crazy”.

More recently, Lyme was in the news with the tragic killing of Pastor Fred Winters at the Maryville First Baptist Church shooting in Illinois.

The IDSA doctors were once again on center stage claiming Lyme disease does not cause violent rages and psychiatric symptoms. Only this time the story is a bit more insidious because a person was murdered and the suspect had adequately

undergone the standard of care for IDSA treatment guidelines for Lyme disease, which should have cured him by their standards.

Recent tests showed that Sedlacek's Lyme disease was fully active as well as the co-infection of Ehrlichiosis. Not only was his Lyme disease not cured with IDSA's protocol, it led to further deterioration to the point of actual brain damage in his left temporal lobe. Sedlacek was also denied further treatment for the Lyme disease from his insurance company based on the IDSA treatment guidelines. The disease ran its course, untouched by the IDSA treatment protocol.

According to Dr. Richard Draper in his article *Temporal Lobe Lesions*, “There is a temporal lobe personality. There is an emphasis on trivia and the small details of daily life. There is egocentricity, pedantic speech, perseveration of speech, paranoia, religious preoccupations and a tendency to aggressive outbursts.”

The question must be asked: if Sedlacek had received proper treatment, prolonged treatment, for his Lyme disease, would the infection have ever progressed to the point of lesions on his brain?

As long as IDSA is at the helm and is able to squash

the competitive point of view, the treatment for Lyme disease and the ability of insurance companies to deny coverage based on IDSA guidelines will dramatically increase in the years to come.

Whatever the financial conflict of interest that was discovered by AG Blumenthal when investigating the IDSA, is the risk to the American society worth allowing IDSA to crush the competing treatment option?

I say no. If IDSA remains unchecked and ILADS is not given equal access to practice their standard of care in Lyme treatment, we will see Lyme patients left to progress to the late-stage symptoms that can be alleviated or even put in remission so that further permanent brain damage does not occur as it has with Sedlacek.

IDSA should be ashamed of themselves. There was a term that was once used to describe the needless and horrific treatment of human beings. It was called “crimes against humanity”.

If there is blame to be placed on anyone in this most recent Lyme disease associated murder, I believe it lays squarely at the feet of IDSA.

Not only did the actions of the IDSA create the treatment guidelines, they have been

used by insurance companies to deny coverage. If Sedlacek had been given longer treatment, effective treatment, the possibility is extremely high that he would have never digressed to the point of homicidal aggression and brain lesions on his temporal lobe while having a fully active infection of Lyme and Ehrlichiosis that should have been “cured” according to IDSA guidelines. This time, they cannot say maybe Sedlacek had some other disease and never had Lyme at all! His current tests, after IDSA approved treatment, showed active infection-- a phenomenon which the IDSA claims does not happen.

Shame on you IDSA... and your crimes against humanity! The death of Pastor Fred Winters lays squarely at your guilty feet, along with the greatly deteriorated health condition of Terry Joe Sedlacek whose life will never be the same again. Shame on you!

pha

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Q&A with Dr. Sam Shor, MD, FACP...cont'd from pg 11

mon to see autoimmunity develop.

Do you specifically treat the autoimmune component of the illness?

No. Treating the underlying infectious process generally normalizes the autoimmune process. If you use ANA elevation as a marker for autoimmunity in a given patient, you generally observe improvement if not normalization of the presence of the autoimmune marker - it goes away. I do not use any immune-suppressing agents. In fact, you want to avoid most rheumatologic drugs such as steroids or strong cytokine inhibitor such as Enbrel, Humira, and other similar medications as they can suppress portions of the immune system that are required to clear the underlying infectious process. Patients that have been on steroids have a far more difficult course because the infectious process has become more deep-seated.

Do you employ any non-

antibiotic treatment options in dealing with Lyme disease?

I am a Western-trained, traditionally-trained clinician. However, in keeping with the recognition that we are dealing with phenomenon that are often poorly understood, involve multiple systems in the body and are difficult to treat, my whole approach to dealing with these illnesses is to keep an open mind and think outside the box.

Since the time that I started treating CFS in the eighties, I have opened my willingness to explore complementary medicine which I believe is absolutely crucial in dealing with these illnesses. Exploring complementary medicine has to be a part of the approach for many patients or they simply may not get well.

With respect to the treatment of Lyme disease, I had to do my due diligence in evolving my treatment approaches in the complementary medicine arena, always keeping in mind that we must first do no harm.

One approach that I uti-

lize is the NutraMedix products. I was particularly interested in the herb Samento which is a purified form of Cat's Claw. Some reports in the literature suggest benefits in treating Lyme disease. I later learned of the Cowden Protocol and have conferred with Dr. Cowden to understand his perspective. I was looking for options that might help some of my patients to get better.

What I found was that three agents from the Cowden protocol are particularly helpful for their antimicrobial effects, namely Samento, Cumanda, and Quina. These have been a benefit in some patients. Some patients have profound responses with just one drop of Samento. I aggressively use Burbur and Parsley to help patients who may experience a Herxheimer reaction. In some cases, I use ½ to 1 dropperful of Burbur as frequently as every ten minutes for a few hours to reduce die-off reactions so that the patient can continue taking their prescribed protocol.

I use Chlorella which has been shown to bind to the

byproducts of the immune response that may be part of an inflammatory response involving cytokines and other chemicals.

I use the Researched Nutritionals product line. I like that the company has made an aggressive effort to have evidence-based recommendations. Many of their products are in keeping with recommendations in other areas in complementary medicine. I have had a number of their products for which a fairly substantial number of patients have experienced an improved sense of well-being, particularly NT Factor Energy™ and Energy MultiPlex™.

If a patient has not responded to treatment after 2-3 months, I may do a DMSA challenge with MetaMetrix and if heavy metals are an issue, I may use CheleX from Xymogen and trace minerals. In these cases, I recommend avoiding tap water and using water filtration to avoid further heavy metal exposure.

I am hoping that in using these agents it will allow me to sustain a patient's remis-

sion.

Can you provide a breakdown of your patient outcomes?

Of 100 patients with chronic Lyme disease that I aggressively treat with formal antimicrobials, at least 80-85% improve. Of the 100, at least 50% go back to normal. There are some residual symptoms in a subset even once you get off antibiotics. Of the 100, there are 10-15% of people that I throw the kitchen sink at and they just don't seem to improve. I refer them to other ILADS doctors such as Joseph Jemsek, MD.

Of the 85% that improve, I have been able to get 100% of these off of antibiotics. I do not have any patients that are on antibiotics now that I expect to require them for the rest of their life. Using alternative approaches, we can generally get away from life-long antibiotic treatment being required.

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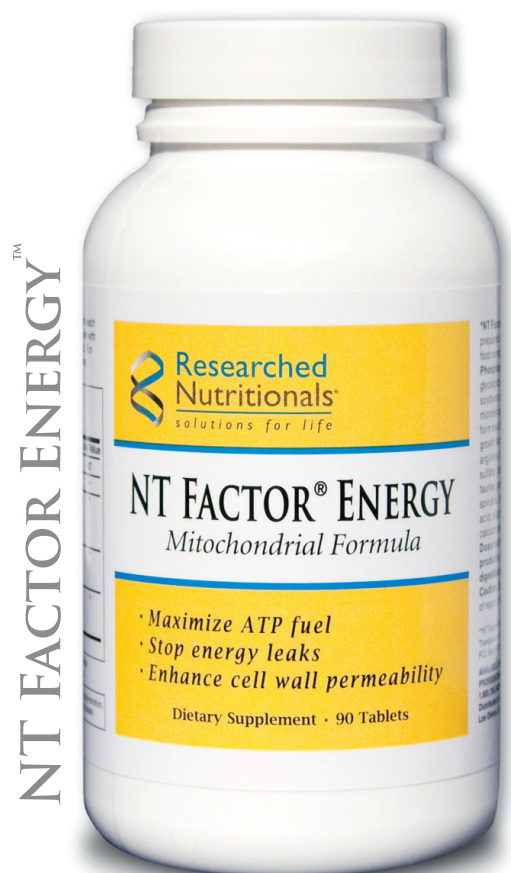
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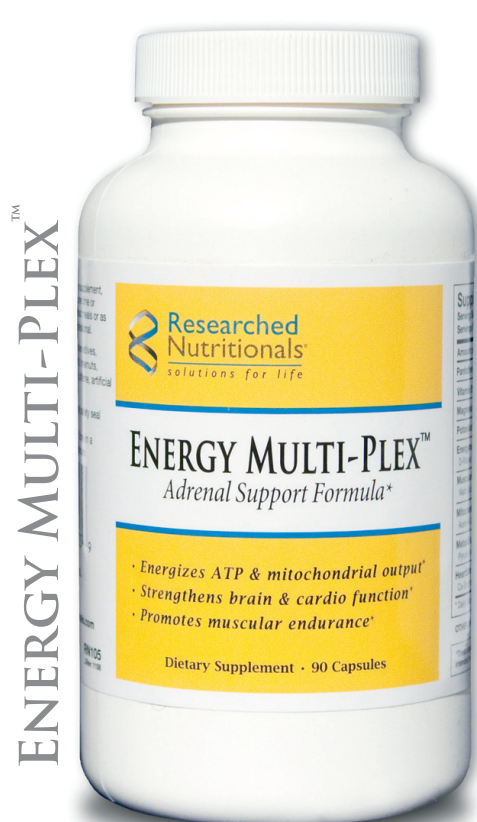


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