From IDSA to ILADS: A Journey Toward Reconciliation

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.

In my book "It's All In Your Head" (A Multisystem Hypothesis) in the Journal of Chronic Fatigue Syndrome, Dr. Shor attempted to explain the "IDSAs to ILADS"...cont'd pg 2

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 neurophysiologies, 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, 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 essay series on Lyme disease (Patient Stories From The Front Lines), revealed stories about neuropsychiatric Lyme disease.

It’s All In Your Head...

Ginsu Knives & Psychiatric Lyme Disease: Cutting Through the Misinformation

by PJ Langhoff

A chronic Lyme patient, was "where is this firestorm of debate?" I decided to write a book on that subject. It is a book that I call "It's All In Your Head," which was released in January, 2008, is dedicated to two patients who took on the issue specifically as a consequence of having Lyme disease. There have been reports that Lyme rage is "inaccurate," or that it is an "atypical" presentation of Lyme-induced brain affectation. What I found, which is not yet backed by clinical trials or lengthy scientific studies, is that most Lyme patients who "Lyme Rage"...

by Scott Fororg

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

A chimpanzee named Travis that attacked its Connecticut owner

The firestorm of debate over whether Lyme disease could be responsible for psychiatric issues including her own lives specifically as a consequence of having Lyme disease. There have been reports that Lyme rage is "inaccurate," or that it is an "atypical" presentation of Lyme-induced brain affectation. What I found, which is not yet backed by clinical trials or lengthy scientific studies, is that most Lyme patients who "Lyme Rage"...
bodies. If there is not a sus-
immune system to create anti-
which serves as a signal to the
Borrelia has the capacity to
disease proper but that there are
tive agent involved in Lyme
diseases. He was exposed to
a disease in the world of Lyme
diseases. Dr. Shor learned more
about Lyme disease after an attempt to pursue his due dili-
gence, he went to his first ILADS meeting in 2001. He states that he was “struck and
doubtful” by the similari-
ties of the issues that were pre-
rented by the ILADS doctors. He found that there was a signif-
ificant overlap between Lyme disease and CFS, and that he had been observing
overly of Chronic Fatigue Syndrome and what ILADS
doctors had been observing
veloping in the world of Lyme disease.
At this point, Dr. Shor
felt that there had to be a com-
munity between these two
orders. 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 increa-
sing that "Lyme disease" is characterized by more than just an infection with Borrelia burgdorferi. He notes
that Borrelia burgdorferi is the a
uveitis and even gets referrals
from cardiologists. 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’ suf-
fing it gave him a whole new perspective from which he could offer patients hope and an
improved quality of life. Dr. Shor continued to assimilate all of the information that he had, 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 ques-
tionnaire that was a subset of Dr. Joe Burrsacano MD’s larger Lyme questionnaire. The intent
was to extract questions that would give a broad picture of the patient’s clinical status and allow
the patient to grade how they felt at any point of time. The questionnaire was used over time to
examine the patient was being treated and could be evaluated to determine whether or not outcomes
where changing. Soon after the ILADS meeting, Dr. Shor took select patients from his CFS popula-
tion and started to investigate
Dr. Shor presents the IDSA vs. ILADS debate
at a Congressional Briefing.

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

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approach
for many
patients or they
simply
may not get well.

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simply because I look healthy. tled with depression.
year and, quite honestly, I bat-
Some of the most trying of the
The following two weeks were
been preparing me for the days
what it means to have the joy
break of 2008, I enjoyed a few
as well as in death.
that HE is what matters in life,
weakness.” Yes, I’ve become
reminded of, 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 under-
stands. 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

When the pain becomes
grip of disbelief that holds cap-
work together to shatter the
midst of our suffering, we will
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
grasp of disbelief that holds capt-
world around us.

I too have learned from your articles, and have referred many to
Linnette currently resides in Belton, Missouri with her husband, John, and their four awesome boys.
Linnette and her sons are cur-
rently being treated for Lyme disease.

Son, I want to live for my boys.
They are gifted boys and I want
to see them do great things in life.

It is also my prayer that
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.

The Poison Plum is a gripping, chilling novel exposing the rampaging epidemic of Lyme disease now sweeping across America and the disease's connection, if any, to the government's top-secret biological research laboratory at Plum Island, New York.

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Dr. Burrascano's 2008 Lyme & Associated Tick Borne Disease Treatment Guidelines

“The Poison Plum is a gripping, chilling novel exposing the rampaging epidemic of Lyme disease now sweeping across America and the disease's connection, if any, to the government's top-secret biological research laboratory at Plum Island, New York.

You can order the book online at the website!
Dear Editor:

When I adopted my son at the age of three, I knew he had been already 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 in a psychiatric hospital. My son had been placed in special education, had been expelled from one school after another for his violent outbursts, and was increasingly unable to function socially. Dr. Benjamin Rush on charges of anti-trust trust violations. In layman’s terms—violent violence were the attempt at some means to control their situation that would have financial gain. The competitor in this medical tug of war is the International Lyme and Associated Disease Society (ILADS). This group has set a treatment guidelines which is the target of IDAS created a set of medical treat- dicatorship.

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 speak- ing, 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 rec-ommendations. 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 treat- ment of Lyme disease. No one disputes the fact that if Lyme disease is caught early and treatment adminis- tered immediately, it can be easily cured with a standard course of antibiotic.

The problem lies in the dilemma of catching it early. The ILADS doctors who have become 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 patients testing positive for Lyme disease have presented with the characteristic bull’s-eye rash. It is very possible to have a rash, on the scalp for instance, that never ever visible. IDSA, on the other hand, insist that the bull’s-eye rash be present over 80% of patients with Lyme disease. But these academic doctors do not treat these patients on a daily basis or less. Lieutenant Joe Sedlacek, CLD patient, was treated by IDSA doctors who did not cure him. Recent tests showed his Lyme and co-infections are active and he has left temporal lobe damage as well due to ineffective short term IDSA treatments that offered no curative value for his late-stage of the disease. New test results revealed the Lyme disease and co-infections are active and he has left temporal lobe damage. He will “IDSA’s Crimes...”

by David Irons

"Unless we put medical free- dom into the Constitution, the time will come when medicine will organize into an under- cover dictatorship to restrict the art of healing to one class of men and deny equal privi- leges to others." The Constitution of this Republic states a high and solemn privilege for medical freedom as well as religious freedom." Dr. Benjamin Rush, signer of the Declaration of Independence

One might wonder why Dr. Benjamin Rush, one of our Founding Fathers in America, could have known over 230 years ago that these same dynamics that would play out before and after the medical controversy, and dare I say, tyranny, that he described then seems almost prophetic in retro- spect.

My pastor is forever reminding people that, “Time proves all things.” And this is certainly the case where the words 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 privileges could not have foreseen or predicted.

The Infectious Disease Society of America (IDSA) has put into place this ter- ritorial over the treatment and diagnosis of Lyme disease that have been brought before the Attorney General of Connecticut Richard Blumenthal on charges of anti-trust violations. The problem lies in the labeling of what did happen to my son. Terry Joe Sedlacek was the witness to what did happen to my son.

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 damage as well due to ineffective short term IDSA treatments that offered no curative value for his late-stage of the disease. New test results revealed the Lyme disease and co-infections are active and he has left temporal lobe damage. He will “IDSA’s Crimes...”. 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 they are afraid of being ostracized. 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, vio- lent behavior and, yes, some- times extreme violent behavior.

Donna Benner, Art Teacher Mother to 15-year-old Nicholas, a great young man.
Those who report experiencing multiple myeloma episodes of wracking pain and 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 apply 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 appointment, but she doesn’t have the energy to style it, as she had before becoming debilitated from Lyme disease and co-infections.

Borellia 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 definitively wrong.

Add painful, swollen joints that hurt with every step and you’re ready to seek a medical diagnos-

This is when the Lyme Odyssey begins. To the detri-

ment 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 medical encounters before a doctor finally deter-

mines the cause of these diverse symptoms – co-infec-

tions of Lyme. The Borellia Complex (LBC), which is a chronic inflammatory state. By this time, the bacterial load has taken perfect advantage and destroyed the physi-

cal body. The anticoagulant sys-

tem 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 abili-
ties and return to their previ-

ously productive lifestyle. Patient maintains a high stan-

dard for their treating physi-

cians and hold them account-

able, whether or not the treat-

ment results in being cured.

Lyme-treating doctors are often increased in patients presenting with these similar symptoms. The goal of these doctors is to restore their patients’ health, which is 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 contin-

ual quest to keep abreast of new developments and discov-

eries with regard to Borellia, Bartonella, Ehrlichia, Babesia, Mycoplasma and viruses, all co-infections that may be comp-

dicating their patient’s health. Treating late-stage Lyme Borelliosis Complex and the other infections that accompanies it, is a learning process. Studying the diseases and gain-

ing experience in the clinical setting provides a critical understanding of the many complexities involved in treat-

ing such a complicated mix of infections. It takes fortitude

by Tina J. Garcia

New Treatment Provides Dramatic Results

...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 Borelliosis Complex (LBC), which is a late-stage disease state.

Envita Natural Medical Centers of America (also in Scottsdale) and David Korn, D.O., M.D.H., D.D.S. is a 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 homoeopathic physician licensed in Arizona. The combination treatment of antibiotics and the use of certain agents that destroy biofilms which sur-

round and protect bacteria has been a catalyst for this Lyme-treating physi-

cians 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 a synergistic approach to destroy biofilms which sur-

round 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

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Ticktock

by Terri Reiser

“...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 Borelliosis Complex (LBC), which is a late-stage disease state.”

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

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 using "standard" medications can have no effect. This kind of pain, when endured over a period of time, can certainly make people feel "crazy" and "crazy out of their mind with pain."
What Psychiatrists Should Know about 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 diagnostic clue:

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, panic attacks, rapid circulations, cardiac conduction defects, word-finding problems, panic/anxiety disorders, and psychiatry mimics virtually any type of psychiatric disease such as schizoaffective disorder, schizophrenia, panic disorder, general anxiety disorder, social anxiety disorder, agoraphobia, obsessive-compulsive disorder (OCD), sleep disorders, attention deficit/hyperactivity disorder (ADHD/ADD)-like syndromes, and Autism-like syndromes.

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 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 neurophilis. Both are caused by spirochetes, are multi-systemic, and can affect a patient neurologically, producing cognitive dysfunctions and organic psychiatric illness. Such symptoms may be diminutive, only surfacing years later.

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

1. Are there markers of neuropsychiatric disease such as erythema migrans rash, arthralgias or arthritis, myalgias, severe headaches, sound or light sensitivities, paresthesias, diffuse fasciculations, cardiac conduction defects, word finding problems, short-term memory loss, tremors, cranial neuropathies, and/or suicidal or homicidal intent?

2. 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?

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

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

5. 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.columbialyme.org.

Other helpful tests may include PCR for Borrelia burgdorferi in blood, serum, cerebrospinal fluid (CSF) and urine, and/or Borrelia antigen testing in urine and CSF.

Because blood tests at the top three general medical laboratories in the nation fail to detect 35% of Lyme antibodies, ILADS recommends use of laboratories that specialize in Lyme and other tick-borne illnesses.

Contact www.lymediseaseassociation.org 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, lymphadenopathy, “psychiatric...” cont’d pg 9

What Psychiatrists Should Know about Lyme Disease
“Psychiatrists” ... cont’d from pg 8

He hopes that the "powers that be, who are putting out blocks, will ultimately have realization so that we can move forward and benefit from it."  

Infer Ther 2004;2(Suppl:S1)-S13. For more information, visit ILADS website at www.ilads.org.

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

- Progressive dementia
- 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 cognitiv e impairments in Lyme disease (from Marian Rissenberg, Ph.D., clinical neuropsychologist)

- Losses in fields of attention/executive functions such as inability to maintain focus or disorganized, difficulty reading, especially for text
- Memory functions (halt- ing speech, disrupted participa- tion 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 if not all of these impairments, if caused by neuroborreliosis, may improve with proper antibiotics combined with appropriate cognitive and behavioral treatments.

Infant Ther 2004;2(Suppl:S1)-S13. For more information, visit ILADS website at www.ilads.org.

Some of the common symp- toms of late-stage (tertiary) Lyme disease and other tick-borne co-infections:

- Profound fatigue
- MD, AIDS and skin flushes
- Night sweats
- Migrating arthralgias
- Muscle pains/twitching
- Severe headaches
- Shifting neurologic pains
- Tremors, shakiness
- Numbness, tingling sensations, pain often shifting and unusual in type
- Cranial nerve disturbance (Facial numbness, hearing loss, gaiting, paralysis, optic neuritis, trouble swallowing, distortion of taste or smell) See Category below.

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

  - Progressive dementia
  - 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
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Most if not all of these impairments, if caused by neuroborreliosis, may improve with proper antibiotics combined with appropriate cognitive and behavioral treatments.
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Email: info@flc.nmss.org

Phone: 1-800-FIGHT-MS
Email: info@msconnection.org

Arkansas
Mary Alice Beer
(501) 884-3502
Phone: (501) 884-3502
Email: beer@artelco.com

California
Dorothy Leland
Website: www.lymedisease.org
alsassoc@alsphiladelphia.org

Colorado
Mary Parker
303-447-1602
mihglticket@yahoo.com

South Texas Chapter
http://www.salsa-south-tx.org/
(210) 733-5204
toll free at (877) 257-4673

Texas
North Texas
walk@northrattlesnax.org/
site/PageServer
321 Greenway Dr.,
Ste.385
Irvine, CA 92618
715-857-5953
s.melson@alsanorthtexas.org
972-714-0088
877-714-0088

The ALS Association
Upstate New York Chapter
325 Route 5 West
Elbridge, NY 13060
315-689-3380
Toll Free for PALS:
1-866-499-PALS
info@alsupportny.org

Lyme Disease Support
Arizona
Southern Arizona - Donna
Maitland, FL 32751
503-978-9854
Fax: (301) 978-9854

Great Philadelphia
ALS Chapter
231 S. Broad Street,
Ste.210
Philadelphia, PA 19102
Phone: 215-643-9307
alassoc@alaphiladelphia.org

Southwest Texas
http://www.als-south-tx.org/
(210) 733-5204
toll free at (877) 257-4673

North Texas
walk@northrattlesnax.org/
site/PageServer
1213 Greenway Dr.,
Ste.385
Irvine, CA 92618
s.melson@alsanorthtexas.org
972-714-0088
877-714-0088

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Upstate New York Chapter
325 Route 5 West
Elbridge, NY 13060
315-689-3380
Toll Free for PALS:
1-866-499-PALS
info@alsupportny.org

Lyme Disease Support
Arizona
Southern Arizona - Donna
321 S. Broad Street,
Ste.260
Maitland, PA 19002
Phone: 215-643-5434
Toll Free: 1-877-GEHRIG-1
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walk@northrattlesnax.org/
site/PageServer
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Ste.385
Irvine, CA 92618
s.melson@alsanorthtexas.org
972-714-0088
877-714-0088

The ALS Association
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Elbridge, NY 13060
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Fax: (301) 978-9854

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231 S. Broad Street,
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Maitland, PA 19002
Phone: 215-643-5434
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(1-877-434-7411)
Fax: 215-643-9307
alsassoc@alaphiladelphia.org

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Denver, CO 80203-3442
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Email: info@nmssga.org

Email: info@ncmsa.org

Phone: 1-800-FIGHT-MS
Email: info@ncmsa.org

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Suite 210
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Phone: 404-256-9700
Fax: 404-256-9700

Alaska
Elbridge, NY 13060
Phone: 713-526-8967

Email: info@ncmsa.org

Phone: 1-800-FIGHT-MS
Email: info@ncmsa.org

Florida
2701 Maitland Center Pkwy,
Suite 100
Maitland, FL 32751
Phone: (407) 478-8888
Email: info@flmss.org

www.nmss.org

Lyme Disease Support
New Mexico
Veronica Medina
(505)459-9858
vmdelman@comcast.net

Oklahoma
Janet Segovia
405-395-0901
Jannet@LDSGorg

Portland, Oregon
Meets 2nd Sunday of each month 2010 NW 22nd Street Second Floor from 1:30 PM.
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Texas:
Greater Austin Area Lyme
Council.  Teresa Jones
tomomite2@yahoo.com

Dallas/Ft Worth
John Quinn
Jquinn@dart.org
214-749-2845

Houston
Contact: Teresa Lucher
lucher@abcsglobal.net

League City/ ClearLake
& NASA Area
Sandia Mannelli
smannelli@comcast.net

Washington State
Alice Zlutkowski
WA-Lyme-owner@
yahoo.com

WI / IL / MN Regional areas
Contact PJ Langhoff
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Western Wisconsin Lyme
Action Group
Marina Andrews
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Lyman's Lighthouse
and abroad.

http://health.groups.yahoo.
com/group/MilitaryLyme/

Lyme Disease Support
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.

http://health.groups.yahoo.
com/group/MilitaryLyme/

Lyme Disease Association
www.lymeendo.org

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Page 10 www.publichealthalert.org Public Health Alert
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 Omniscie and Buxin. 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 atarax. It may require high doses and require treatment for protracted periods of time. Bartonella is easier to track as the majority of people have some sweating and this is an easy symptom to track. 

Following Bartonella is more successful treatment following Bartonella is more successful treatment than Babesia. If CD57 is below 40, most patients and adjust treatment. 

With Babesia, when you notice that the sweats are gone and stop treatment, do you believe that the organism 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 care, you do not expect any recurrence of symptoms unless there is a re-exposure. These are generally 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 relapse of the 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 have the lab that does the CD57. Most of their technology is acceptable although 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. 

Our 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 if a validation test from LabCorp, then I will use IgM and IgG. 

I do preliminary co-infection testing through LabCorp. They are very good at picking up Babesia. I have gotten lots of positives and I am on the East coast. It is important to do a screening test for co-infections. Facilities vary on the east coast and may not offer the screening tests. 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 qualifications 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 interpret by CD57 is elevat- ed and the patient is presenting with many of the symptoms. Likely CD57 can be found elevated such as Babesia or Bartonella. 

Do you believe that autoimmune disease plays a significant role in the presence of symptoms that you treat patients when their own bodies begin to turn on themselves?

Autoimmunity in my view is only a secondary phe- nomenon. 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 IgG level which indicates that there is not a profound 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, home into cells of macrophage type and in the process, there is a remnant destruction of the body and 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 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 the infection is. 

In Borrelia, this is not what happens. The immune system struggles to clear the Lyme infection. It only intermit- tently perceives its presence due to a number of mechanisms that Borrelia has acquired which allow it to evade the immune system. If enough of the infectious agent is present so that the infection is exposed to enough of the protein the organism of the mammal is healthy enough to perceive its presence, the body generates the acute or chronic infection mechanism which has evolved mechanism to hide and thus the immune sys- tem perceives that the infection has been cleared when it 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 hypereactive 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 Lyme disease, then this would fit the paradigm that the body is constantly trying to clear the infection.

Unfortunately, since the immune system is in a "revved up" state in generating responses to things that it should not be and thus it is not unique "Q&A...cont'd pg 14"
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 amply dismissed or strangely misdiagnosed—throughout the 30 years following its “discovery,” has blighted the historical excellence of modern American Medicine.

After all the years, neuroborreliosis is still actually considered rare by a majority of physicians, most of whom are spirochetically naïve. Officially, doctors, most of whom are neuro-Lyme remain invisible to their ailing children. Tragically, they persist in seeking help for those whose diagnoses are solely based on outdated-fashioned concepts limited only to the aforementioned views, swollen knees with positive EII 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 heard to create a controversy of my published and unpublished works on the subject of Borrelia’s neuro-psychiatric 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 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 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 usually inadequate, sometimes cruel, diagnostic and treatment neglect experienced by victims of chronic Lyme borreliosis and its co-infections.

As a consequence, dismissive and flippant doctors 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 the 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 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 unknowingly 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.”

Alan G. Barbour, MD: “These tick-borne infections are notable for multiphasic autoimmune genetic variation through DNA recombinations in the case of relapsing fever, the occurrence of and persistence in the brain of Lyme disease, and invasion of and persistence in the brain of these disease.”

www.ucihs.uci.edu/microbio/
occurred in their loved one before tick-borne infection. When Lyme patients report a history of being bitten from severe brain inflammation and/or chemical imbalance due to neuroborreliosis, or other effects of Lyme on the senses, mind 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, it can become unmanageable, and even "standard" pain medications can have no effect on this kind of chaos. This enduring over a period of time can certainly make someone feel like they are "crazy" - crazy with pain, especially when there is no relief, or when they are told by doctors, nurses, scientists, or family members. And I contend that these problems are not the only ones caused by 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. Even those who have no symptoms of brain dysfunction occur all too frequently within the peripheral nervous system. Many patients who are diagnosed with tick-borne illness or not.

An interesting comment from an academician/ physician who is not the one you might expect to hear from on this one. Academicians and physicians, your "academicians" have a lot to test!" Because it is true. Academicians are revealing a very knowledgeable about Lyme disease. I am telling you for the first time, the academic one currently promoted. And what happens to the patients if the same experts who dictate current information to the media are expected to be seeking specialty in Lyme Disease (CDC), or through clinical practice guide-

Whether or not there appear symptoms such as... chronic progressive encephalomyelitis, cerebellitis, spastic paraparesis, ataxia, transverse myelitis, cranial nerve palsies, and mental disturbances.” Last, the publication indicates that the organ-

Dr. Krauss’ comments seem to reflect positive findings of the drug treatment. But what happens when patients become more notice-

Based on then, the medication that the treatment may become necessary. When Lyme is treated correctly, there will be no apparent disappearance of symptoms.”

Additional factors that might be responsible for the effectiveness of a Lyme disease agent, but not in the form of a natural product.

According to the book, the Lyme disease agent, doxycycline, is packed full of research that illustrates that these patients experience symptoms during phases 2 or 3 of infection, and their physicians must question the validity of claims made by a handful of infectious disease experts and their associates when it comes to the availability of all appropriate research evidence. At times, the current experts employed by IDSA to publish research and spout counterfactual science, rather than just science. And the acknowledgement by Lyme literature, and their associates in earlier published research. Published patients, or those with chronic, persistent and potent-

An article referred to "chronic" Lyme disease indicated that two of the three stages of Lyme "potentially" involve the CNS, stage 2 causes such as meningitis and stage 3 causes such as neuroborreliosis. The third stage was referred to as "chronic" neuro-

A Lyme patient can become quickly overwhelmed and this can lead to episodes of uninteresting rage. Patients describe the episodes as "coming out of left field."
begin a new and hopeful treat- ment in July; most of the ex- pense of the biote 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 ignoring the fact that the mur- derer is using “Lyme disease” as an excuse for his defense. All the while the media is only one side of the treatment debate when they interview doctors about what Lyme dis- ease 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 proto- cols. This only adds to the dic- tatorial 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 diagnosis in Illinois 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. Last month we learned a tru- spin that story by saying that unequivocally Lyme disease does not cause rashes or violent behaviors. They blamed the incident on the medication the chimp was being given.

Any respectable Lyme treating physician knows about the “temporal lobe lesion” (for short) reaction that often occurs when the antibiotic kills off the bacteria. Only the patient starts to release toxins into the body. This reaction causes many symptoms that range from a worsening of all Lyme symptoms temporarily to ex- citation and mood swings, to severe pain. These are all a sign that the treatment is working and killing the bacteria. Many doctors have tips for coping with the temporary herx reac- tion that will pass as the antibiot- ics 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 “crazy.”

Recently, Lyme was in the news with the tragic killing of Pastor Fred Winters in Chicago. The pastor was killed by a drug which is a purified form of herb Samento

I have had a num- ber of patients who have experienced an imme- diate improvement if not normaliza- tion of the presence of the autoimmune markers – it goes away. I do not use any immune-suppressing agents. In fact, you want to avoid anything that might suppress porters of the immune system that are required to clear the underlying infectious process. Patients that have been on steroids for a while have a little more diffi- cult course because the infec- tion’s immune response has become more deep-seated.

Do you employ any non-

antibiotic treatment options in dealing with Lyme disease?

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

mon to see autoimmunity.

Do you specifically treat the autoimmune component of the illness?

No.  The 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 tend to get a great improvement if not normaliza- tion of the presence of the autoimmune markers – it goes away. I do not use any immune-suppressing agents. In fact, you want to avoid anything that might suppress porters of the immune system that are required to clear the underlying infectious process. Patients that have been on steroids for a while have a little more diffi- cult course because the infec- tion’s immune response has become more deep-seated.

Do you use 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 CPS in the eighties, I have opened my willingness to explore comple- mentary medicines which I believe is absolutely crucial in dealing with these illnesses. Exploring alternative medicin- es 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 a lot of diligence in evolving my treatment approaches in the complemen- tary medicine arena, always keeping in mind that we must first do no harm.

I use Chlorella which has been shown to have a nutritive benefit. I use the NutraMedix prod- ucts. I am particularly inter- ested 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 per- spective. 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 respons- es 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 1/2 to 1 dropperful of Burbur as frequently as every ten minutes for a few hours to reduce die-off reac- tions so that the patient can continue taking their prescribed protocol.

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