



the

Lyme Times

NUMBER 33

Education, Support, Advocacy, Research

SUMMER 2002

LDA News

Mid-country affiliate joins LDA

In June 2002, Lyme Association of Greater Kansas City officially became the fifth affiliate of the Lyme Disease Association. The LAGKC covers Lyme issues in Kansas and Missouri and meets at St. Joseph's Hospital Community Center in Missouri. Its primary goals are to provide services to persons diagnosed with Lyme disease through meetings and media and to promote cooperation in the Greater Kansas City medical community.

The Association's most recent success was its effort to get the Mayor of Kansas City to adopt a proclamation designating May as Lyme awareness month. It has also assisted with the Emerging Infections of the Central States accredited medical conference for physicians.

Officers are President, Ed Olsen; 1st VP, Evelyn Steeley; 2nd VP, Karen Welch; Secretary, Kathy White; Treasurer, Ray Schmitz.

See **Mid-country** on page 33

Inside...

Children sell lemonade for Dr. Jones' patients. Pg. 37



Members of the Governor's Commission on Lyme Disease and Other Tick-borne Diseases watch Rhode Island Governor Lincoln Almond signing the Lyme Disease Diagnosis and Treatment Act on August 1. (L-R) Dr. Debra J. Solomon, State Representative Peter Ganait, State Senator S. Sosnowski, Dr. Patricia Nolan, RI's Director of Health, Joseph Larisa Jr., Chief of Staff

Rhode Island governor signs new Lyme Bill

Lyme Disease patients in Rhode Island had reason to celebrate earlier this summer as their state legislature unanimously passed a law titled, "The Lyme Disease Diagnosis and Treatment Act." The bill was sponsored by State Senator Susan Sosnowski and co-sponsored by State Representative Peter T. Ginaitt. Senator Sosnowski

was quoted in the Block Island Times (June 22, 2002), as calling the law "a monumental first step."

The law protects physicians in Rhode Island from being subject to disciplinary action from Rhode Island's Board of Medical Licensure and Discipline solely for prescribing, administering or dispensing long term

See **Rhode Island Bill** on page 41

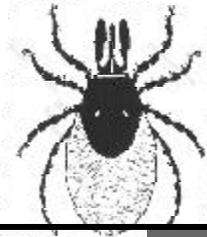
IX ICLB rejects many abstracts - protests planned

A group of scientists, physicians and patient advocates angry at what they perceive as a biased review process for the IX International Conference on Lyme Borreliosis and Other Tick-Borne Diseases (ICLB), have planned an alternative symposium

at the same hotel during the ICLB. Sponsored by the International Society for Lyme and Associated Diseases (ILADS), a professional organization, the alternative symposium will run for two days (August

See **ICLB** on page 45

NUMBER 33
SUMMER 2002



the **Lyme Times** ©

Publication of the Lyme Disease Resource Center

In this issue...

From the Editor

- 1 LDA News**
- 3 Guest Editorial**
- 5 Heroes**
- 6 Front Lines**
- 7 Opinion**
- 13 Medical Hypotheses**
- 19 Beginners' Pages**
- 22 Caveat Emptor**
- 32 More LDA News**
- 38 Patient Story**
- 40 Regional News**
- 46 Conferences**
- 47 Subscription Form**
- 48 Calendar**

Special articles

- 9** Lyme-literate in-patient psychiatric facility needed, by Sandy Berenbaum, CSW-R, BCD
- 24** When Lyme Disease affects the brain: what social workers need to know, by Cynthia Onorato-Herms, MSW
- 31** Can Lyme Disease Cause Psychiatric Disorders? by Joan Arehart-Treichel
- 33** LDA President Pat Smith tours California, by Pat Smith

Dear Readers,

Dr. Fallon's plea, opposite, is not what is usual for an editorial, but as I came to the end of this issue in the wee hours of a summer morning, trying to meet my deadline, I realized that I had forgotten to leave space for what I consider a very important plea.

When New England Medical Center's Mark Klempner, MD, needed patients for a treatment study, the Lyme Times cooperated by providing space and writing articles to explain the study to potential enrollees. In that case, we feel we were betrayed. When the Data Safety Monitoring Board unblinded the results to take a look part way through the study, they concluded that the treatment group fared no better than the placebo group. This was sufficient cause to terminate the study.

We were not surprised that the treated patients did not do particularly well - all had failed a similar regimen of treatment before being enrolled. There are many as yet unanswered questions. A meeting which was to have occurred last fall was cancelled after 9/11, and my letter outlining the abysmal failure of the Advisory Committee on which I served, has been ignored.

The worst offense was the publishing of the study results as though they had proved that long term treatment for Lyme disease was worthless. This conclusion was not

warranted by the study design, and in fact we were assured by NIH officials that the NEMC study was but the first of a series of treatment trials. Now, however, the published results, with the collusion of the National Institutes of Health, are being used to deny treatment to chronically ill patients. This is criminal.

All this by way of introducing Dr. Brian Fallon's study, and encouraging you and your family members to consider applying. It will be exceedingly difficult, if not impossible, for this study to enroll enough patients to be able to draw statistically valid conclusions. Dr. Fallon has been a long-time friend of the Lyme disease patient community, and is the director of the new research center funded by the Lyme Disease Association and their affiliate, Greenwich Lyme Disease Task Force.

It is a daunting thought to sign up for a placebo-controlled trial, but the potential for larger benefit is great, should this study succeed. We recommend Dr. Fallon and his study to you, and applaud your willingness to consider applying. As you will see from reading other stories in this issue, patients do not lack for courage and committment.

Phyllis Mervine, Editor

The Lyme Disease Resource Center was founded in 1990 as a nonprofit education and communications center for the public, for Lyme disease patients, for physicians, and other interested people. In 2002, LDRC affiliated with the national Lyme Disease Association, Inc. The goals of the LDRC are to educate the public about Lyme and other tickborne diseases, including risk factors and prevention; to provide services for Lyme disease patients and their families and friends; to provide a forum for physicians and health care professionals for the exchange of ideas and information about symptoms, diagnosis, and treatment of Lyme disease; to be a communications center for individuals and groups who are working to help patients with Lyme disease; and to encourage Lyme disease research.

the Lyme Times

Summer 2002

Publisher

Lyme Disease Resource Center, Affiliate of the Lyme Disease Association, Inc.

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The Lyme Times (Library of Congress card no.92-595999) is published four times a year by the Lyme Disease Resource Center, PO Box 1423 Ukiah CA 95482

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Individual subscription rates 1 year (4 issues): domestic \$25; Canada & Mexico \$35; Foreign \$40. Institutional/Library rates \$50. US funds only, please. Send check to LDRC, PO Box 707, Weaverville CA 96093

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Include both old and new addresses, including zip code.

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Number 33

Guest Editorial

Brain imaging and treatment study needs more patients

Healthy controls also sought

by **Brian Fallon, MD**

The Brain Imaging and Treatment Study at Columbia University is continuing to look for patients and healthy controls, age 18-65. Patients are eligible if they have a current positive IgG Western blot and current problems with memory that started after getting Lyme disease and that persisted despite having had at least 3 weeks of IV antibiotics in the past.

Thus far, patients have participated from as far away as Washington state. We are grateful to the many patients who have tried to enter our study but who were rejected due to the stringency of our criteria (about 3000 patients). We are also very grateful to the eligible patients who have participated in the brain imaging and treatment study thus far. We continue to need more patients. Please contact 212-543-6510 if you think that you might be eligible.

We are also urgently in need to healthy controls. The best controls are relatives of patients, as they would have similar socioeconomic backgrounds as our Lyme patients. We are particularly interested in controls who have less than a college education.

Control subjects are not as easy to find as you think. Because we do compensate controls subjects for their time (up to \$750 over the course of their participation), not infrequently we find subjects trying to participate who hide their past medical, drug, or psychiatric problems just so that they can get into a study and earn some extra money. That obviously needs to be avoided as it



Dr. Brian Fallon speaks at Educational Forum at Greenwich High for public school teachers and staff. Story on page 46.

would mess up our results. So, we are sending out a plea to the Lyme community. If you have relatives who wish to help in the Lyme disease cause and who live within driving distance of Columbia Presbyterian Medical Center, please have them contact us for possible participation in our study. Controls get one set of brain imaging and several test courses of cognitive function. The number to call is 212-543-6510 or email culyme@aol.com.

Thanks very much.

Letters

Medical board attitudes obstruct effective treatment

What is more exasperating than having hurdles placed in the way of basic medical care by a restrictive Board of Medical Examiners(BME)? My wife, a family practice MD, has been suspended for more than 4 years for having the bad luck of having both chronic neuroborreliosis AND hypersomnolence (proven to require non-standard doses of a class IV stimulant to control,) so she has double the trouble. She exhibited emotional distress from the neuroborreliosis which the Board mistook for mental illness. When the Board found she was prescribed non-standard high doses of the stimulant pemoline they suspended her on the unsupported assumption that her emotional distress was from "drug abuse." Our Oregon BME went so far as to report her (Texas) doc to his BME. He presented her chart to them for review and they immediately dismissed the complaint as "unfounded." The Oregon BME seems to hold the view that non-standard prescribed amounts of a proven to be non-addicting, non-euphoric stimulant should be seen as drug abuse.

Similarly, for Lyme diagnosis/treatment, we are forced to travel out of Oregon. It has become a financial disaster attempting to meet the obligations to fly cross country in order to maintain long term medications. Our Columbia-affiliated NY doctor performed the initial diagnosis and prescribed the first IV antibiotic treatment. Here in Oregon, the first IV was administered, then the doctor told us that he no longer would treat her. The Lyme recurred and a second Oregon doctor tried to follow up with a second IV treatment. He did so but suddenly ceased treatment, closed his medical practice and could not follow her any longer. I do not know why he closed his medical practice but my guess is that the Oregon Board

harassed him for continuing the IV treatment. After all, they had already interfered with her long-term treating Texas physician!

Recommendations are very simple: "Move." Moving would make us refugees in our own country. Due to my work, moving is impossible, so every day we wake up to a fight to find basic medical care. Justice is a word that doesn't come up anymore. Lyme treatment has stalled out. The disease seems to come and go but what is constant here is fear.

BME actions are those of a ponderous blunt instrument. Doctors are frightened of "being found out" (and ultimately they refuse to prescribe). The BME attitude has over the years evolved to become institutionalized oppression. I may only be able to testify about one patient whose health is declining but this has how it's been for us.

I read an article a few years ago that expressed an AMA opinion that medications should be given in the amounts that are thought to affect a cure even if they exceed the standard dosages. I know I didn't imagine reading this. What ever happened to this kind of common sense?

**Bill Tyner, for Sandra Tyner, MD
Grants Pass, Oregon**

Records of deceased Lyme expert are still available

Do you know where to reach medical records from Dr. Paul Lavoie in San Francisco? He was my doctor around 1993. He was the first doctor who stated that I am disabled from Lyme disease. Since I am now in a fight for disability, I must gather up as many records as I can. Thank you for being there.

**Paula Sten
Atlantic Mine, Michigan**

Dr. Lavoie's records are being stored at A & P Moving Company in Novato, California. Their phone number is 415-883-2391 and the

Records Department will provide copies of your medical records for a small fee.

Article useful to school staff

Your Lyme Times continues to be invaluable. Thanks for sending me an extra copy of your last issue. I am a volunteer in the local elementary school system. Quite a few children have psychiatric or cognitive difficulties. I suspect some of them have Lyme disease. I sent pages 17 and 18, "Lyme Disease – a Psychotherapy Perspective," on to the staff at the school, to help those who work with special education kids.

I know my subscription renewal isn't due until July, but I wanted to send it now to show my support.

**Mimi Winer
Wayland, Massachusetts**

No matter how long we have been doing this work, we still appreciate positive feedback. Thank you.

Patient needs flexible job

I am a Lyme patient who needs additional income to supplement Social Security. I no longer have any savings to keep me afloat. I live in Los Angeles' west side and have a car. My physical endurance and mental clarity are fair to good, depending on what day you ask. I am unable to do a 9-to-5 day due to "naps" needed, and it's hard to keep a schedule of specific days to work, but I have good output on days I'm feeling good. I'm in my thirties, educated, well-groomed, honest and reliable. Please call. I will consider any type of work.

**Drew Godwin
Los Angeles, California
310-645-5858
email DRWZPAD@AOL.COM**

Lyme cover-up like tobacco cover-up

The whole Lyme cover-up, i.e. Lyme denial by the Ivory Towers, reminds me of the tobacco industry which even recently said:

“And there is no evidence to support the claim that tobacco use is harmful to one’s health.”

So when I tell people about the denial of Lyme disease by major researchers (everyone wants to know who is doing research, and I tell them that the research is not being done and the Lyme literate doctors are being persecuted). I then tell them the tobacco statement to prove my point.

Wendy Feaga, DVM
Ellicott City, Maryland

That's not Lyme brain - everyone has “piles”

You may not remember me, but I sent a check more than a year ago for a subscription to the Lyme Times. Somehow the check got misplaced. You eventually found it when it was outdated and suggested I send another check. I intended to do so but lost your letter in the “pile” on my desk. Then in December I received back issues along with the old check and a note that I was given a one year subscription for being so patient when actually I was delinquent! So thank you so much for your kindness. Enclosed is a “donation” check for \$50. You guys are doing a great job. Thank you so very much. Next time I’ll try real hard to be more prompt.

Andy Breidenbach
New City, New York

If you ♥ the Lyme Times, please support us by subscribing today! See form on page 47.

Lyme vaccine finally pulled, but disease remains rampant

by **Douglas Dodge**

The LYMERix vaccine developed by Yale University and marketed by GlaxoSmithKline has been withdrawn from the market. From the start, the U.S. Food and Drug Administration had found something to worry about with this vaccine. Last year, it agreed that the decision to discontinue the vaccine was overdue.

To justify the withdrawal, announced in February, Glaxo and Yale complained of poor sales for a vaccine that they knew had been approved only for people ages 15 to 70. It was a vaccine that offered only 80 percent protection after booster shots for which the FDA never approved a schedule. The vaccine on its own may trigger Lyme disease.

It was sold as a vaccine to be taken by all, under all circumstances – never mind misdiagnosed or untreated infection.

God, country, Yale, and GlaxoSmithKline have yet to come up with the cure for Lyme disease which might be lying hidden in Yale and Washington files.

Dr. Allen C. Steere, Yale-trained chief investigator and head of the program for LYMERix, and the University of Connecticut’s Dr. Hallie Krider declared they would not take the vaccine themselves. Many physicians know that LYMERix is a product born of self-interest. It should be allowed a cooling-off period of at least a year to observe immune responses; and not marketed until Lyme disease tests are proved reliable and available.

Lyme disease still vies with AIDS as the fastest-growing infectious disease in the country. The Centers for Disease Control admits that under its restrictive surveillance definition, it receives and reports only 10 percent to 15 percent of actual Lyme cases.

Those numbers could represent 10 percent of the millions - a quarter of the population, according to many respected epidemiologists - who will go to their deaths never knowing that the quality of their lives had been affected by the physical or psychological aspects of Lyme disease.

LYMERix was fed to the public after supposedly exhaustive trials and safety studies. Program investigators brushed off adverse reactions and side effects. In one case, a woman was told she had post-menstrual syndrome.

Finally, in a joint announcement, Glaxo and Yale mounted one of the stupidest sales pitches ever imagined. They tried to push their presumably valid product into a market that had already produced perhaps 2 million would-have-been candidates for their vaccine. Their hard sell: “More than 99,000 cases have been reported to the CDC from 1982 to 1996.”

Yale’s Lyme Disease Clinic has been disbanded; Yale’s annual Lyme Disease Symposium shut down. What remained of Lyme disease work at Yale was spun off to L2 Diagnostics in 1998. This lab occupies itself with diagnosing Lyme and lupus, and will probably turn out to be the only laughable company in New Haven’s biotech boom overseen by Yale’s Office of Cooperative Research.

A month before Glaxo’s decision to pull the vaccine, federal health officials had warned of record highs for Lyme disease in recent years. Our mild winter is good news for ticks, bad news for those who might still believe in LYMERix, and won’t find their booster shots on the market.

Douglas S. Dodge, a Yale alumnus, lives in Guilford, Connecticut. This article appeared in the New Haven Register.

The four-handled cup

by Virginia T. Sherr, MD

Joanne looked at me in utter anguish. “I’ve ‘lost it.’ You have to help me.” My mild attempt at humor —“Lost what exactly?”— did not even rate a thin smile. As it turned out, she was in a state of near panic over a realistic fear of losing her wits.

“My entire career was spent running a complicated business office,” she began. “It was my responsibility to see that the company ran like a fine Swiss watch. The demands were incredible so I had to handle them by coordinating everything—all the unexpected glitches, mishaps, and misunderstandings. I did it well. I could do many things at the same time: talk on the phone, create directives for the staff, add up a column of figures, and download data on the computer—never even feeling ruffled. I loved the challenge of it and enjoyed my job. I liked the excitement, but most of all, I enjoyed creating order out of chaos!

“Staff members appreciated my skills, too,” Joanne continued. “They had an office party for me once and gave me a gift—a pretty cup, but an odd one. It had four handles and an inscription ‘*You can handle anything*’. Nothing I ever received meant that much to me. Now, I can’t even bear to look at it because I felt I had to resign my job due to changes in me. I got so I couldn’t multi-task anymore. At first, I just noticed I was having trouble doing more than one thing at a time. Then I got confused at what people said to me, at what I was supposed to be doing or what I had done with even *one* thing. I couldn’t keep straight the decisions that I had made and who I had told about them – even if I remembered having made them.

“When I began to misplace important data and to lose my

personal things, I knew I was *adding* to the disorder, no longer *creating* order and that double-stressed me. I began to obsess about it day and night. The thoughts of my possibly having disrupted the business and added to the chaos were the worse ideas of all. Those thoughts tortured me. I couldn’t stand it. I conjured up all kinds of terrible disasters that might result from my ineptitude. I could not sleep then either because of these fearful thoughts. Completely exhausted, I resigned from the most ideal, best-paying job I could ever have had. But even that did not help! I continued to obsess, thinking the same thoughts over and over again, which still left me unable to sleep. Please do something for me because I am not myself. I am irritable, and I wake up tired because there is something wrong in my head. I am so afraid I am going crazy.”

I found myself wishing that I had known Joanne before she resigned her much-loved job. She had no idea that her central nervous system was infected from a nine-year distant, untreated tick bite although careful history taking and my advanced reference laboratory testing for spirochetal DNA showed that to be true. Luckily, she was able to achieve sound medical improvement with the help of two physicians who specialize in the treatment of Lyme disease. A widely experienced Colmar, Pennsylvania, physician worked with her for a year, treating her with several antibiotics as it became clear to him that these were necessary. Her headaches, confusion, irritability, fatigue, esophageal spasms, TMJ, muscle pains, restless leg syndrome, and night sweats (all due to tick-carried Lyme disease, ehrlichiosis, and babesiosis

infections) abated. She was delighted and grateful.

Joanne’s Lyme-magnified obsessive thoughts and tendencies to constantly recheck things in an effort to create outward order as a partial antidote for her inner confusion began to respond to my prescriptions of Zoloft when given in sync with the antibiotics. Fortunately, the maintenance dose of Zoloft was reducible (often not the case) as she improved physically. Zoloft (sertraline) is an anti-depressant medication frequently used for the treatment of obsessive-compulsive symptoms. When eventually, following a year without needing any antibiotics, her somatic symptoms began to recur, Joanne chose to seek help from a Lyme specialist in Bala Cynwyd, PA because of his well-known work in repairing Lyme-damaged immune systems. He encouraged her efforts in boosting her immune system against infections while continuing her antibiotic and anti-babesiosis medications as needed.

Joanne was triumphant during her last visit to my office. While she had been maintained on Amoxicillin 1000 mg three times daily during her second year of treatment, she and her doctor had been able to discontinue it totally approximately three weeks prior to that session. She enthused, “I have come so far. Now I can do several things at once again. I would suffer all the aches and pains I have



“You can handle anything.”

ever had in preference to having that mental anguish again. Now, I even have figured out how to deal with the few obsessive symptoms that are left over.

“What happened to me was like a trip to hell! I never want to return there! I’m getting that four-handled cup out of the closet and inviting over old friends from the office. I haven’t wanted to see anybody socially for more than 2 years but now I am ready. My husband and I are going to celebrate my escape from

Hades with them.”

Later, I heard from her sister that the reunion became quite a party what with the 4-handled cup getting a real workout. Apparently those present thoroughly enjoyed toasting the fact that Joanne and her doctors had salvaged what she understandably believed she had lost forever—her own mind.

Dr. Sherr practices medicine in Pennsylvania.

patients who remain untreated by legions of “evidence-based” physicians. The concept of “evidence-based medicine” was developed by managed care firms to avoid paying for treatment.

If the highest standard of care was absolute adherence to evidence-based medical studies, we would not need doctors, as computers could read test results and prescribe more efficiently than mere humans. Experience, and careful attention to our patients’ stories, teaches us things more subtle, less quantifiable, and creates the substrate for optimum care.

You are correct that some patients may be adversely affected by IV antibiotic treatment. Some patients also die from aspirin every year. There is a benefit-risk ratio to every decision in medicine. My practice is to describe that ratio to patients so they may make the most informed decision about their own lives. I do not make the decisions for them.

You are also correct that IV antibiotic treatment carries a greater risk and should not be considered until other treatments are tried or the urgency of the symptoms demand such action. Oral and IM antibiotics are usually quite well tolerated and provide help without having to consider the IV route until further down the hierarchy. Regrettably, many patients are denied these as well, without adequate explanation. Since you specifically addressed ceftriaxone, I would like to know your position on the full spectrum of treatments for patients with symptoms of unproven etiology that fall into the categories we are discussing here.

As a psychiatrist, I treat a dozen unprovable diseases each day and am accustomed to providing care when the diagnosis is descriptive rather than quantitative. I am more comfortable than you to treat when evidence-based medicine proves inadequate to address suffering, as it often does.

Opinion

Evidence-based medicine: multiple perspectives

Dr. Oster is responding to Dr. Brand's article in a previous issue. We offered Dr. Brand an opportunity to reply, and fortuitously, Drs. Bransfield and Shepler had posted opinions on the same topic in the internet group Mental Health and Illness (MMI). We begin with Dr. Oster's letter.

I wish to commend your publication of commentary by thoughtful physicians, contributing objective information in an area such as Lyme disease, which harbors so much anecdote.

Dr. Brand’s commentary (*Reporting some doctors may protect others, Winter2001/Spring 2002*) leaves open the difficult issues concerning patients who demand treatment for undetermined causes, and desire to receive reimbursement for same. While empiric treatment for a diagnosis of exclusion is frequently carried out for more specific symptoms, such as asymmetric polyarthritis, studies have clearly shown that this approach is not beneficial for the subtle syndromes that most of your audience concern themselves with. This is because most of those cases are likely to be due to some thing other than Lyme disease.

The risk of empiric therapy outweighs the potential benefits in those situations, as exemplified by the

increasing concern regarding acalculous cholecystitis and other complications of long-term ceftriaxone therapy. Additionally, therapeutic trials should not be permitted to create a false sense of security where the diagnosis remains in doubt.

Lastly, the professional (and legal) standard of care is the established boundary, not the point of view of the lobbyist or political activist. Those demanding leading edge or anecdotal therapy, may well be first in line for redress should there be an adverse outcome. For these reasons, and many others, I applaud evidence over anecdote.

Henry A. Oster, MD
Ventura, California

Dr. Brand replies:

Everyone applauds “evidence over anecdote.” With regard to Lyme and related diseases, our knowledge base is limited, and there is not enough universally acceptable “evidence” to address the suffering

The choice of a physician faced with such matters is whether to play it safe and let the patient suffer, to “do no harm,” or to courageously venture ahead of the curve, and treat even when less than absolutely positive about diagnosis. In our litigious and paranoid society this is always a risk, and fainthearted physicians do not treat the more difficult diseases, such as Lyme.

The issue of reimbursement is not a matter for ethical physicians. Insurance companies have no business second guessing doctors, and, if I had any spare time, would consider addressing legally their practicing medicine without examining the patient, and without a license. Patients pay premiums and insurance companies pay bills. Managed care is beneath contempt and I do not deal with such companies in my practice. Neither should anyone.

Evidence-based medicine does not treat Lyme disease except in the most obvious, textbook cases, i.e., those with a bulls-eye rash, aching knees and florid western blot results. Lyme is ubiquitous and should remain on the differential diagnosis list until a proven, evidence-based diagnosis is made. Until that is accomplished, subtle multisystem complaints with unexplained neurological symptoms point to the presumptive diagnosis of Lyme, and we have yet to develop a reliable test that definitively rules out Lyme.

Absence of proof is not proof of absence. Just the opposite. Somehow, the ubiquitous, vague and unprovable “fibromyalgia” and “chronic fatigue syndrome” are universally accepted by the same doctors who rail against the diagnosis of Lyme disease in patients with more specific symptom clusters.

The bottom line: A suffering patient deserves the best treatment we can provide, and it is our duty to develop a hierarchy of reasonable benefit-risk options, beginning with the most effective and least harmful. If the first choice works, fine. If not, we

must keep going, always measuring the ratio and letting the patient decide how much risk and adversity they wish to tolerate vs how much disease related suffering they undergo.

While your note addresses what we should not do to help these patients, it fails to mention what we should do, other than refuse treatment.

Richard Brand, MD
New City, New York

Dr. Bransfield writes:

This discussion touches on a core conflict in the whole managed care crisis. Insurance companies, managed care, “evidence-based” medicine and disease management focus upon well-defined treatments of well-defined diseases. In the every day practice of medicine, most diseases are not well understood and not well defined. We treat patients with diseases: we do not treat diseases. I contend it is malpractice to merely treat a disease. If others accept this view, the whole concept of disease management for the establishment of diagnosis and treatment guidelines would be considered malpractice, and justifiably so, in my opinion.

Whenever diagnostic or treatment guidelines are published, there is always a disclaimer of responsibility by those who publish the guideline. No professional society, insurance company or other organization or individual ever assumes responsibility and accountability for diagnostic and disease management guidelines. If the individuals who make these guidelines do not stand behind them, why should we?

Those who take a hypothesis to explain a disease and promote it to an authoritarian view are violating the scientific method when they ignore and dismiss evidence that may undermine their belief as being merely subjective, anecdotal, etc. Since much is not known about medicine, in the real world all treatments are empirical and subject to constant revision if the clinical course is contrary to a

prejudged view of the diagnosis and needed treatment.

Back to Lyme disease. At NIH, the diagnosis of Lyme disease, and in particular chronic Lyme disease, is conceptualized as a pyramid. At the apex are the cases that everyone agrees is Lyme disease. At the base are cases that everyone agrees may be some type of condition, but not Lyme disease. In between are cases that some call Lyme disease and some do not. When we perform research or collect epidemiological statistics on any disease, we like to use the apex of the pyramid as a reference point. Insurance companies invariably select the most restrictive (and cheap) diagnostic and treatment criteria and use skewed “evidenced-based” arguments to justify their position. Therefore, they often incorrectly use the epidemiological criteria, research criteria, criteria for Lyme, criteria for arthritis, rather than other manifestations of late stage disease, lab tests with a high cut off point to define the clinical syndrome, etc.

Lyme disease, like many conditions is a clinical diagnosis. We make a diagnosis by looking at the weight of evidence in the presentation of any given patient. Often, patients do not fit into a clean diagnostic category. We therefore need to consider their complaints are caused by a presentation of the disease not currently recognized by the currently flawed diagnostic guidelines, some other disease, or some uncategorized disease. We still have a responsibility to treat the patient to the best of our ability, even when it is contrary to someone’s view of the nature of any particular disease.

Robert Bransfield, MD
Red Bank, New Jersey

Dr. Shepler writes:

I am struck by the legal analogies. Note that the vast majority of legal claims of all sorts fail due to lack of “evidence.” Doctors are being pressured to gather less and less “evidence” of illness in their use (or

lack thereof) of patient histories and physicals and laboratory testing. If no “evidence,” the conclusion is that there nothing wrong. Your (health care) claim fails.

In law, the justification for having to have fairly high standard of proof (evidence) has to do with issue of justice and fairness—but those concerns don’t operate to any meaningful degree in health care, other than the arguments about avoiding waste so that the maximum number of people may benefit.

While the argument that avoiding waste so that the maximum number of people can benefit is important and powerful, it would seem that is not the reason why physicians and patients are being forced to provide “proof” of illness. Rather, the end is corporate profit and an attempt to limit the number of individuals who will benefit from health care resources.

Lynn Shepler, MD, JD
Mountain View, California

client, and had referred many in the past), she never followed through. This was my BETTER experience.

Second experience - a seriously at-risk anorectic 20 year old that I referred to a prominent sub-acute inpatient facility had a very long history of Lyme disease, and had been treated by two Lyme-literate doctors over several years. Her anorexia symptoms profoundly worsened when she went off of IV antibiotics, and she refused to take any oral medication. She had been admitted to the facility with significant paperwork attesting to her medical diagnosis and treatment history.

Initially, I did not discuss Lyme in depth with her primary therapist, knowing that, regardless of the cause, she was at risk of dying of anorexia, and that she was in the hands of the “experts.” As her condition worsened, and the treatment team saw this pattern as very unusual, given their past treatment successes, I suggested an outpatient consultation with a Lyme-literate psychiatrist, to evaluate the role of tick-borne diseases in her anorexia, to add that possibility to the picture.

After an initial positive response to the possibility of the consult, the primary therapist became increasingly guarded. Eventually she told me that the psychiatrist on the team said that the young woman “did not have Lyme,” and he would not agree to the consult. An inpatient psychiatrist with no experience with tick-borne diseases had discounted the medical information given upon admission that supported the medical diagnosis, documentation from TWO LYME-LITERATE DOCTORS who treat medical illness!

This is the way the “science” goes on the other side. What appears to be driving the psychiatric facilities is commitment to not wanting to know (in the first case, avoiding training for the staff, and in the second case, denying proper diagnosis to the patient.)

Lyme-literate in-patient psychiatric facility needed

by Sandy Berenbaum, CSW-R, BCD

There is an urgent need for Lyme-literacy in psychiatric hospitals. Lyme patients with the most severe psychiatric presentation of symptoms sometimes need inpatient treatment, usually to keep them from committing suicide. They need to be treated with respect, as do their referring doctors, who have taken on the challenge of treating the organic cause of their mental illness. The currently diagnosed patients, however, are not the only reason that psychiatric facilities need to be Lyme-literate. There may be many patients in these facilities who have Lyme disease, who have not yet been diagnosed, because no psychiatrist has looked at the possibility of an organic cause for their mental illness.

For the sake of both of these categories of patients, inpatient facilities need to be open to tick-borne diseases as causes of mental illness, and need to have staff that is trained to deal with these patients.

I have had two experiences during the past year that leave me with the impression that these institutions are not even open-minded about the possibility of Lyme, let alone Lyme-literate.

An adult client with severe Lyme encephalopathy, with no mental illness prior to the Lyme was hospitalized at a prominent inpatient facility in New York State, a facility that I have had close ties with in the past. During her hospitalization, I was in contact with several professional members of her treatment team. They had little knowledge of what Lyme could do to the brain, but were open to what I told them, and accepted the journal articles I sent to them (primarily articles written by Dr. Fallon). One staff member wondered, in a private conversation with me, whether there might be other patients in that hospital with undiagnosed Lyme.

Following my client’s hospitalization, I spoke with the clinical director of the facility, having had strong connections and excellent communications with her in the past. I offered to conduct an in-service training for professional staff, offering to pursue the possibility of bringing a Lyme-treating doctor or Lyme-literate psychiatrist with me for a comprehensive in-service. Politely stating that she would consider it and get back to me (being careful, I’m sure, not to alienate me, since I had referred this

The Lyme professional community needs a psychiatric facility that is open enough to allow for the possibility of tick-borne diseases playing a role in mental illness. Psychiatrists and other mental health professionals need a hospital they can refer their high risk patients to that will not undermine medical treatment.

Perhaps a first step could be taken by a Lyme-literate medical researcher who could design a study of hospitalized patients in a Lyme-endemic area. With the patients worked-up for Lyme, including PCR testing, as well as tested for the co-infections, the study could simply see if there is ANY yield, are there patients who have undiagnosed tick-borne

diseases in mental hospitals? Is the organic source of their mental illnesses being overlooked? Then, see what happens when antibiotics are given (note Ginny Sherr's excellent article in the last Lyme Times - a reversal of personality disorders in Lyme patients, a new approach to treating personality disorders?)

More work is clearly needed in this area.

Sandy Berenbaum works at the Family Connections Center for Counseling in Wappingers Falls, New York.

See the article on psychiatric disorders caused by Lyme disease, on page 31.

actually find the biological causes of his illnesses. His former colleagues at Nevada County Behavioral Health, where a patient killed staff members last year, think he is unfit to care for his son.

And so his son sleeps half the day, walks around in a fog, allows Haldol and Clozaril to reduce what little N-Acetyl Aspartate (NAA) he has in his brain. (NAA is a measure of neuron integrity and health.) He passively sits while the drugs reduce his levels of IL-1 and IL-2 from his body that has been chronically manufacturing them not just in response to Lyme but a plethora of other antigens. He gets a weekly blood test to assure he does not have agranulocytosis and takes 1500 mg. Depakote to make sure he doesn't have seizures. The treatment is working. He is no longer manic. What is happening in his brain is not known or measured. Therefore it isn't a problem. But his father thinks his son is getting a chemical lobotomy.

Maybe they will have to put the father away too. He is obviously getting manic and paranoid. And his book which will soon be published? Such grandiosity. What a shame.

At a NAMI meeting his father asks a psychiatrist who serves on the California equivalent of the NY OPMC [Office of Professional Medical Conduct], how he explains the fact that 33% of psychiatric patients have Lyme antibodies while 19% of normals have these same antibodies. His answer? Were the mental patients homeless? Lots of Lyme in those hobo camps, no doubt.

So while city folk back East fight your battles, out here in Lake Lymebe gone, we know what to do with all the patients who still are sick. We punish the hell out of them and their families until they learn to get with the program and stop making waves. We don't have Lyme out here, just mental illness. And if they won't be helped and become homeless and get Lyme in the woods, well, can't say we didn't warn 'em.

The news from Lake Lymebe gone

by Dave Moyer

Out here in the West, far from the political controversies in the East, where the men are strong, the woman are good looking and the kids are all above average, a young 26-year-old male languishes in an intermediate care mental health facility under a temporary conservatorship while Nevada County Behavioral Health seeks to obtain a permanent conservatorship for a year.

The man, whose exercise-induced mania had been resolved at home for a month, after one day of either forgetting or choosing not to take his medications, refuses to take any medications or supplements because of his desire to go to a hospital where he could help others. He does. Meanwhile, the county is aware that his father, a former employee, has been seeking out alternative treatments for what is clearly his "BIPO-LAR ILLNESS." But the folks in Lymebe gone know better. They are traditional folk with strong religious practices. They believe in the DSM-IV

Bible handed down from their forefathers. These folks choose to rescue this young man from his well meaning, but obviously misdirected father, who has attempted to break through the denial of his son and the medical establishment by getting additional assessment and treatment for the neuroLyme disease. He even writes a book on the subject. The young man's father continues to insist that his son has a number of diagnosable and treatable conditions, not the least of which is neuro Lyme, a disease that impairs his son's ability to do what is necessary to maintain his sanity, whether it be taking Synergy supplements, medications, other specific immune enhancing supplements, getting enough water, or enough sleep. He has tried to get him to get an EEG, to contact Columbia University for neuroLyme trials, to get an MRI and a SPECT. His colleagues around the county tell him how lucky his son is to have a father who is concerned enough to try to

PS The staff keep asking why Chris is there. He doesn't seem to belong. Gives concerts of his original songs nightly.

Dave Moyer, LCSW, BCD, Lt Col USAF, Ret. is the author of a book, *Too Good To Be True? Nutrients Quiet the Unquiet Brain*, that will be published later this year. It addresses

the role of nutrition in restoring stability to those with bipolar disorder and other central nervous system disorders. To obtain more information about the book, you may email the author at dmoyer@telis.org.

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state and local levels, Lyme Disease activist groups are a political force that demand attention. They also provide invaluable educational and informational resources to patients and their doctors.

Through such advocate organizations, patients have the opportunity to provide data that effectively contradicts the medical establishment view that chronic Lyme disease is not caused by ongoing spirochetal infection and therefore should not be treated with long term antibiotics. They can and do critique the few studies that form the basis of this contested view, which has been embraced by many insurers and HMO's anxious to reduce the use of expensive antibiotics.

Because I can recall stories of treatment-resistant chronic tertiary syphilis-the classic spirochetal disease-I certainly feel physicians should err on the side of long-term antibiotic treatment until evidence to the contrary proves otherwise. This evidence should be sufficient to satisfy even advocacy groups. Doctors should listen to their Lyme disease patients and give them the benefit of the doubt regarding a clinical trial of long-term-antibiotics.

Unfortunately, physicians who have provided long-term antibiotic treatment have faced persecution in the form of adverse licensing action by state medical boards or dismissal from panels of health insurers and HMOs. It seems insurance companies are more interested in saving money than treating patients with a debilitating chronic disease. Such physician persecution in this unresolved treatment controversy is intolerable and deserves to be condemned by all physicians and organized medicine.

Lyme Disease patient advocacy is just one example of the modern health care consumer movement that is changing the face of medicine. When patients become consumers in this sense, the doctor/patient relationship improves. Organized medicine needs to reach out and participate with

Consumers need our support

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Robert J. Lull, MD

I recently attended a meeting of a local Lyme Disease Association and learned some important lessons about the emerging health care consumer movement and trend toward disease-specific patient activism. I'd like to share the insights I gained from that meeting since it relates directly to the theme of this issue of *San Francisco Medicine*. These insights also apply to other ill-defined or rare diseases, such as chronic fatigue syndrome, fibromyalgia, gulf war syndrome, and a variety of illnesses possibly associated with environmental causes.

First, I was utterly dismayed at the stories told by individual patients of their disastrous encounters with many physicians who were uninformed about Lyme disease. Many doctors pontificated their incorrect views (such as the view that a negative ELISA test means the patient does not have Lyme disease) and missed early diagnoses of the disease when antibiotic treatment might have been most helpful. More distressing was the fact that most of these physicians never really listened to their patients. The patients were forced to see multiple physicians (often more than 10 doctors) before finding one who made the correct diagnosis. It was only after learning

“Organized medicine needs to reach out and participate with patient advocacy groups seeking to improve our health care system.”

more about Lyme disease on their own, that the patients realized how ignorant most physicians are about the nuances of presenting symptoms, the difficulties in establishing a correct diagnosis and the controversies surrounding treatment duration.

The situation was far worse for patients who developed chronic Lyme disease. The cause of continued debilitating systemic symptoms and the role of long-term antibiotics to treat them is still hotly debated. The patients felt abandoned by the medical establishment, which seemed to ignore their testimony about antibiotic-related symptom improvement.

So they organized an activist group, like the one I was visiting that day, to make sure their views and needs are not ignored. At national,

patient advocacy groups seeking to improve our health care system. Our patients as consumers will accept nothing less-nor should they.

Dr. Lull is President of the the San Francisco Medical Society.

they have ruled it out with the ELISA, which has a woeful 50 percent accuracy rate.

Lyme disease activist speaks up

by Lee Lull

Lyme disease and patient advocacy go hand in hand. It all began back in the early 1980s when Polly Murray, a mother in Lyme, Connecticut, first insisted that the department of health investigate a proliferation of atypical juvenile arthritis cases in her neighborhood. It has been an up-hill battle ever since as Lyme disease continues to go undiagnosed, misdiagnosed and untreated.

Lyme disease activists have proliferated right in step with this rapidly emerging disease (See CDC morbidity tables). Their activism is driven by a persistent informational void, a void that enables differences of opinion on all aspects of the disease and allows for the proliferation of misinformation. Much remains to be learned about this disease but, in the meantime, insurance companies continue to deny treatment for many beyond some arbitrary amount of time, and too few physicians are aware that continued symptoms often equate to continued infection; that the spirochete can persist despite seemingly adequate treatment.

Lyme patients are acutely aware of the factors that abet their non-diagnoses and that deprive them of needed treatment. That is why 500 patients recently appeared before New York legislators, and why a similar number yet again went to Rhode Island legislators. And that is why, three times a year, sick patients from all over California make the trip to Sacramento. They go to testify before the State Lyme Disease Advisory Committee (LDAC) in hopes that they can compel a reluctant Department of Health

Service (DHS) to address the many misconceptions about Lyme disease right here in California.

One myth is that Lyme disease is rare in California. Sadly only one county in California (Mendocino County) has been thoroughly studied for risk to date. Shockingly it was found to have a nymphal tick infectivity rate comparable to those in

California's nymphal tick infectivity rate is comparable to that in the Northeast.

endemic Northeastern states! The nymphal tick is the major vector in California; it is as tiny as a poppy seed and most people never even see it. Infected ticks have been identified in 41 of our 58 counties to date. The actuality is that it is the diagnosis that is rare, not the disease.

Lyme disease is not always easy to diagnose-even more difficult when the differential is never entertained and the physician states with great authority, "We don't have Lyme disease here." Only half of those infected ever get the pathognomonic expanding rash, Erythema Migrans (EM), that mandates immediate treatment. And it turns out that the famous bull's eye rash is not the most common rash after all-just the easiest to identify. There is no 100 percent accurate diagnostic test yet available. Patients often test negative and still have disease. Despite this fact, ill informed physicians continue to think

Another myth is that Lyme disease is just an arthritic illness. Lyme disease is a multi-system, complex illness akin to syphilis, replete with protean presentations that wax and wane, a pattern often mistaken for hypochondriasis, but typical of spirochetal infections. It is a disease where early diagnosis and treatment are crucial to prevent an insidious nightmare of great morbidity. A slew of "non-specific" symptoms sends patients careening from doctor to doctor. Lyme disease has been misdiagnosed as multiple sclerosis, aseptic meningitis, sleep disorders, psychiatric disorders, plantar fasciitis, sinusitis, optic neuritis, Bell's palsy… to name a few. It is not a ten-minute diagnosis.

One study found that the average Lyme disease patient sees more than 12 doctors before diagnosis is attained. This means that diagnosis is often too late for an easy cure, necessitating lengthier treatment courses.

Physicians capable of forming a partnership with their patients are most able to see the entire constellation of symptoms. This requires that they actually listen to the patient. Physicians who know that Lyme disease occurs right here in the Bay Area and throughout California are most apt to make the correct diagnosis.

Physicians interested in the diagnosis and treatment of Lyme disease are encouraged to contact me for referrals. There is a growing demand for Lyme specialists in California. Please email: leema@earthlink.net.

Lee Lull is a grandmother, ex-nurse and founder/coordinator of the Marin County Lyme Disease Support Group. She currently serves as an appointee on the CA DHS Lyme Disease Advisory Committee.

Medical Hypotheses

Lyme, an Infectious Disease and a Neurotoxic Illness

by Ritchie Shoemaker, MD

Medicine continues to change as our knowledge expands. While there are new illnesses, some emerging from alterations in habitat created by changes in our lifestyle and the chemicals we use (and then add to our environment), the changes in medicine described here really reflects our “new” knowledge about disease processes that we have recognized using different names. I want you to know about chronic illnesses caused by biotoxins. And I want you to start recognizing that many of the syndromes diagnosed everyday by physicians often are actually caused by biotoxins. Start saying goodbye to some recent additions to the list of conditions whose presence can not be proven by a diagnostic test. Say goodbye to clinical diagnoses as fibromyalgia, irritable bowel disease, and memory impairment from reaching age 45, stress, tension and depression. Not everyone with headaches, for example, will have a biotoxin as the culprit, but when headaches occur in an illness that also includes memory problems, muscle pain, shortness of breath, sensitivity to bright light and others, take a closer look. Biotoxin illnesses are all around us. We simply need to recognize them.

This is a whole new field of medicine. Diagnosis and treatment of acute and chronic neurotoxin-mediated illness are developing now. Complete with an academic literature, a diagnostic biomarker, a unique series of questions used in history, physical findings and a unique laboratory data set, this new field of medicine focuses on illnesses that occur following exposure to biotoxins. They are easily recognized, increas-

ingly common and best of all, they are treatable.

Chronic illnesses caused by biotoxins are recognizable by the number and grouping of the symptoms they cause. First, the presence of a biomarker, visual contrast sensitivity (VCS), demonstrates the effects of neurotoxins on neurons that are part of optic nerve. The enhanced involvement of pro-inflammatory cytokines, especially TNF (tumor necrosis factor alpha), and clinical response to toxin-binding therapy with cholestyramine (CSM), are other facets of the case definition of what is a biotoxin mediated illness. Of equal importance for the case definition is showing that potentially confounding conditions have been ruled out.

The art and science of medicine apply to this field, just as they do to any other group of illnesses. What is so different about these biotoxins is that they make us sick through a newly recognized mechanism of action. Almost daily, we find a new microorganism causing symptoms previously blamed on something else. Age, stress, IBS, allergy, asthma, overweight, fibromyalgia are actually chronic, neurotoxin-mediated illnesses (CNTI). Taking a neurotoxin history requires every one of the old fashioned, bedside clinical skills that somehow have gone by the wayside in the high-tech world of Modern Medicine. As Sir William Osler, the father of American medicine said at the turn of the century, “The patient will tell you what is wrong, if you let him.”

The first well-defined CNTI was

named the “Possible Human Illness Syndrome,” (PEAS) by the Centers for Disease Control (CDC) in 1998-9. The unique group of symptoms acquired in the wild in a small number of patients exposed to putative toxin(s) made by dinoflagellates, including *Pfiesteria piscicida*, that reside in the estuaries of the Eastern Shore of Maryland’s Chesapeake Bay was published in 1997 (Shoemaker RC, Maryland Medical Journal 11/97). The landmark article describing PEAS as a CNTI, with symptoms, VCS deficit, lack of confounding factors, exposure and response to CSM, was only recently published in Environmental Health Perspectives (Shoemaker and Hudnell 5/01). The role of pro-inflammatory cytokines in PEAS was documented for the first time (Ramsdell) in the same issue of EHP.

There are many organisms that cause illnesses that fit the case definition of a CNTI.

The CNTI patient is chronically ill. He has many symptoms on a daily basis but the symptoms change from day to day. While there may be good days and bad days, the symptom complex never goes away on its own. It is the changeable, multi-organ symptom complex that provides the clinician the historical basis to seek out the full list of symptoms. Once symptoms are carefully defined, the clinician must narrow the possible environmental exposures to a workable few before attempting to positively identify the source of a CNTI. When the differential diagnosis includes such entities as sick building syndrome, cylindrospermopsis, *Lyngbya wollei* exposure and Lyme Disease, most physicians will be completely lost. So are their long suffering patients. Sometimes the answer to the basic question, “Doctor, what do I have?” isn’t clear until a diagnostic trial of CSM, with daily VCS monitoring, is performed. Sometimes the answer only becomes known what the patient has recovered and CSM is stopped.

If the physician can be certain that

the CNTI is related to a tick bite, or exposure to an area where others had tick bites, and a reasonable course of antibiotics has not resolved the illness, the clinician must look for the markers of inflammatory cytokine activity before attempting treatment with CSM. No other CNTI, not even ciguatera, is associated with such a firestorm of cytokine effects occurring after beginning therapy as is seen in chronic, neurotoxic Lyme. We have clear clinical data supporting the concept that Babesia co-infecting Lyme patients also engenders a powerful inflammatory cytokine response. It shouldn't be surprising that the clinical problems presented by co-infected Lyme-Babesia patients are difficult to treat. In these patients, we are looking at two different kinds of neurotoxins (maybe more) and two different kinds of cytokine responses.

So what are some key points in a neurotoxic history?

A patient will be chronically fatigued, or weak, with multiple cognitive impairments, headache, multiple eye symptoms (sensitivity to bright light, redness, tearing, blurred vision), chronic sinus congestion, cough, shortness of breath, muscle aches, cramps, chronic, non-specific abdominal pain and more. Lyme is a common cause of these symptoms, but not all patients have all the neurotoxic symptoms. Look for presence at least 4 of 9 symptom categories. (See list.)

Neuropathic symptoms must be evaluated carefully. Ask the patient about tingling and numbness when it is noted to be in a non-anatomic distribution. If a patient has a diagnosis of a pinched cervical nerve or carpal tunnel syndrome, is the distribution of nerve impairment anatomically correct? If not, think neurotoxins.

Second: Does the patient have unusual neuropathic symptoms, like "an ice-pick pain" that sticks in one spot for a fleeting moment, repeatedly? Does the patient have a pain that feels "like a lightning bolt" that

shoots deep into a muscle group and explodes? Recently, I interviewed a patient in Denver who had been sick since 1980, following a hiking trip in the Bitterroot Valley in Montana. He had seen over 50 physicians (only recently he had been diagnosed with Lyme and Babesia) and spent huge sums of money. No one had ever asked him the "lightning bolt" question and yet his pain exactly fit that unusual description. "That's it, that's exactly what it feels like!" Ask the unusual pain questions.

Look for presence of at least 4 of 9 symptom categories:

- Nerve**
 - Muscle**
 - Brain**
 - Eye**
 - Sinus**
 - Lung**
 - GI tract**
 - Joints**
 - Skin**
-

Third: ask about unusual skin sensitivities to light touch, warm drops of water and a constant pins and needles sensation.

Fourth: Do a VCS test! At the Lyme Disease Association meeting in Princeton, NJ, 11/00, I tested 41 patients, all of whom had persistent symptoms despite careful antibiotic treatment. 38 showed the typical deficit. Why? Antibiotics don't kill neurotoxins and Borrelia makes neurotoxins. If the patient is blind (as in one recent case from Massachusetts), do a Retinal Flowmeter study. The hypoperfusion in retina, neural rim and lamina cribosa is (to date) only seen in Lyme, but hypoperfusion in neural rim alone can appear in other

neurotoxic illnesses.

Fifth: If you hear of optic neuritis, retrobulbar optic neuritis, transitory scotomata and cone-rod dystrophy, think Lyme first, but think of neurotoxic Lyme with direct cytokine mediated hypoperfusion. For those patients, with vision itself at risk, you will have to treat the cytokine component of the illness before you begin antibiotics. Never let anyone prescribe steroids for optic neuritis unless you know that a neurotoxin is *not* involved.

What are the main confounding variables that create confusion regarding Lyme Disease as the diagnosis as opposed to some other neurotoxin mediated illnesses?

Don't forget that patients can have 2 or 3 sources of environmentally acquired illness. Rule out alcoholism, chronic solvent (occupational) exposure, hydrocarbon exposure (especially glycol ethers), and occupational exposure to heavy metal fumes and dusts as well. Ask about estuarine exposure to Pfiesteria and Chattonella dinoflagellates, toxin-forming fungi in closed circulation buildings, consumption of tropical predator fish such as barracuda, jack, red snapper and grouper. Make sure no one went swimming in the lakes of Central Florida with the dead pelicans or dying alligators. Ask if the patient drank the public water from areas of Florida that are heavily contaminated with blue green algae toxins, such as microcystin, anatoxin a and cylindrospermopsin. Make sure, as well, that the patient didn't work on lands that suffered crop damage and re-cropping problems following pesticide use.

How can the VCS test help determine progress in treatment?

The test scores in the high frequencies aren't often used in diagnosis of CNTI, though they also show deficits similar to the mid-frequency scores. About 12 hours before a Herxheimer reaction is going to begin (as well as intensification

from CSM), the Row E score and then the score in row Row D will fall too, usually at least 2 blocks. Resolution of the Herxheimer and intensification both will be heralded by a rise in first E and then D scores.

The pattern of improvement of VCS and symptoms in neurotoxic illnesses, including Lyme, approximates an elongated S, with an initial flat line, followed (usually in 36 hours!) with an initial rise. That leads to an exponential rise, which tapers to a low angle, becoming parallel to the horizontal axis. If the resolution of the exponential curve ends with persistent symptoms noted in a Lyme patient, the physician needs to be thinking about the possibility of occult co-infection or continued presence of living spirochetes. These patients need more antibiotics.

Finally, the shape of the VCS curve at the end of CSM therapy tells us a lot about what is occurring in the neurotoxic patient. If the patient remains well, continue to observe for late relapse, but likely the illness was caused by an exogenous exposure. If the curve suddenly drops, beginning at 36 hours following cessation of CSM, be thinking re-exposure. This reacquisition is particularly well demonstrated in patients with sick building syndrome. A gradual deterioration, occurring over 2-3 weeks, usually indicates an endogenous neurotoxic process, such as seen in some patients with chronic soft tissue injury, a few fibromyalgia patients and many with chronic fatigue syndrome.

What is all this talk about pro-inflammatory cytokines?

This is the era of cytokine theory and cytokine therapy! When Dr. Ian Clark postulated the cytokine theory of cerebral malaria in 1991, he was 10 years ahead of his time. The basic cytokine model of illness and normal function includes different compounds made by T helper lymphocytes (Th-1 are inflammatory, including interferon, TNF alpha, IL-1, IL-1 B, and IL-12; Th-2 are anti-inflamma-

tory, including IL-2, IL-4, IL-8 and in some cases IL-6). This list is by no means complete. We are only beginning to see the importance of colony stimulating factors, for example.

Pro-inflammatory cytokines are also made by fat cells in great quantities; transcription of these cytokines is controlled by a large family of cytokine nuclear receptors. A variety of compounds can activate the cytokine receptors. Cytokines provide a wonderful targeting

Caveat emptor:

“This model is simplistic and new information will refine or refute these current ideas.”

mechanism for cells of the body to respond to local attacks, and systemic insults (sepsis) as well, but when these overlapping, redundant systems of cell to cell communication, acting on cell surface receptors and nuclear receptors alike, are out balance, illness will result. When cytokines are “out of balance,” think first of fat cell production and think of neurotoxins turning on the fat cell production machinery.

Neurotoxins activate excessive release of pro-inflammatory cytokines. Neurotoxins can also selectively activate cytokine nuclear receptors. If TNF is released by macrophages following the interaction with a bacterial lipopolysaccharide located on the cell membrane or cell wall of the bacteria, say from a *Borrelia* spirochete infecting a localized region, the TNF will bind to a receptor on an endothelial cell. When the receptor on the capillary endothelial cell is activated by TNF, a “downstream” series of effects occurs,

including production and release of adhesion molecules. These molecules function “like glue” to hold migrating neutrophils in place, focusing the release of other cytokines released by the neutrophils directly on the point of attack. The stacked up neutrophils reduce downstream blood flow, literally by blocking the blood vessels. The blood vessels which are blocked, or at least restricted in downstream flow (hypoperfusion) are capillaries. The blockage is temporary, it has nothing to do with other blockages due to cholesterol, or platelets when the blood vessel itself is inflamed (vasculitis). This is a newly recognized mechanism of disease causation.

If neurotoxins activate cytokine receptors in adipocytes, however, lots of bad things can happen. Our research suggests that this fat cell release of pro-inflammatory cytokines is the main source of symptoms in chronic Lyme disease.

Fortunately, the macrophage/monocyte response has ample counter-regulatory balances. So, unopposed cytokine damage from intravascular organisms either resolves (the host lives) or it doesn't (the host dies, sepsis can be lethal!). The extravascular organisms, especially Lyme and their fat-soluble ionophore (cross from cell to cell) neurotoxins, can cause continuous activation of adipocyte cytokine nuclear receptors. The patients with these neurotoxins don't die. They stay sick, but they only die, and hear me clearly when I tell you that this is a hot topic in neurotoxin research, when individuals with particular susceptibility factors, some as yet unidentified, when they suffer multiple repetitive exposures.

Binding neurotoxins out of extravascular circulation with cholestyramine can set off a “storm” of cytokine release, heralded by a rise of TNF mRNA (not from buffy coat fraction!). When patients suffer the effects of a rapidly rising TNF (TNF mRNA is a marker for subsequent

TNF activity), whether from antibiotic treatment, CSM treatment, or not, the result is predictable: patients feel terrible! Much research needs to be done here as well. This model is simplistic and new information will refine or refute these current ideas.

The obesity and diabetes literature gives us room for optimism regarding cytokine receptors gone awry and TNF mRNA warning us about cytokine mediated misery about to occur. Another major group of nuclear receptors found essentially only in fat cells, PPAR gamma, when activated, provides at least 5 separate layers of gene activity that control or down-regulate the cytokine receptor effects. Finally, a counter-balance to the adipocyte cytokine nuclear receptors!

- 1) TNF alpha transcription is directly down regulated
- 2) The production of the 75 KD soluble TNF alpha receptor is down regulated, sparing the release of adhesin that causes hypoperfusion.
- 3) The activity of a bile canalicular organic anion transport protein is up regulated, promoting excretion of neurotoxins into bile and the waiting binding sites of CSM!
- 4) Fatty acid transport into adipocytes, reduces insulin resistance and enhances direct uptake of glucose into muscle beds.
- 5) Uncoupling protein-2 is up regulated, generating heat for the local inflammatory response.

How can we use PPAR gamma to help us treat the symptoms caused by neurotoxins?

If we look at PPAR and the cytokine super family of nuclear receptors as "equal and opposite," we can drive PPAR and override cytokine effects by simply prescribing one of two thiazolidinedione (TZD) medications, each of which is a PPAR agonist, that is FDA approve to aid in treatment of Type II (insulin resistant) diabetes. The drugs, rosiglitazone (Avandia) and pioglitazone (Actos),

work to help treat insulin resistance by forcing PPAR to transcribe two proteins that each help move glucose into liver and muscle cells more efficiently. PPAR can do lots of wonderful thing for lowering cholesterol and helping insulin resistant patients lose weight, but only if they follow a no-amylose diet (see *Lose The Weight You Hate*, RC Shoemaker, M.D. 7/01). The data supporting use of rosiglitazone in a weight loss program in non-diabetics was presented 6/20/01 at the 83rd Endocrine Society Meetings, Denver, Colorado.

Some physicians are cautions about using Avandia or Actos because the first TZD, Rezulin, did have an association with liver injury. Prudent blood testing will ease everyone's mind, as neither Avandia nor Actos causes hypoglycemia (<1%) or liver damage.

The levels of interactions of multiple redundant cytokine systems and nuclear receptors also include direct activation and/or sequential inhibition of many enzymes critical to synthesis and regulation of hormones that also affect the symptoms of CNTI, especially adrenal, thyroid, gonadotrophins and hypothalamic pathways. The coming months will likely bring a flood of additional information regarding cytokine control of hormone-neurotoxin interactions to the forefront of biotoxin research.

For those of us who see the chronic illnesses caused by neurotoxins as a reproducible syndrome, with day-to-day variation of multiple organ system dysfunction, causing multiple, predictable symptoms, the future is bright. As we continue to learn more about the extent of neurotoxic illness in our society and expand our research base regarding chronic fatigue syndrome, Gulf War Syndrome, fibromyalgia and chronic Lyme Disease, to name just a few, we expect to see a quantum leap in reduction of human suffering. In just a few years, beginning with the first of an ongoing

series of Pfiesteria outbreaks in the Pocomoke (MD) River, we have seen our work recognized at the highest levels of peer-reviewed medicine, international neurotoxicology conferences and multiple academic conferences across the US.

The challenge for CNTI-practicing physicians and researchers, too, is to bring these new concepts to the Nation's primary care physicians who must learn the new concepts and how use of new diagnostic modalities like VCS and the Heidelberg Retinal Flowmeter actually measure hypoperfusion caused by cytokines at the capillary level in retina and the neural rim of the optic nerve. Our goal is simple: improvement of quality of life for millions of affected patients. As we throw out old, useless diagnoses, like fibromyalgia, and old, useless ideas such as, "Lyme Disease is cured by 3 weeks of antibiotics," we must continue to reevaluate our emerging field of medicine critically, for we know that "Today's Knowledge is Tomorrow's Old, Useless Ideas."

As the healing of long suffering patients continues, Today's Knowledge is welcome.

Dr. Shoemaker is a family practice physician in Pocomoke, Maryland. He has a Background in ecology and molecular biology and has worked with US EPA NHEERL neurotoxicologist, H. Kenneth Hudnell, Ph.D [see paper on page]. Shoemaker was Maryland's Family Practice Doctor of the Year, 2000, finalist AAFP National FP Doctor of the Year, 2001. He is author of 5 books, has multiple publications in peer-reviewed journals, and has made multiple presentations at national and international conferences. He has a website at www.chronicneurotoxins.com.

See following article by Dr. Hudnell on toxins, and the Patient Story on page 32 by Dr. Shoemaker.

Chronic Lyme disease symptoms may be caused by toxins

by H. Kenneth Hudnell, PhD

The arbiter of “chronic Lyme disease/post Lyme disease” (illness after competent antibiotic treatment) may be neither infection nor response of that infection to antibiotics. It may be the response of symptoms, measures of visual contrast sensitivity, and levels of some proinflammatory cytokines (e.g. TNF-alpha; 1,2) to a toxin binding agent such as cholestyramine (CSM). CSM is a nonabsorbable polymer which uses an anion-exchange capacity to bind toxins in bile. (see appendix)

Cartwright suggests that toxins are released before/during/after killing *B burgdorferi*. (3) If some patients are unable to naturally eliminate the toxins efficiently, they could develop chronic illness. If the toxins accumulate in bile and enter the GI tract, treatment with CSM could vastly enhance toxin elimination rates by binding the toxins before they can be reabsorbed with bile through enterohepatic re-circulation. When the toxins are eliminated, the inflammatory response should subside, vision should return to normal and symptoms should resolve - the patients should recover.

This is the paradigm we believe explains chronic illness from putative *Pfiesteria* toxins. Initial research showed a deficit in visual contrast sensitivity, an indicator of the ability to see low contrast visual patterns. (4,5) Subsequent research conducted in collaboration with Ritchie Shoemaker, MD, [see previous article] associated the vision deficit with a symptom complex in patients with exposure to estuaries inhabited by *Pfiesteria*. 6,7 CSM treatment led to dramatic improvement in the patients. (6,7) Subsequent research showed that blood flow rates were reduced in

the microvasculature of the retina. (unpublished data) Colleagues working at a NOAA facility parentally isolated a toxin from *Pfiesteria* tank water which elicited an inflammatory response. (8) A proinflammatory response can be elicited in both the central nervous system and the periphery. The response, therefore, could potentially explain the fluctuations in retinal blood flow and rapid

Read about patient successfully treated according to Dr. Shoemaker's protocol on page 38

changes in vision during exposure and treatment, as well as the symptoms of reduced cognitive function, weakness, tiredness, joint and muscle ache, pain, etc.

This paradigm has also fit the post-Lyme patients treated by Dr. Shoemaker and those treated by other physicians following the patient's completion of questionnaires, a vision screening test and receipt of the treatment protocol at Dr. Shoemaker's website <http://chronicneurotoxins.com>. (unpublished data)

I hope the concept of chronic biotoxin-mediated illness isn't viewed as too radical to be considered. Our data suggest it may generalize to a number of other illnesses caused by toxins from a variety of organisms. The proof is in the CSM treatment results.

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- Appendix - Cholestyramine use in toxin elimination.
- * Excerpt from Shoemaker RC & Hudnell HK. Possible estuary associated syndrome: Symptoms, vision and treatment. *Environmentla Health Perspectives*, 109:539-545, 2001.
- * The TPC toxin(s) thought to be responsible for PEAS were not the first toxin(s) which had been effectively eliminated by CSM treatment. Case reports or animal studies suggested that

CSM binds and enhances elimination rates of many organic toxins including Kepone (28,29), DDE (30), other organo-chlorine pesticides (31), polychlorinated biphenyl compounds (32), clostridium difficile toxin (33,34), *Escherichia coli* and *vibrio cholera* toxins (35,36), a cytotoxin(s) from an unidentified gastrointestinal microorganism(s) (37,38), the mycotoxins, ochratoxin A (39,40) and fumonisin B1 (41), the cyanobacterial toxin, microcystin LR (42), the fusarium toxin, zearalenone (43) and a toxin from the Chinese herbal product, Jin Bu Huan (44). Those toxins which circulate systemically were thought to enter the small intestine with bile and become bound by CSM, thereby interrupting enterohepatic recirculation and preventing systemic recirculation. CSM, a highly charged quaternary-ammonium resin, may act as an absorbent by binding toxins through its strong anion-exchange capacity or by entrapment of molecules in its polymeric structure. CSM taken orally is not absorbed due to its large molecular size and is not metabolized in the digestive system. The clinical improvement seen in the cases treated with CSM was thought to be due to interruption of enterohepatic re-circulation of toxin(s). Confirmation of this hypothesis will not be possible until the toxin, or suite of toxins and their metabolites, are identified. There are intriguing studies underway (45,46) that focus on the three-dimensional structure of organic toxins and the existence of a molecular dipole in those toxins, particularly in polycyclic ether toxins identified in other dinoflagellate species (47) and in carboxylic acid ether toxins of fungal species (40,45,46), into which the quaternary ammonium side chain of CSM fits exactly, much as it fits into particular crown-6-ether structures (48). Further research is needed to clarify the mechanisms by which CSM leads to the elimination of the TPC and other organic toxins.

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 **** These comments are my own and don't reflect Agency policy ****
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Beginners' Pages

What's in a name? Lyme disease - a complex?

by Jon Strong

Our understanding of Lyme disease has been growing slowly over the past several years. It was initially thought by people like Dr. Steere to be a simple infection by a single type of bacterium, the *Borrelia burgdorferi* spirochete, that caused a well-defined set of symptoms and could be easily treated. But evidence has been mounting in recent years that illustrates just how naive and inadequate that viewpoint has been.

It was initially thought that Lyme disease, as a "simple" spirochetal infection, was the cause of a type of progressive arthritis that could be stopped with simple mono-antibiotic therapy. Within a few years, it started to become clear that the same illness could also wreak havoc in the central nervous system and brain, the heart, the skin and various major organs. It also started to become clear that the illness was difficult to accurately detect and diagnose, and often did not respond to antibiotic therapy as was originally thought.

Our understanding of "Lyme disease" expanded to allow for the fact that it could be chronic, multi-systemic, progressive, treatment-resistant and ultimately devastating for the patient.

Recent research has increasingly indicated that *Borrelia* comes in a variety of forms, and that it is often accompanied by other infections such as ehrlichiosis, babesiosis and bartonellosis that may have been delivered by the same vector. Furthermore, evidence seems to be mounting that strongly suggests a synergistic interaction between *Borrelia* and these other infections that may make symptoms far worse.

Even the most conservative of
Number 33

doctors now grudgingly acknowledge that *Borrelia* is difficult to reliably detect in patients. It appears that the coinfections may be equally difficult to observe and identify with current technology. There is also evidence that there may be a neurotoxin component to this, as well as a possible autoimmune aspect to the illness. This makes specific diagnosis and successful treatment of the overall illness difficult, analogous to trying to fight an unknown number of enemies who are armed with unknown weapons while you are blindfolded.

We have been concerned that the term "Lyme disease" is believed by the majority of the medical profession and the health insurance industry to mean a simple *Borrelia burgdorferi* infection that can be reliably detected and then treated with 3 weeks of oral antibiotics. Discussion has centered on coming up with a new name for the illness to reflect our increased understanding of its complex nature, a major goal being to distance the true illness from the narrow definition that Dr. Steere and the health insurance industries apply to it. But walking away from the name Lyme disease while we still cannot reliably identify the various components of the illness as they manifest in different patients may only serve to split the community and confuse the issue still more.

Lyme disease has not changed since the name was first coined, named after the town in Connecticut where a housewife named Polly Murray called attention to the first cases. Our understanding of the illness has evolved. Lyme disease is still a complex illness, caused by varying combinations of pathogens that may or may not have been

delivered to the patient by the same vector at the same time. *Borrelia* seems to be the common factor, and is often accompanied - and complicated - by Ehrlichia, Babesia, Bartonella and possibly autoimmune and neurotoxin components.

Changing the name would make it too easy for less-informed doctors and health insurance companies to apply the simple-minded definition of "classic Lyme disease" to a patient's problems along with the classic simple-minded treatment while claiming that the other problems we've noted are "rare complications." The first people to see icebergs described them as large chunks of ice floating on the water, but when we learned that this only took into account 10% of the real situation, we didn't rename icebergs — we re-educated people about the size and complexity of icebergs. If we do that with Lyme disease, then there won't be room for people like Dr. Steere to continue to claim that most icebergs are small floating islands of ice.

It has taken more than 20 years, but doctors are increasingly understanding that Lyme disease is difficult to reliably diagnose and may be very difficult to treat. Instead of discarding that hard-won victory, we should expand on it. We should help to spread the knowledge that it is a disease complex determined potentially by several factors.

The name should continue to be recognizable, and if changed at all, should only be slightly expanded to reflect our increased understanding of the fact that there are so many factors involved. Therefore my vote is for calling this illness "Lyme Disease Complex," based on the #1 definition for "complex" in the American Heritage dictionary: "A whole composed of interconnected or interwoven parts: a complex of cities and suburbs; the military-industrial complex."

Mr. Strong is a regular contributor to the Lyme Times. He has had Lyme disease for at least 12 years.

Prime season to contract Lyme disease in California

by John Hall

One of the top 10 myths surrounding Lyme disease is that it is not found in California. Relying on that bit of misinformation presents a health threat that often is little publicized. The numbers of people infected with Lyme disease in California may be low - only 0.2 cases per 100,000 people, according to a U.C. Davis report -but the number represents scores of victims.

Like much else about the disease, from diagnosis to treatment, the numbers are subject to dispute and surrounded by controversy. Even if less than 100 Californians are infected with Lyme Disease each year, as stated in the UCD report, or if the number is closer to the 345 reported by the state Department of Health Services in 1990, the effects can be devastating for those infected. The national average is 6.58 cases per 100,000 people.

"I wouldn't be surprised if 30 or more people in Calaveras County have it. We know at least four people in the Glencoe area have it," said Steve Diers, an East Bay Municipal Utility District ranger/naturalist, who himself has chronic Lyme disease.

Just one case of Lyme disease was reported to the Calaveras Public Health Department in 2000, said Linda Parker, department director. The state Department of Health requires cases of Lyme disease be reported within seven days of diagnosis. But there are a number of reasons why some cases may not be reported to county

health departments, Parker said. Among them is the fact that reports are filed in the county in which the diagnosis is made. So if a Calaveras resident, whose physician is in Amador County, were diagnosed with Lyme disease, it would be reported to Amador's health department, not the department in Calaveras County.

Another reason may be that doctors are not complying with the reporting requirements. Or, Lyme

simply is not being diagnosed.

A ticks' life

Long thought to be confined to black-legged ticks - also known as deer ticks - on the East Coast, *Borrelia burgdorferi*, the cork-screw shaped bacterium that causes Lyme disease, is also carried by the Western blacklegged tick. The Western blacklegged tick has been reported in 56 of California's 58 counties. It is most commonly found in the humid coastal areas and on the western slopes of the Sierra Nevada mountain range.

Ticks feed just three times in their two- to three-year life cycle. As

larvae, they take a blood meal in order to molt and become nymphs. They take a blood meal again as nymphs to become adults. Then they take a final blood meal as adults. This is particularly important for the females because they need this meal in order to produce eggs. After she lays her eggs, the female dies. The eggs hatch and the larvae re-start the cycle.

Most cases of Lyme disease are the result of tick exposures in March through July when nymphs, or immature ticks, are most active and people spend more time outdoors. Forestry, agriculture and ranching are high-risk occupations for tick exposure. Individuals with high risk of contact with ticks include biologists, forest, park and game rangers,

The California Dept. of Health Services (DHS) has just produced a new brochure. Copies may be obtained by calling 916-324-3738. The complete brochure may be viewed and downloaded (as PDF file) from the DHS website at <http://www.dhs.ca.gov/ps/dcdc/dish/>

- Ixodes pacificus* found and tested positive for *Borrelia burgdorferi*, the Lyme disease agent (41 counties)**
- Ixodes pacificus* found (14 counties)**
- Ixodes pacificus* not found to date (3 counties)**

The western black-legged tick (*Ixodes pacificus*) has been found in 55 of 58 counties to date. The map generalizes available data, and patterns may vary within counties.

Lyme Disease in California

- Ixodes pacificus* found and tested positive for *Borrelia burgdorferi*, the Lyme disease agent (41 counties)**
- Ixodes pacificus* found (14 counties)**
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The western black-legged tick (*Ixodes pacificus*) has been found in 55 of 58 counties to date. The map generalizes available data, and patterns may vary within counties.

surveyors, woodcutters, gardeners, cross-country runners, hikers, campers, hunters, and trail builders and users. Children are a particularly high-risk group because they play outdoors.

The nymphs are often found in moist leaf litter in oak woodlands, madrone and redwood forests, mixed chaparral, and fir needle duff. Nymph ticks may account for two-thirds to three-quarters of all Lyme disease transmission, according to Robert Lane, professor of Parasitology and tick biology at the University of California, Berkeley. Because nymphs are more likely to feed on people, and are less likely to be noticed because they are tiny, they have the time necessary to feed and transmit the bacteria, typically after feeding for two or more days. Less than 2 mm in diameter, a Western blacklegged tick nymph is about the size of a poppy seed, or the period at the end of this sentence.

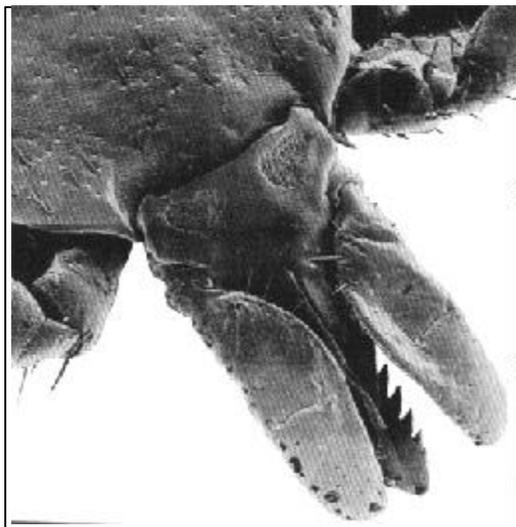
Adult ticks also can transmit the bacteria, but adult ticks are larger. They are more likely to be noticed and removed from a person's body, and are less likely to have sufficient time to transmit the bacteria. Although adult ticks are active from October through June, they are most active during the cooler, more humid months of the year, particularly December through February, when people spend less time outdoors or wear additional clothing that may provide added protection. Adults are found along trails, with 80 to 90 percent of them found on the up-hill sides of trails in shaded, moist north-facing environs.

Ticks do not fly, jump or drop from trees or brush. They wait, or quest, on low vegetation or grass about knee height, 24 to 26 inches, above the ground. They will wait for months, if necessary, for an animal or human to brush past them, allowing them to transfer to the host.

Ticks can attach to any part of the human body, but are often found in hard-to-see and hairy areas such as the groin, armpits and scalp. Many

believe ticks must be attached for 48 hours or more before the bacteria are transmitted from their guts. However, a new strain of *Borrelia* is found in the ticks' saliva, allowing a much shorter transfer time.

In addition to Lyme disease, the Western blacklegged tick is also a carrier of Colorado tick fever, human granulocytic and monocytic ehrlichiosis, *Bartonella henselae*, Rocky Mountain spotted fever, tularemia and Babesiosis. The bite of one tick can infect the victim with one



Close-up of tick mouthparts

or more, or any combination of these diseases.

Prevention is best medicine

The best, and least costly, treatment for tick-borne disease is prevention. Individuals should dress appropriately. For instance, they can reduce exposure by not wearing shorts in tick habitat. It's also a good idea to pull socks over your pants, tuck pants into your boots and tuck your shirt into your pants. Wear a hat. Also, wear light colored clothing so ticks can be seen more easily. Apply Permanone (0.5 percent Permethrine) to clothing to repel or kill ticks. Apply insect repellents containing 25 percent or less of DEET on the exposed skin of adults, 10 percent on children. People should conduct tick checks on themselves and their children frequently.

Environmental precautions also should be taken. These include removing brush from along trails or other areas of high activity, mowing grass along trails, and from around buildings and camping areas, and checking pets for ticks.

Removing a tick

An embedded tick must be removed as soon as possible to reduce the risk of disease transmission. However, it also must be done carefully so parts of the tick are not left in the skin and the contents of its gut are not injected into the bite victim. Using either a tick-removal device, such as a Pro-Tick Remedy or a Ticked Off, or a fine-point tweezers, place the tips of tweezers or the edges of other removal devices around the area where the mouthparts enter the skin. With a steady slow motion, extract the tick by pulling it away from the skin or sliding the removal device along the skin. Do not jerk, crush, squeeze, twist or puncture the tick.

Do not coat the tick with Vaseline or other greasy substances, nor hold cigarettes or other hot objects to it. These actions could cause the tick to regurgitate the contents of its gut into the bite victim. Do not handle ticks with uncovered fingers unless absolutely unavoidable. If fingers must be used, protect them with rubber gloves, plastic or even a tissue. Following extraction, disinfect the area around the bite site.

If the tick is to be tested for disease, place it in a sealed bag or vial - with a label noting the date and bite victim's name - with a lightly moistened paper towel or piece of cotton, and send it to a reliable laboratory.

This is the first in a series of articles concerning Lyme disease published in the Calaveras Enterprise, San Andreas, California. Contact John Hall at jhall@calaverasenterprise.com

Caveat Emptor

The Computer Probe Analyzer and Other Medical Frauds

by Tom Grier

About five years ago I gave a talk on Lyme disease in Virginia Minnesota. (Virginia is right in the heart of the famous Mesabi Iron Range in Northern Minnesota.) Afterwards, a very excited woman approached me, and was very anxious to tell me that she had finally without any question confirmed that she had active Lyme disease. Further more, she was able to tell me that her infection was mostly situated in her spleen!

Being very curious at this last detail I asked how she knew that the infection was specifically in her spleen? I expected an answer like her liver and spleen were enlarged and tender, or she had a biopsy and culture done, but what she said was quite disturbing.

She explained about seeing a homeopathic healer who specialized in Naturopathy. This practitioner had the patient fill out a questionnaire and then asked the nature of the visit or complaint. After this was done there would be a cursory physical exam.

The patient went on to tell me how she was led to a computer in another room. She was told to stand with her hands out to her sides and to hold a metal probe in one hand that was attached by a wire to the "health-body analyzer computer". As the patient stood there, the practitioner would wave a second probe over the organs of the body.

On the computer screen there would be a read out of fairly innocuous things like: "There is a small but benign lesion on the left ovary. There is a fibrous mass on the sternum. There is a healed greenstick fracture of the second right rib, etc." This would continue until finally the

computer displayed a blinking red light and made a warning beep. Then the read-out on the computer would display something like: "SPIRO-CHETES DETECTED IN THE SPLEEN. LYME DISEASE DETECTED!"

This of course confirmed what the patient wanted to hear and it was indisputable! After all a computer had made the diagnosis!

This story would be disturbing if I had only heard it just once, but I subsequently heard of three more patients from the same area all going to this practitioner, all with similar results. These patients were educated, seemingly intelligent men and woman of varying ages. One patient was even in college to study physical therapy, yet he seemed to be taken in just as easily as the others. Only one of the patients was even slightly skeptical.

Desperate patients seek desperate measures

This machine of course is a total fraud. No computer can probe the human body and then print out a chart of all of the diseases and ailments that a patient. This is just science fiction. The con-artists merely program into the machine exactly word for word what they want it to say. Similar machines have been debunked over the years and have been found to be made from parts of old computers that can be obtained used for under \$100.

If the patient had come with a history of heart disease the machine would have detected the heart disease, but treating something as well-defined and serious as heart

disease would almost certainly lead to legal problems, so the con-artist will also detect a second but less well defined malady like, "Body-Fatigue" and prescribe a course of natural treatments. This is how they make their money! They get the patient to commit to a monthly course of treatments that cost hundreds of dollars and are at best harmless supplements, and at worst potentially harmful – like hydrogen peroxide.

The treatments will vary from highly diluted homeopathic nostrums, to things like homemade "allergy drops" placed under the tongue. Other treatments can include aromatherapy, electro-magnetic massages, magnet therapy, sound therapy, light therapy, and a whole host of other questionable treatments. All of these are purposely treatments that are non-specific and non-invasive and are not available anywhere else. The treatments are unproven therapies that rely entirely on anecdotal evidence and personal testimonies.

The therapies by cons are as innocuous as they can conceive of because too many complications would mean investigations, so ultrasonic treatments and the like are often used. In most cases, regardless of the illness, there will be a course of fairly expensive herbal and vitamin treatments that are nothing more than over-priced off-the-shelf supplements.

I once bumped into a salesman at a party who told me he could get me fake Rolex watches if I ever needed them. It was his job to call on beauty centers, hair dressers, spas, chiropractors and treatment centers and sell them "customized products." These were generic vitamins, herbs and shampoos that could have custom labeling put on according to the customer's specification. They could even have their own company name if they liked. These so called custom designer products keep the consumer coming back for products that are often nothing more than

generic versions of name brand products but at twice the price. They kept the accounts active by introducing new products each month.

He was quick to brag at how their line of shampoos and vitamins were the cheapest available and could afford the highest profit margin. He said that often the bottles and labeling was worth more than the product they contained. After seeing several questionable medical devices being advertised in an entrepreneurial magazine, I wondered if there wasn't an underground market of merchandise and salesmen that made these products available nationwide.

A year later I thought I had heard the last of Lyme patients in support group seeking out these quacks, when a former Lyme patient returned to our Duluth support group. She was concerned and very scared because along with other Lyme symptoms from five years earlier, a new complication had developed. She now had a disturbing heart arrhythmias called atrial fibrillation. She was promptly referred to a doctor who put her on antibiotics and her atrial fibrillation went away.

A few months later when she was feeling much improved, she returned to the support group to tell her story. To my surprise she told us all that we were poisoning ourselves with antibiotics, and had to get off of them immediately! She was quite emphatic and very agitated that we were still pursuing medical solutions. She credited a naturopath with her complete recovery. She had been told that what she had wasn't Lyme disease but was a series of food allergies that were detected in a very "scientific" method.

This patient was told to hold a food or allergen in her right arm and

then told to extend her left arm straight out to her side. The healer then pushed down on the arm to assess strength. If the arm was weak, the patient had an allergy to the food or substance in her right hand. After that she was probed with a computer-body analyzer and then placed on a diet that included carnitine, co-enzyme Q10, acidophilus, and multi vitamins. The cost for this scientific diagnosis? Almost \$400 for her exam and a one month supply of vitamins – vitamins that she insisted were better than anything in the stores!

Since this patient had seen a different practitioner that was using

exams and procedures. Why? It appears that her "energy centers were low." How did she know this? Amazingly, she was now able to have her body computer-analyzed over the phone, without ever leaving home! Simply by moving the phone receiver over her body the homeopath 150 miles away could detect energy changes in her body, and prescribe treatments. How convenient! Now as long as the patient has a VISA card, she doesn't even have to leave the house!

Here's a physics lesson. How many forms of energy are there? We can detect heat, magnetism, electromagnetic energy like light and radio waves, there are strong and weak nuclear forces, and there is gravity. So which of these "ENERGIES" does the phone receiver pick up? What energy is so easily measured that it can be transmitted via phone lines 150 miles? Please, please trust me. This is a fraud, a hoax, a sham. These people seem nice but they lack any morals at all if they can take money from the sick patients and fill their heads with this kind of hocus-pocus.

What I once thought were a few isolated cases of over-zealous believers of metaphysical mumbo-jumbo, has now become a full-fledged underground industry of medical fraud. Someone is selling these machines and somehow finding a market for them. Where are these things being marketed? As it turns out, this and several other questionable devices are advertised through entrepreneurial newsletters. "Make a \$1000 a week at home!!!" Or "Medical Miracle that the government doesn't want you to own", and that kind of thing.

Such devices are advertised in the back of magazines that cater to the

Online Resources

Some resources that are helpful to sort out fact from fraud, and are resources to report fraud when you see it are the following telephone numbers and web sites:

Untruthful medical claims for a product or service? Call the Fair Trades Commission at 1-877-382-4357 or fill out an on-line complaint form at www.ftc.gov

Do you want to report adverse side effects from a supplement, a medical treatment, or a drug? Call the Food and Drug Administration at 1-800-FDA-1088 or contact them on-line at www.fda.gov/medwatch/report/hcp.htm

Consumer Medical Health Information: either write to the Pueblo CO address or go on-line where you can down-load and print out most of the pamphlets, including information on health fraud and medical scams:

Consumer Catalogue, Pueblo, CO 81001 or on-line at www.catalog.pueblo@gsa.gov

Finally, <http://www.quackwatch.com/index.html> and <http://www.hcrc.org/>

the same type of body-analyzer machine, I realized that this is probably a wide spread type of fraud. It was only a short time later that I had seen "Prime Time" do a segment on medical fraud, and there among other dubious medical devices was the very machine that had now bilked a half a dozen Lyme patients from Northern Minnesota out of thousands of dollars.

After six years of following a stringent regimen of diet and exercise, the same patient who insisted she was cured, was still having monthly

independent spirit, and do-it-yourselfers. Eventually these devices fall into the hands of an entrepreneur who has charm, intelligence, and absolutely no scruples. If you think these people are kind and benevolent, just see how charming they are when you run out of money or question their methods.

There is of course no such thing as a computer-probe body analyzer, nor can you detect allergies by judging the strength of a person's arms. These things seem too silly to believe in, and yet desperate patients are being taken in everyday by such frauds. The only thing these dubious treatments will cure you of is bloated-wallet syndrome.

(Steere, 1989) and ophthalmologic (as cited in Fallon et al., 1995). Most often Lyme disease is described as an initial flu-like illness with sore throat, and/or stiff neck. This may or may not be accompanied by a rash. Descriptions of this rash, diagnosis and treatment can be found elsewhere (Burrascano, 1997). Illness may progress to have accompanying joint involvement, particularly of the large joints such as the knee. Other symptoms may include profound fatigue, fever, chills, malaise, anorexia, nonproductive cough, pharyngitis, testicular swelling, conjunctivitis, photophobia, periorbital edema, meningitis, cranial neuritis, radiculoneuritis, facial palsies, irritability, poor memory, concentration, emotional lability (as cited in Lane & Parker, 1989).

When Lyme Disease affects the brain: what social workers need to know

by Cynthia Onorato-Herms, MSW

Introduction

Lyme disease is currently the fastest growing infectious disease in the nation. Lyme disease illnesses have been documented in medical literature back to the early 1900's (Persing et al., 1990). It was not until the 1970's that researchers recognized the different manifestations were in fact the same disease. They dubbed this re-emergence of the disease, Lyme disease, after the town in Connecticut where researchers first studied the new outbreak of this disease. Reforestation of suburban areas has been blamed for the recent increase in Lyme disease cases (as cited in Carter, 1996).

Known as Lyme disease or Lyme borreliosis, the Centers for Disease Control (CDC) reports that there were more than 16,000 cases reported by 48 states to the CDC in 1999 (CDC, Fact Sheet: Lyme Disease).¹ Over 105,000 cases have been reported since 1982 (CDC, Fact Sheet: Lyme Disease).

Lyme disease is most prevalent in the Northeastern states from Massachusetts to Maryland; the North Central States, especially Wisconsin and Minnesota; and on the West coast, particularly northern California (CDC, Public Information Guide).

Nervous system involvement occurs in 15-40% of patients with Lyme disease.

Lyme disease has been reported in all of the continental United States and in countries around the globe. Connecticut leads the nation in the highest incidence rates reported with an average incidence of 98 out of 100,000 with some townships reporting rates in excess of 1000 per 100,000 (MMWR, 3/16/01 and CDC, Information on Lyme disease).

Lyme disease is a multi-systemic bacterial infection. The infecting agent is a spirochete, *Borrelia burgdorferi* (Bb). Most often this spirochete is transmitted to the host through the bite of an infected tick. The progression of the disease can range from an acute, self-limiting infection to one that is chronic, debilitating and refractory to treatment. Reported manifestations of Lyme disease include dermatologic, neurologic, cardiac, rheumatologic

Perhaps because the first descriptions of the reemergence of the disease were rheumatologic, other manifestations seem to have been downplayed. In Murray's book (1996) describing her struggle to have an official investigation of the illness(es) that were plaguing her family and others in her community, she expresses dismay that many of the symptoms were being downplayed, underestimated and overlooked by researchers. These symptoms were non-arthritic in nature. In patients with chronic Lyme disease it is most often the neurologic aspects of this disease that make this illness most debilitating. Moreover, many recent case studies have concluded that the clinical presentation of Lyme disease may be dominated by severe psychiatric syndromes (Barnett, Sigmund, Roelcke & Mundt, 1991; Fallon et al., 1995; Kohler, 1990; Waniek, Prohovnik, Kaufman & Dwork, 1995)

When Lyme disease affects the brain it is often referred to as Lyme neuroborreliosis or Lyme encephalopathy, although there is no one accepted name for this illness. While it has been shown that Bb can cross the blood-brain barrier and directly infect the central nervous systems and the brain (Oksi et al., 1996), the

actual pathogenesis of the neurologic involvement is not yet clearly understood (Oksi et al.). It is reported that nervous system involvement occurs in 15-40% of patients with Lyme disease (as cited in Caliendo, Kushon, & Helz, 1995).

Lyme disease has often been compared to neurosyphilis in its presentation (Fallon et al., 1995; Stein, Solvason, Biggart & Spiegel, 1996). Syphilis is also a spirochetal illness that is multi-systemic, affecting any organ or system in which blood can transport the pathogen. It can affect the patient neurologically, produce cognitive disjunction and/or manifest as mild to severe organic psychiatric illness.

Lyme disease can be a persistent, chronic illness in some patients (Asch, Danuta, Weiss, Peterson & Weinstein, 1994; Benke, Gasse, Hittmair-Delazer, & Schmutzhard, 1995; Krupp, 1991;) that can be severely debilitating (Liegner & Selman, 1992; Weder, Wiedersheim, Matter, Steck & Otto, 1987) and sometimes, though rarely, results in death (Liegner et al, 1994; Oksi et al.; Waniek, Prohovnik, Kaufman & Dwork, 1995).

For social workers dealing with chronic Lyme disease patients, and/or psychiatric patients in endemic areas it is important that workers understand the varied presentations of Lyme disease. As in any chronic illness, increasing knowledge of the disease and the way it affects the body and mind can decrease anxiety in the patient. (Kerson & Kerson, *Understanding Chronic Illness*, p. 277). Helping patients and their families understand the illness, understanding ways the worker can be more helpful to the patient and possibly helping a patient and doctor investigate a possible diagnosis for an illness that has eluded diagnosis and/or successful treatment can be immeasurably helpful to your client.

This paper will look the psychiatric manifestations of Lyme disease, reviewing several case reports in the

literature that report psychiatric manifestations as the predominant feature in the presentation of the illness. It will look at techniques used to help discern organic psychiatric illness due to Lyme disease from primary psychological illness. Other neurologic and cognitive dysfunctions associated with Lyme disease will be examined. Implications of such findings will be reviewed and practical information for the practitioner in working with the chronic Lyme disease patient will be discussed.

Psychiatric Manifestations.

As predominant or presenting symptom

Studies have indicated that

As many as 70% of Lyme disease patients report depressions lasting at least two weeks occurring at some point in their illness.

organic illness is not uncommonly missed in illnesses with psychiatric presentations (as cited in Johnson, 1984). Some organic illnesses that have psychiatric presentations are: "syphilis, AIDS, viral pneumonia, carcinomas, hypoxia, endocrinopathies, vitamin B12 or folate deficiencies, temporal lobe epilepsy, Wilson's disease, and collagen vascular diseases such as systemic lupus erthematosus."(Fallon et al, 1997). As more and more case reports are published, it seems Lyme disease needs to be added to this list.

There have been several case reports where psychiatric symptoms were the predominant, presenting and sometimes the only presenting symptom of the disease. Case Reports Stein, Solvason, Biggart and Spiegel (1996) describe a case where a 25 year old woman, diagnosed with chronic

paranoid schizophrenia, had been psychiatrically hospitalized with the following symptoms: atypical (auditory and visual) hallucinations, grand mal seizures, confusion, combativeness, delusions, sleep disorders, hypersexuality, suicide attempts, and paranoia. The patient eventually became profoundly depressed and presented in a vegetative state. Subsequent testing revealed a positive response to antibody test for Lyme disease. Prolonged antibiotic treatment eventually resolved all symptoms. She was eventually able to return to work. Ceasing antibiotic treatment quickly brought on relapse of symptoms and antibiotic therapy was re-initiated.

Caliendo, Kushon, and Helz (1995) report on a case where delirium was the predominant symptomatology for a 64-year old woman admitted to the hospital. Her symptoms included confusion, agitation, hallucinations (having conversations with angels), disoriented thought processes, irritability, poor concentration, reduced levels of consciousness and eventually heart block. After variable test results for Lyme disease and subsequent antibiotic treatment, symptoms of delirium improved and remained absent at six month follow-up.

Others have reported significant incidence of delirium in Lyme disease (as cited in Caliendo, Kushon and Helz, 1995). Pfister et al. (1993) report on a case of catatonia in Lyme disease infection in a 19-year old man. Besides intermittent stiff neck and radicular pain in one leg, this patient presented to a psychiatric hospital with "acute catatonic and paranoid symptoms including negativism, stereotyped movements, delusional ideas of persecution and acoustic hallucinations" (Pfister). He was anxious and helpless at the time of admittance. One month after antibiotic treatment for Lyme disease with supportive psychiatric medications the patient was free of all symptoms

and at three and five months follow-up there were normal neurologic and psychiatric findings.

Andrew Pachner, M.D. describes a case of obsessive/compulsive disorder in a 12-year old boy that was eventually attributed to Lyme disease (Ravin, 1991). This previously healthy boy compulsively rode a stationary bicycle, unwilling to stop for meals, school work, or any other activity. This boy lost 30 pounds and lost all interest in school, and friends. The boy had suffered, two years earlier, bouts of swollen knee that was treated with antibiotic therapy. When Pachner evaluated the boy in the psychiatric unit, he recommended treatment for Lyme disease. The boys symptoms resolved almost immediately and the boy return to a normal lifestyle. Pachner (Ravin) also describes treating a 21-year old man for Lyme disease that had a history of violent outburst, confusion and wild laughter.

Fallon, Nields, Parsons, Liebowitz and Klein (1993) describe three cases linking panic disorder, depression and mania to Bb infection. In a later report Fallon et al. (1995) describe two cases where psychiatric symptoms were the predominant symptoms in Late Lyme disease. The first case describes a woman whose symptoms included mood fluctuation "from marked agitation to severe depression accompanied by suicidal threats. Auditory hallucinations and paranoid delusions emerged along with a full manic syndrome. She became violent—Slapping her son repeatedly and breaking furniture." (Fallon et al., p.295). The second case psychiatric symptoms developed 21 months after illness onset and included irritability, panic attack, intrusive obsessional thoughts with checking, depression, mania, rapid mood swings, suicidal thought, paranoid delusions and auditory hallucinations.

Other case reports include atypical schizophrenia-like illness and cases indistinguishable from endogenous schizophrenia to be due to

Lyme disease (Barnett, Sigmund, Roelcke & Mundt, 1991). Van der Bergen, Smith and van der Zwan (1993) report a case presenting with psychotic decompensation with visual hallucinations, disorientation to time and place, and associative thinking. Fallon et al. (1997) reports that a study showed that as many as 70% of Lyme disease patients report depressions lasting at least two weeks occurring at some point in their illness. It is indeed frightening to think that there may be many people

Failure to diagnosis Lyme borreliosis early may allow the infection to progress, thus raising the risk that a treatable illness will become a chronic, debilitating one.

confined to psychiatric hospitals that may have an undiagnosed, treatable illness such as Lyme disease.

New diagnostic techniques may help

Fallon et al. (1997) describes some of the diagnostic techniques helpful in clarifying the diagnosis in some of these cases. Neuropsychological testing and SPECT (single photon emission computed tomography) and other brain imaging technologies have been extremely helpful in clarifying diagnosis (see Fallon et al, 1997), as traditional blood testing is far from conclusive and diagnosis difficult in many instances (Burrascano, 1997; Liegner, 1993, 1994). Fallon et al. (1997) also offers five considerations social workers in psychiatric settings and other practitioners may find useful in differentiating psychiatric symptoms due to Lyme disease from those of a primary psychological etiology:

1. Are there markers for non-psychiatric disease such as: "erythema migrans rash, arthralgias or arthritis, myalgias, severe headaches, increased sound or light sensitivity, paresthesias, diffuse fasciculations, cardiac conduction delay, word-finding problems, short-term memory loss, cranial neuropathies, and/or radicular or shooting pains?" (Fallon, 1997).

2. Is psychiatric disorder atypical or unusual?

3. Is there poor response to medications traditionally viewed as helpful for the particular symptoms.

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

5. Is there no history or family history of psychiatric disturbances?

Fallon suggests an organic etiology must be considered for new onset psychiatric disorders in patients over the age of 40, whose disorder is without apparent cause. Fallon, Nields, Parsons, Liebowitz and Klein stress "Failure to diagnosis Lyme borreliosis early may allow the infection to progress, thus raising the risk that a treatable illness will become a chronic, debilitating one" (1993, p263). In cases where psychiatric manifestations of Lyme disease are present, psychiatric hospitalization may be required. Treatment, however, must focus on underlying illness, while providing supportive psychiatric medications for symptomatic relief.²

Some treating clinicians (who prefer to remain anonymous) have expressed frustrations when attempting to treat the Lyme patient with severe psychiatric manifestations. They feel psychiatric hospitals are reluctant to administer the medical treatment necessary which frequently requires the use of intravenous antibiotic medications, and non-psychiatric hospitals are unwilling or unable to adequately treat the patient with severe psychiatric presentations.

Also cited as a problem is the lack of understanding about the disease in psychiatric hospitals.

The Lyme disease patient who has a major depression or other psychotic symptoms would not benefit from the more standard hospital routines established to benefit the psychiatric patient. Specifically fixed schedules, that might be irreplaceably helpful to the psychiatric patient, may be impossible for the Lyme disease patient to maintain. This creates unnecessary anxiety and stress for the patient. Lyme disease patients may incorrectly be seen as lazy or non-compliant when they stay in bed, arrive late or miss appointments, or forget to take medications. It is for these reasons that all practitioners should have a more complete understanding of the illness.

Other Neurologic and Cognitive dysfunctions

Many other medical articles have been published describing ways Lyme disease affects the brain and its functions. Scelsa, Lipton, Sander and Herskovitz (1994) found recent onset headaches in over 50% of the patients studied hospitalized with neurologic Lyme disease. Brogan, Homan, & Viccellio (1990) describe a case of progressive headache leading to grand mal seizure activity and a strokelike syndrome. Two other cases associating stroke with Lyme disease have been published in the medical literature (May & Jabbari, 1990; Uldry, Regli, & Bogousslavsky, 1987). Rosenhall, Hanner and Kaijser (1988) reported on a study finding significant incidence of *Borrelia burgdorferi* infection in patients where vertigo was the sole or major presenting symptom. Ten out of 73 patients with vertigo were found to have Lyme disease. In all 10 cases the vertigo was severe and incapacitating.

Many Lyme disease patients complain of chronic fatigue and sleep disorders. Most common sleep-related complaints among Lyme patients are difficulty initiating sleep, frequent and early waking, daytime

somnolence and fatigue (Greenberg, Ney, Scharf, Ravdin, & Hilton, 1995). Greenberg, Ney, Scharf, Ravdin, & Hilton (1995) concluded in a study comparing sleep patterns in Lyme disease patients versus healthy controls that sleep in people with Lyme disease have decreased sleep efficiency, prolonged sleep latency, and more fragmented sleep patterns that may be less restorative and lead to daytime fatigue and somnolence. These sleep disorders do not appear to be related to psychopathology

The fluctuation of deficits in patients over short spans of time suggests to Rissenberg & Chambers that the impairments are physiological rather than structural problems.

(specifically depression) or resulting from arthritic pain.

Lyme encephalopathy, primarily disturbances of memory, mood and sleep, has been commonly discussed in the Lyme disease literature. Kaplan, Meadows, Vincent, Logigian & Steere (1992) concluded that Lyme encephalopathy "is caused by CNS dysfunction and cannot be explained as a psychological response to chronic illness." Krupp et al. (1991) also found problems in memory, verbal fluency, word finding problems, impaired concentration. Rissenberg and Chambers' 1996 study supports the findings of Krupp et al. Their study very effectively elucidates the experience of neurologic Lyme patients and is summarized below.

Rissenberg and Chambers (1996) studied the neuropsychological characteristics of 49 patients with Lyme disease through comprehensive

neuropsychological testing. They found that Lyme disease patients showed deficits in directed, sustained and divided attention, planning and organization of responses, temporal ordering, verbal fluency, abstract reasoning, speed of processing and motor programming. Their study suggests that the pattern of deficits is non-focal in nature and primarily impacts attention and reasoning. The fluctuation of deficits in patients over short spans of time suggests to Rissenberg & Chambers that the impairments are physiological rather than structural problems. As supported by the findings of Kaplan, Meadows, Vincent Logigian and Steere (1992), these cognitive difficulties are not secondary to depression and anxiety.

Rissenberg and Chambers found rather depression and anxiety increase with cognitive impairment and are secondary to the impairment. Rissenberg and Chambers point out that like patients with brain injury, the Lyme disease patient might 'look fine' while experiencing extreme difficulty with very basic work, social and day to day functioning. This is a very common complaint among Lyme patients, that their disabilities are 'invisible' and others doubt the severity, extent or even the existence of their illness. Rissenberg and Chambers liken some of the cognitive problems to those seen in patients with attention deficit disorder (ADD). They, however, make the distinction that unlike patients with ADD who have attention difficulties because they have too many thoughts competing for attention, Lyme disease patients have difficulty bringing any thought into clear focus. In short, Lyme disease patients with cognitive problems have difficulty thinking.

Fallon & Nields (1994) discuss other symptoms patients with late stage Lyme disease experience. These symptoms include fluctuating symptoms of "profound fatigue, sleep disturbance, photophobia, auditory hyperacusis, extreme irritability or emotional lability, word-finding

problems, dyslexic-like errors when speaking or writing, and spatial disorientation” (Fallon & Niels, 1994, p. 1573). Fallon & Niels also reported disturbances in taste and smell and list the following atypical neurologic presentations: “blindness, progressive dementias, seizure disorders, the Tullio phenomenon, strokes, extrapyramidal disorders, amyotrophic lateral sclerosis, Guillain-Barre syndrome, and progressive demyelinating-like syndromes mimicking sclerosis” (p.1573).

Rissenberg and Chambers (1996) give examples of specific functional deficits and what impact those deficits have on the day to day functioning of Lyme disease patients. Using their example, their findings coupled with the findings of Fallon and Niels (1994) will be examined to help demonstrate how these symptoms and cognitive deficits impact the patient with neurologic Lyme disease and their implication in the treatment setting.

Photophobia - sensitivity to light.

Patients with photophobia will frequently wear sunglasses even inside buildings. They will be distracted by bright lights. Efforts should be made to accommodate the photophobic patient by dimming lights and having patient sit in a position where they are not looking directly into a light source, be that artificial or sunlight. Practitioner should not mistake the wearing of sunglasses as having some deeper psychological implication.

Auditory Hyperacusis - sensitivity to sound.

Patients with hyperacusis have measurable sensitivity to sound; hearing noises not heard by those without this condition. Sounds can actually cause pain to the patient with hyperacusis. Sounds can also cause significant distraction in thought. This symptom alone can render a person severely disabled, being essentially home-bound to avoid assault by sound. Driving becomes extremely hazardous as unexpected

sounds can distract the driver away from attention to the road. People with hyperacusis can use earplugs or hearing protectors to lessen the sound levels. Anti-convulsant medications like carbamazepine (Tegretol) can be helpful (Fallon, 1995). It is often sounds that go unnoticed by the unimpaired person, such as the sound of running water, the ticking of a clock, the vibration of rubbing hands across clothes that may lead the person with hyperacusis to loudly protest the offending sound.

This extreme sound sensitivity can make interviewing patients very difficult. Sudden sounds are distracting and can interrupt thought processes. People with hyperacusis can appear to be acting in an odd fashion, wincing and becoming distracted by things not apparent to another person. Practitioners can accommodate this sensitivity by turning off or turning down telephone ringers or beepers. Conduct interview in quiet settings. Be aware of background noises that may be distracting patient, such as vacuum cleaners, computer printers, elevator bells, white noise machines, aquarium filters and air pumps or background music. In extreme situations sounds can bring a patient to tears or cause physical illness such as vomiting or losing one’s balance. Hyperacusis can have a devastating impact on one’s home and social life as well as their work ability.

Extreme irritability and emotional lability.

This has often been described as getting enraged at incidents that would not normally cause one to get upset. For example, moving items on a table might lead a Lyme disease patient to a sudden outburst. Often patients become unrelenting in their protest to the extreme of appearing paranoid. In Lyme disease support groups patients have coined the term “Lyme rage” to label the experience. The threat of violence is possible. A patient described deliberately running

her car into a tree, and backing up and repeating the action three times over an incident she could not even recall at the time. Practitioners should not feed into these extreme behaviors, however recognizing what is occurring can be helpful in managing a situation.

Word finding problems and dyslexic-like errors when speaking or writing.

The Lyme disease patient often has problems finding the correct word for what they are attempting to express. It is much like the “tip of the tongue” experience everyone experiences from time to time. Lyme patients often find others filling in the blanks for them when they are speaking. They might also use incorrect words, such as “vacuum utensils” instead of “vacuum attachments”. They frequently explain what they mean instead of using the word they are attempting to find, such as “go get the thing that I keep my money in” instead of “go get my wallet.”

Dyslexia-like errors occur not only with numbers but with antonyms like “front” and “back” and homonyms when writing like “four” and “for”. Understanding the meaning of sentences with double negatives can also be difficult.

Spatial disorientation.

This often manifests itself in clumsiness, dropping things, walking into things, misjudging distances. This can result in many bruises, minor injuries or major injuries. This can also affect how one perceives his or her environment, being unable to comprehend all that is in their field of vision and being unable to make sense of an object or event in relation to others around it. This obviously make driving hazardous.

Attention and mental tracking difficulties.

Rissenberg and Chambers (1996) describe this as “the ability to direct and maintain one’s focus on a

particular event or idea” and/or the ability to simultaneously attend to two or more things at one time. This is most evidenced by distractibility, remembering what one just said or was just doing. Should not be mistaken for “mental blocking” when occurring in an interview. Forgetting where one put their keys is a good example of attention problems rather than memory problems. Not knowing where one’s keys are is more likely due to the fact that one was not paying sufficient attention to the action of placing down one’s keys, rather than just forgetting where they are. This also affects the ability for multi-tasking, taking notes when paying attention to what is being said, monitoring a pot on a stove while talking to another person.

Memory - retaining new information.

Rissenberg and Chambers (1996) use the examples of “a tendency to lose things, miss appointments, repeat one’s self.”

Speed of processing and motor programming.

From Rissenberg and Chambers (1996) “the ability to think and respond quickly, critical to understanding speech which occurs at a fairly constant rate” resulting in “difficulty understanding or keep up with conversations, functioning in a timely manner in day to day situations, meeting deadlines.” This may be crucial to be aware of when giving a patient direction for taking medicines. This may also impact the patient’s ability to arrive on time to appointments without getting lost.

How Social Workers Can Help

Traditional case management and husbanding of resources can be extremely useful to the Lyme disease patient. Patients that are chronically ill may need help identifying and applying for income, housing and food supports. Patients may also need help in medical insurance claims, legal matters, disability issues, etc. Supportive therapy for the patient

and sometimes significant others may be helpful. When children have Lyme disease families may need assistance advocating for special educational needs. Educating the client about the illness can help alleviate anxiety over the illness. Referrals to information sources and support groups can also be helpful.

Understanding the ability Lyme disease has to manifest psychiatrically may help elucidate a psychiatric presentation that has eluded diagnosis and/or been refractory to treatment. It is important that the worker understand, as much as possible, what the Lyme disease patient is experiencing. Validating their experiences is also essential. Chronically ill Lyme disease patients have frequently suffered many losses in their lives: loss of health - both physical and mental well-being, loss of job and/or ability to earn a income, loss of social contacts, stresses on relationships and marriages, increasing isolation. Lyme disease patients frequently complain that people continually doubt their illness and tell them, “But you look good!” when they are barely able to function. Knowing that symptoms fluctuate and that makes planning difficult is also important for the practitioner to understand. Uncertainties about diagnosis, treatment and prognosis of this illness also place a great deal of stress on the patient. Being supportive and understanding can make the world of difference to the Lyme disease patient.

Footnotes

1 It is significant to note that the number of reported cases does not represent actual cases, the definition used to qualify a disease as a reportable case of Lyme disease is a definition that is only used for surveillance purposes only. It is intended as a benchmark and used to track trends in the disease. It is not intended for clinical diagnosis purposes or to portray the actual incidence of the disease. Physicians are mandated to report cases of Lyme disease to their states. The states, in ten, report the numbers to the Centers for Disease Control. The general consensus seems to be that the surveillance defini-

tion only reflects a small portion of actual cases. It is difficult to say with any accuracy what the actual numbers are. Recent attempts to standardized blood testing for Lyme disease has sacrificed sensitivity in testing for specificity, meaning that it is now more likely that a positive Western Blot blood test represents an actual case of Lyme disease but leaves the door open for the likelihood of a greater number of false negatives. This leads to fewer reportable Lyme disease cases.

2 Dr. Fallon, in his 1995 Forum for the Harvard Mental Health Letter, suggests the following therapies for Lyme disease: Intravenous antibiotics may be needed for neurologic Lyme disease. “For sleep disturbances and neuropathic pain, low doses of the tricyclic antidepressant amitriptyline (Elavil) are helpful; for agitated depression, a tricyclic antidepressant or selective serotonin reuptake inhibitor such as sertraline (Zoloft); for attention disturbances and fatigue, bupropion (Wellbutrin), floxetine (Prozac), or a stimulant such as methylphenidate (Ritalin); for sound sensitivity and mood fluctuations, the anticonvulsant carbamazepine (Tegretol); for anxiety, clonazepam (Klonopin) or alprazolam (Xanax).”

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Can Lyme Disease Cause Psychiatric Disorders?

by Joan Arehart-Treichel

Antibodies to the bacterium that causes Lyme disease have been found in a number of psychiatric patients, suggesting that Lyme disease might trigger psychiatric illness.

Lyme disease is no small health threat to persons living in the Northeast, the Mid-Atlantic states, Wisconsin, Minnesota, and northern California. True, the first signs of its onslaught are usually no more than flulike symptoms. But it is also capable, over the long haul, of inflicting a variety of other physiological insults—say, muscle pain, arthritis, heart inflammation, severe headache, stiff neck, or facial paralysis. Now a new study adds one more malady to that list: psychiatric illness. The study was conducted by Tomáš Hájek, M.D., a psychiatry resident at the Prague Psychiatric Center in the Czech Republic, and his colleagues. It is reported in the February *American Journal of Psychiatry*.

There were several reasons that Lyme disease piqued the interest of Hájek and his colleagues. For one, Lyme disease is the most frequently recognized arthropod-borne infection of the central nervous system in Europe, as well as in the United States. Second, the bacterium that causes Lyme disease—*Borrelia burgdorferi*—belongs to the same family as does the bacterium that causes neurosyphilis. Around 1900 neurosyphilis accounted for some 10 percent to 15 percent of psychiatric hospital admissions, but because of penicillin treatment, it is now an uncommon disorder. And third, anecdotal reports have suggested that Lyme disease can lead to psychiatric consequences—say, mood changes or depression.

Hájek and his coworkers decided

to undertake a study to explore this possibility by comparing the prevalence of antibodies to *B. burgdorferi* in psychiatric patients with the prevalence in healthy comparison subjects. If a higher prevalence of such antibodies were found in the former, they reasoned, it would

Thirty-six percent of psychiatric subjects, but only 18 percent of controls, had at least one kind of antibody to B. burgdorferi. These results thus implied an association, perhaps even a causal link, between Lyme disease and psychiatric illness.

bolster the case that Lyme disease can lead to psychiatric illness. They recruited more than 900 psychiatric patients admitted to the Prague Psychiatric Center between 1995 and 1999 for their study. About a third of the patients had anxiety disorders, a third mood disorders, a quarter schizophrenia or other psychotic diseases, and the remaining subjects personality disorders, delirium, dementia, or other conditions. All of the patients agreed to have samples of their blood screened for antibodies to Lyme disease. The researchers also selected some 900 healthy subjects to serve as controls. These individuals had been recruited during the same

period for an epidemiological survey of antibodies to *B. burgdorferi* in the general population of the Czech Republic.

Blood samples from the approximately 1,800 subjects were then sent to the National Reference Laboratory for Lyme Disease of the Czech Republic. The samples were analyzed to see whether they had antibodies reacting against *B. burgdorferi*. Two different types of antibodies were scrutinized. One was IgM antibodies, which move into gear early against an infection. Another was IgG antibodies, which peak some six weeks after an infection has set in.

Hájek and his team then compared the prevalence of IgM antibodies directed against *B. burgdorferi* in the psychiatric subjects with the prevalence in the control subjects. They found that 30 percent of psychiatric subjects had IgM antibodies to the bacterium, whereas only 10 percent of controls did—a highly significant difference. They then compared the prevalence of IgG antibodies directed against *B. burgdorferi* in the psychiatric subjects with the prevalence in the control subjects. They found that 5 percent of psychiatric subjects had IgG antibodies to the bacterium, whereas only 2 percent of controls did—again, a significant difference. When they pooled these data, they found that 36 percent of psychiatric subjects, but only 18 percent of controls, had at least one kind of antibody to *B. burgdorferi*. These results thus implied an association, perhaps even a causal link, between Lyme disease and psychiatric illness.

However, Hájek and his colleagues went further to determine whether the relationship they had found was real. They matched some 500 psychiatric subjects with some 500 control subjects on the basis of age and gender—two possibly confounding factors—and compared the prevalence of antibodies to *B. burgdorferi* in the two groups. Once again, the results implied a link between Lyme disease and psychiat-

ric illness. Whereas some 33 percent of psychiatric subjects had at least one kind of antibody directed against *B. burgdorferi*, only 19 percent of controls did—a highly significant difference.

“These findings support the hypothesis that there is an association between *B. burgdorferi* infection and psychiatric morbidity,” Hájek and his team concluded in their study report. “In countries where this infection is endemic, a proportion of psychiatric inpatients may be suffering from neuropathogenic effects of *B. burgdorferi*.”

Richard Balon, M.D., a professor of psychiatry at Wayne State University School of Medicine in Detroit, worked at the Prague Psychiatric Center a number of years ago. Psychiatric News asked him to comment on the center and the quality of research done there. “It is a solid place, with a good reputation, and finally, with a group of young, enthusiastic researchers such as Hájek,” he said. Ivan Tma, M.D., Ph.D., a psychiatrist with Charles University School of Medicine in Hradec Kralove, the Czech Republic, expressed sentiments to Psychiatric News that were similar to those of Balon: “The Prague Psychiatric Center is the prestigious clinical and research center of the Czech Republic. . . . [So] I personally have no doubt about the quality of work done there.” As far as the results that Hájek and his colleagues obtained, Balon had this to say: “They are both interesting and important. Of course they need to be replicated to make sure that they are solid.” Indeed, “the results of the study are rather surprising and provocative,” Tuma opined. “I hope it will lead to replication in other parts of the world.”

Even if Lyme disease turns out to be capable of triggering psychiatric illness, of course, some important questions need to be answered. For instance, what types of psychiatric disorders can it provoke? “It would be interesting,” Balon said, “to see

the comparison of seropositive and seronegative psychiatric patients with regard to diagnosis.” Tuma made a similar comment: “Although several studies have suggested that cognitive deficit is a symptom in Lyme disease, it is not clear whether this impairment is general or relates to specific cognitive functions. It would be interesting to examine the cognitive functions in both seronegative and seropositive groups.”

Also, could early antibiotic treatment prevent Lyme disease from leading to psychiatric consequences? It would be valuable, Balon noted, “to see how patients who get early

antibiotic treatment for Lyme disease compare psychologically with those who get later treatment or none at all. That would have a bearing on decisions about early intervention.”

The study was financed by a grant from the Internal Grant Agency of the Czech Republic. The study report, “Higher Prevalence of Antibodies to Borrelia Burgdorferi in Psychiatric Patients Than in Healthy Subjects” is posted on the Web at <http://ajp.psychiatryonline.org> under the February issue. Am J Psychiatry. 2002.159;297. Reprinted by kind permission from the American Psychiatric Association.

More LDA News

Lyme Disease Association supports UMDNJ researcher with \$80,000 grant

The Lyme Disease Association (LDA), a non-profit corporation dedicated to promoting Lyme disease prevention, education and research, has contributed \$80,000 to the Foundation of UMDNJ to fund research being conducted by Steven Schutzer, MD at the UMDNJ-New Jersey Medical School.

According to President Pat Smith, after its establishment in New Jersey in 1990, the LDA became a national organization two years ago and now has thousands of members throughout the country, including five affiliates and a chapter. Through the LDA, Ms. Smith is working on a national level to promote awareness of Lyme disease and other tick-borne diseases by presenting fully accredited medical conferences for physicians, testimony to public officials, school programs for educators and seminars for businesses and the general public.

The LDA has previously funded

the work of Dr. Schutzer, which has resulted in published peer-reviewed literature articles on Lyme disease. The current grant to Dr. Schutzer will fund a genetic study related to Lyme disease.

“We have respected the work of Dr. Schutzer for many years and are very happy to be able to support him at this time,” Ms. Smith said. “We are excited about the new technologies that he will be using to assist us in solving the Lyme disease puzzle.”

Lyme disease is an infection caused by a spirochete (spiral-shaped bacterium) that is transmitted to humans by the bite of an infected tick. It is now the most common tick-transmitted infection. Over 109,000 cases have been recorded since the disease became reportable. When diagnosed early, it can be successfully treated with antibiotics and serious complications of the disease can be avoided.

“We are deeply grateful that this group of concerned New Jerseyans have taken a leadership role in the fight against Lyme disease and that they have provided this critical support for our research efforts,” said Michael Bassoff, president of the Foundation of UMDNJ. “Their financial support shows us that they believe in the work being done by Dr. Schutzer and his team and have confidence that, through more effective therapies, better treatments will someday be found for Lyme disease.”

Reported in Foundation of UMDNJ's Outlook, Spring 2002. Reprinted by permission

The LDA will award grants in varying amounts up to \$25,000 for research that could potentially lead to a cure for chronic Lyme disease. Completed forms are due by September 20, 2002. Future grants could possibly be considered at a later date.

Applications and proposal information will be reviewed by a committee including physicians. Recommendations will be made to the LDA Board of Directors, which will have the final vote on the projects.

For more information contact Lymeliter@aol.com or call 888-366-6611.

A personal account

LDA President Pat Smith tours California

by Pat Smith

Speaking in California about Lyme disease was really no different than speaking on the east coast about the disease. The cast of characters was the same: the concerned patients, the unknowledgeable public, the “cautious” officials, the skeptical medical profession and the nervous few who dare to admit the disease into their medical paradigm.

Although my trip got off to a bad start when I was informed in Newark that my suitcase was overweight and I needed to repack—“Into what?” I asked with dismay, as I was handed a cardboard box—my trip improved as I touched down in California. The warmth and appreciation of the patient community who opened their hearts and homes to me was touching. Due to their generosity, I was able to travel from Carlsbad in the south to Chico in the north. They housed me, chauffeured me and fed me throughout the trip. Their stories of personal tragedy inspired me to complete the 13 days, often with two and three events scheduled each day.

The hospitality and acerbic wit of Myrna Vallejo, Lyme Disease Support Group of San Diego County, opened my “tour” where I spoke to a full house (hers) at a luncheon in southern California about what is happening nationwide with Lyme and what the LDA hopes to accomplish by aligning with other organizations nationwide. I spoke with Antoinette Grewal, a productive CA activist and her daughter, who are working on the education issue in CA, and I first met Barbara Barsocchini, Vice President of our then newest affiliate, Lyme Disease Resource Center (LDRC), and Earis Korman, with whom the LDA had long communicated on Lyme issues, and who was instrumental in planning my next forum of the Orange County/LA Support meeting at St. Mary’s Medical Center in Jamaica Bay. In between talking (me), Myrna supplied me with a delicious variety of foods.

I navigated the fabled California freeways in my rental car and arrived in Marina Del Ray in time to meet two newly arrived LDA reps, Edina Gibb and Pat Loughran. That night, several

from page 1

Mid-country affiliate links east, west

The Association publishes a newsletter, *Prime Time Lyme*, whose editor is former Association President Mary McCutchan. LAGKC also produces a brochure on Lyme disease and has a hotline 913 438-LYME. Their website is at <http://community.lawrence.com/info/lymeAssociation>

LDA President Pat Smith commended the LAGKC for taking on a difficult task of educating about tick-borne illnesses in an area of the country which often refuses to recognize the existence of Lyme disease.

“This is an established group that has already accomplished significant goals. LDA salutes them for their efforts and we look forward to an effective partnership—sharing ideas and coordinating efforts,” she said in an interview with the Lyme Times.

“Welcome aboard, Kansas City,” she added.

LAGKC joins other Lyme Disease Association affiliates: The Greenwich Lyme Disease Task Force (GLDTF) in Connecticut, Lyme & Associated Diseases of the Brandywine Valley (LADBV) in Pennsylvania, Lyme Disease Network (Lymenet.org) in New Jersey, Lyme Disease Resource Center (LDRC) in California and also the Pennsylvania Chapter, Lyme Disease Association and the Manhattan Lyme Disease Support Group in New York. All have united under the LDA banner to join in the national battle against this devastating illness. Their common goals are to provide services to persons diagnosed with Lyme disease through educational campaigns, meetings and media and to promote cooperation in the Lyme disease community.

of us had dinner with a California judge and his wife who has Lyme disease. We spend many hours discussing ways to combat not only the disease but also the apathy in political and medical circles. He figures into my trip later.

The next morning we followed Barbara to St. Mary's where I spoke to a full house, including at least one physician. Three hours later, they continued plying me with questions. The judge however, had wrangled an invitation for me to an important dinner with hundreds of lawyers and several officials, with whom he was able to arrange seating. I was spirited out of St. Mary's, and I drove an hour away to the dinner. I spoke to a state and a federal official there and made several good contacts for future use by CA or the LDA.

I spent several days with Oscar-nominated actress Mary McDonnell, *Dances with Wolves*. I found Mary charming, warm, and thirsty for knowledge about Lyme disease. The LDA, with Mary's help, set up video teleconferencing from a Malibu hotel with Brian Fallon, MD, Columbia University. Mary, Barbara and I had a real time Q&A with Dr. Fallon, emphasizing the neuropsychiatric aspects of the disease. Mary had learned first hand the devastating effects of the disease from her cousin, Pat, whose husband died after a lengthy bout with Lyme.

Doctor Greg Bach, Professional Advisory Board Member for the Pennsylvania Chapter, Lyme Disease Association (PCLDA), and Jeri-Lynn Weir, Co-president PCLDA, Edina Gibb, LDA County Coordinator, and Pat Loughran had previously met with Mary to discuss the effects of Lyme disease. After my three days with Mary in California, she agreed to become a spokesperson for the Lyme Disease Association. A few days after I returned home from California, I attended the Columbia University luncheon honoring the effort of our affiliate, Greenwich Lyme Disease Task Force (GLDTF), and LDA and

our initial commitment to the endowed Lyme disease research center. Mary flew to New York to join us for the luncheon and met Dr. Brian Fallon and Dr. Carolyn Briton in person. Dr. Briton, Columbia neurologist, had given the LDA powerful video presentation for the Albany hearings.

On my last day on the southern leg of my trip, Barbara Barsocchini arranged for me to be interviewed for a TV program on Lyme disease, which continues to air, for Malibu Public



New health department brochure reveals that Lyme is found in most counties. Pat Smith travelled from southern to northern California, meeting with activists throughout the state.

Television. Barbara proved to be a delightful host and knowledgeable interviewer. Before I traveled North, I also received word that the Lyme Association of Greater Kansas was interested in coming on board as an affiliate of the LDA. I had conferenced with them and we had emailed back and forth prior to my trip. This was affiliate number five.

Flying north, I was singled out for a wand and luggage search on my flight to Palo Alto, making me cognizant of the strict procedures put in place to screen for terrorists. There was something about that episode that made me confident the government was doing its job. It also made

me continue to wonder why we had not yet developed strict screening procedures for *Borellia burgdorferi*, a terrorist of another sort, an unseen enemy slowly marching its way across the nation almost unopposed by those who are charged with stopping its carnage.

Tour of iGeneX lab in Palo Alto

The Harris were wonderful, although Dr. Harris may have some observations on the heft of my suitcase he was too polite to mention, and the tour of iGeneX Labs was elucidating, as I was able to actually see firsthand some of the tests being performed and meet those responsible for carrying them out. I was surprised at the amount of interest in the LDA and Lyme disease from iGeneX staff.

Karen Chew was my next host, and her friendliness, not to mention her penchant for fabulous cooking, was not dampened even when my suitcase knocked over her lemon tree. She introduced me to someone whose avocation, I believe, makes her a valuable ally to the Lyme community. Karen drove me to the lovely Sacramento Valley, home to the meeting of the California Lyme Disease Advisory Committee (LDAC) where I was able to finally put faces to the names of many Lyme activists whom I had communicated with over the years and who are doing a great job in California, including Peg Leonard and Nancy Brown. The judge I mentioned earlier showed up to hear me speak, but unfortunately, had to catch a plane before that happened at the end of the day.

Since the council limits speaking time, most patients banded together and gave me their time to speak. Chairman Bob Lane started adding up times as he called upon patient after patient who said "I give up my time to Pat Smith." It brought tears to my eyes that these patients, many who had driven for hours to get there, gave up their time for a virtual stranger. Bob agreed to give me 15

minutes, which the health department representative was not happy about. However, he pointed out I came all the way from NJ and the patients willingly gave me their time.

For me, the Committee's prior discussion was a little bit like *déjà vu*, since I had been a member and chair of the NJ Governor's Lyme Disease Advisory Council before it became, in my opinion, heavily populated with less than patient friendly reps. I commented on the pamphlet the CA Committee was developing and gave a summary of what was happening with the disease nationwide and also the measures some states were taking politically. I finished with a warning that from what I had seen on my trip to date, California was where the east coast had been 6-7 years ago, but California had an advantage – the history of the east. CA could use that experience to implement laws and policies, which could prevent thousands of patients from becoming sick and debilitated.

I believe what I said was well received, and some health department officials who attended asked for copies of the speech to be disseminated. Unfortunately, I spoke extemporaneously, but the entire event was videoed courtesy of Dr. Lynn Shepler, who agreed I could have a copy of the tape, which I am anxiously awaiting. Dr Shepler has been a continued critic of LDAC and was instrumental in helping obtain open forums.

Several activists arranged a dinner meeting after the LDAC meeting. I was delighted to meet LDRC's Lobbyist Herb Dorken and see Dr. Marilyn Barkley, University of CA, Davis, again. Dr. Barkley has performed considerable research on Lyme disease, some LDA funded. I was also pleased to meet Dr. Terese Yang, a physician who has helped so many patients in southern California. Many activists were present and it was a lively dinner exchange.

Visiting Chico Hyperbarics

Carol Martin, Danville/East Bay
Number 33

Lyme Group Leader, a dental hygienist who was successful in getting an article published on the dental implications of Lyme disease, was my next host who drove me to Chico where I finally met Mitch Hoggard, a registered pharmacist, who runs Chico Hyperbaric. The depth of his knowledge on the intracellular activity of Lyme disease left me in awe, and also made me realize the old adage, "The more you know, the more you know how little you know," certainly applied to me and my knowledge of Lyme disease. Mitch has helped many people in the chamber, and being inside his 6-person chamber put a real face for me on what many Lyme patients must do to regain some of their former health.

Mitch arranged a luncheon where I spoke to several doctors about Lyme disease. I felt they were interested but nervous, and I knew then it wasn't only the disease that had reached our western shores, but also the political winds tinged with fear of Lyme disease. Why, I wonder, do Ebola, cancer, AIDS not strike the same level of fear?

That night, Marlene Hauk, and others from the Butte County Lyme Disease Support Group, organized a wonderful forum at the Enloe Conference where I spoke again about the nationwide political implications of Lyme disease. Here I finally met Art Doherty who, I was honored to find, drove many hours to meet me. Art's cataloguing abilities on his online site and his willingness to research articles has often helped the LDA when it has had to make presentations to officials.

Carol and I went on to San Francisco where LDA's newest partner, LDRC President, Phyllis Mervine, and Dr. Ray Stricker arranged a meeting with activists in the hospital there. Dr. Robert Lull, President, San Francisco Medical Society, came to hear me speak. He has already taken an open position on Lyme at the Society meeting where Lyme is sometimes touted to be over-

hyped, and we are fortunate to have him on board.[*Ed. note: See Dr. Lull's article on page 11.*] This meeting lasted several hours and lead up to a dinner with activists including the Greenwich (CT) LD Task Force's own Karen McCartin, whom I had met before in Connecticut but not on her current home turf. At the dinner, I learned one fact from a professional that continues to confound me—she got Lyme disease in a CA desert and has the proof. Subsequently, ticks they dragged for there were also found to be infected with *Borellia*. Officials are not taking her situation seriously.

Somewhere on the trip I also learned a second fact that bothered me. I knew that Bartonella had been found in ticks in CA, but I was not aware that one of the universities was already testing patient samples and showing positive Bartonella.

Wearily, I returned to the hotel anticipating a good night's sleep before the next day's departure only to find myself yards away from one of the most spectacular fires experienced in San Francisco—the burning of portions of Cannery Row, a 5-alarm event. From my hotel window I gave a blow-by-blow radio interview of the fire. Needless to say, I slept little and felt lucky that Phyllis was able to drive me to the airport on schedule in the morning. My flight was relatively uneventful, although my suitcase left on a later plane out of Chicago so it arrived at my home a day later than me, at 6:30 am, I might add.

I felt the CA trip engendered lots of goodwill; it was positive to meet the activists there and personally interact with them. I met and spoke with many whose names are not mentioned above because of space limitations. But I thank all who helped, came, or just cheered me on from the sidelines. I came back east thinking we have made progress, we have joined hands coast to coast to stop the spread of this debilitating disease. Patients, at least, have realized that Lyme is Lyme is Lyme no matter where you find it.

Greenwich Task Force involved in multiple community education projects

by Lauren F. Brooks

The Greenwich Lyme Disease Task Force (GLDTF), a Connecticut affiliate of the Lyme Disease Association, has long enjoyed a friendly working relationship with the Greenwich Chapter of the American Red Cross. Our latest project has us working closer together than ever before on a very exciting project!

Our two organizations along with the Greenwich Department of Health Laboratory are producing Tick Removal Kits. With proper tick removal critical to avoiding infection from an infected tick, having a kit with the proper tweezers, instructions and materials will undoubtedly save many people from the perils of contracting a tick borne disease.

Our goal is twofold: one, meet the growing demand from our community for a means of proper tick removal, and two, provide kits for the Greenwich Schools to be available for field trips and in nurses' offices. The kits, which will be packaged in a custom Red Cross logo bag will retail for approximately \$15 and be available before the start of school. Our hope is that this project will some day reach a much larger audience and that kits will

be available nation wide, raising the awareness of the importance of proper tick removal.

Many thanks to the Greenwich Chapter of the American Red Cross and to the Greenwich Department of Health for your continuing support of the Greenwich Lyme Disease Task Force and our efforts to educate the public about tick-borne illness.

On Saturday, April 6 and Sunday, April 7 we participated in "Karnival for Kids" sponsored by the Greenwich Chapter of the American Red Cross. There were two days of entertainment (rides, shows, and special guests) geared to young children through grade school age. The Greenwich Police Department was on hand to finger print kids, Emergency Medical Services and the Fire Dept. showed off their trucks and ambulances. This was the second year that the GLDTF was asked to

participate. We manned our table and spent both days educating parents and kids about Tick-borne illness. It was a great audience to reach - very receptive!

For a two week period in June "Safety Town" was sponsored by the Greenwich Chapter of the American Red Cross and the Greenwich Junior League. Safety Town is a program that teaches pre-kindergartners how to safely enjoy the world around them. I gave four 1/2 hour presentations on Lyme disease to parents, over the course of two weeks, while their kids participated in safety events. Presentations were attended by 50-60 parents and were quite well received.

GLDTF, in partnership with the Greenwich Public Schools, produced a video featuring Dr. Brian Fallon and others speaking about Lyme disease and how it might be identified in the school environment. It's a very exciting project that we hope will be a model for the State of Connecticut. It addresses educator education and protocol in identifying kids at risk for Lyme disease. [See photo next page]

Lauren Brooks is Vice President for Education for the GLDTF

Below: Julia Knox and Lauren Brooks (l-r) standing by our display table.

Right: Greenwich paper covered the "Karnival for Kids."





Lemonade for Sale

Two little girls, Toni and Dana Blanchard, (L and R), twin daughters of Greenwich (CT) Lyme Disease Task Force co-president Diane Blanchard, assisted by their friend Margaux (center), daughter of GLDTF Board Member Julia Knox, decided to raise money for “children who couldn’t afford medicine” of their doctor, Charles Ray Jones (featured in *Heroes in Lyme Times* #32). Brother Gregory Blanchard and little sister Samantha Knox (right inset) helped by buying lemonade and helping set up the table. The amount raised was not reported.



Massachusetts representative & Visiting Nurses host Lyme forum

Massachusetts State Representative Michael Rodrigues and the Westport Friends of the Visiting Nurses Association of Southeastern Massachusetts sponsored a community forum on Lyme disease April 25 in Fall River Massachusetts.

Featured speakers were Lyme Disease Association President Pat Smith and Bela Matyas, MD, Medical Director of the Epidemiology Program of the Massachusetts Department of Public Health.

Dr. Matyas provided an excellent slide presentation on ticks and Lyme disease in the state. Ms. Smith discussed the overall political climate surrounding Lyme disease nationwide, the difficulty of patients obtaining treatment and other co infections.

The next day, Ms. Smith accompanied Dr. Matyas on Grand Rounds at St. Ann’s Hospital where she was able to participate in the question and answer session after Dr. Matyas presentation. Several physicians approached her after the event to ask questions about the disease.



At left: (L-R) LDA president Pat Smith; Dr. Brian Fallon; Dr. Leo Shea, clinical neuropsychologist at the Rusk Institute; Sandra Berenbaum, Clinical Social Worker; and Greenwich Dept. of Health director Caroline Baisley participate in GLDTF-sponsored educational forum. Story on page 46.

Patient Story

“Someone has to tell!”

After 15 years of misdiagnosis and absolute misery, a tormented Lyme patient finally gets her life back

by Ritchie Shoemaker, M.D.

Pharmaceutical rep Greg Lloyd could hardly believe his eyes.

He'd just watched a patient with Chronic Lyme Disease (CLD) jump off her chair and race outside to turn off her car lights. “I can't believe it,” Greg told the doc he was visiting. “Is that really the same woman who was in a wheelchair three weeks ago? And now she's running? Who'd have ever thought that a Lyme patient could get so much better so fast?”

“I'm really thrilled to see that my medication helped Janice so much!”

Ask Janice Boyce to tell you about the 15 years she spent struggling through “the sheer hell” of Chronic Lyme, and this 51-year-old wife, mother and former professional nurserywoman will begin by telling you how sad and angry she became when she couldn't find any doctors who knew how to help her.

“I got a close look at how our medical system really works, and it left me so frustrated that I just broke down and cried,” says this lifelong resident of Delmar, Delaware, while describing her agonizing odyssey as the victim of a biotoxin-caused illness that physicians failed to identify - even when she begged them to uncover the source of her ailment.

“I spent a decade and a half feeling so sick that I could barely crawl out of bed in the morning,” she recalls. “My muscles ached and my joints hurt so bad I couldn't even walk at times. My vision went blurry and I had terrible struggles with

confusion and brain fog and memory loss.”

Desperate for any kind of relief but also increasingly exhausted, Janice went from one doctor to the next in search of an accurate diagnosis. But she never did obtain the relief she sought - even though she spent thousands of dollars on doctors who told her at various times that she was suffering from “fibromyalgia” (a “pseudo nervous disorder” that has never been shown to actually exist), and “chronic fatigue syndrome” (nobody knows what causes it), and “rheumatoid arthritis” (an immune disease that lasts a lifetime) . . . and even “major depression” (a handy catch-all diagnosis that usually makes its appearance when doctors find themselves stumped for answers).

Janice took dozens of different prescription drugs for her symptoms, which were variously ascribed to these imagined ailments over the years. Yet her painful symptoms refused to go away. How could she have known that her doctors had failed to spot her ongoing CLD . . . an oversight which probably occurred after she scored a “negative” on the highly dubious and unreliable ELISA lab test, which too often gives false results in suspected cases of Lyme?

Question: Why weren't Janice's doctors savvy enough to discount the untrustworthy ELISA results and recognize a typical case of Chronic Lyme Disease at its most debilitating? And why did they refuse her

repeated requests for even a brief trial of antibiotics?

Answer: Unfortunately, most physicians today don't really understand the physiology of biotoxin-based illnesses such as CLD, because they don't really understand how organic poisons such as those spawned by the Lyme bacterium can continue to make people sick, by traveling outside the bloodstream long after the bacteria themselves have died.

With her illness undiagnosed and her symptoms unrelieved, the valiant Janice Boyce did her best to function as a wife and mother in spite of her physical misery. Hollow-eyed and teetering on the verge of collapse, she dragged herself through the days and then lay sleepless through many of the nights.

Her case underlines the crucial importance of recognizing that chronic symptoms which involve muscle, nerve, brain, sinus, eye, lung, joints, GI tract and skin are often the products of a “neurotoxin syndrome” - a predictable sequence of physical ailments triggered by nerve-damaging biotoxins that migrate from cell to cell inside the body.

Although few American physicians realize it yet, the neurotoxins that attacked Janice are part of a group of new, emerging diseases triggered by changes in our environment. These new illnesses, often spread by toxin-manufacturing organisms, are sometimes linked to mutations caused by pollution; others are the result of changes in our lifestyles.

Make no mistake: These new families of “neurotoxin-mediated” diseases are here to stay, as our increasingly stressed environment reels beneath the impact of the more than 60,000 industrial and agricultural chemicals now being used in the West each day.

As recent research has shown, these toxin-spawning organisms take different forms in different regions of

the world. Among the major culprits today are toxin-forming dinoflagellate microorganisms (such as *Pfiesteria*), which increasingly occupy estuaries; indoor fungi (such as *Stachybotrys*), which can cause Sick Building Syndrome; blue-green algae of the kind that cause microcystis and cylindrospermopsis (with the latter organism now attacking many lakes in central Florida), and even a group of malaria-like “apicomplexan” organisms, one of which, *Babesia*, sometimes co-exists with CLD in the same patient.

Although the disease agents vary, the symptoms produced by neurotoxin-mediated illnesses are predictably present. They include chronic fatigue, headache, muscle aches, blurred vision, joint-pain, sensitivity to bright lights, abdominal cramps, confusion, memory loss and “skin-tingling.” These symptoms change from day to day, but no day is ever entirely free of them.

At the root of all of these symptoms is a similar grouping shared by each of the small toxic molecules that helps it dissolve in human fatty tissue. Once dissolved, the molecules set off the manufacture of some exotic compounds known as “pro-inflammatory cytokines.” These powerful substances bear names such as “TNF alpha” and “IL-1B.” But the nomenclature matters less than the biochemistry, when it comes to cytokines; the key thing to remember is that these organic compounds pack a terrific punch, which results in all those muscle aches, headaches and swollen, throbbing joints.

There’s no doubt that the cytokines are major players in the development of neurotoxin-related symptoms of the kind that tormented

Janice so. But how do you measure molecular agents invisible to the naked eye? Until recently, confirming the presence of neurotoxins required the pinpointing of their deleterious effects on blood flow in capillaries along the neural rim of the optic nerve head - a hugely complex process involving the use of a \$50,000 laser Doppler machine, which can document improvement in blood flow after treatment.

Is it any wonder that patients such as Janice Boyce went undiagnosed?



A happy Janet Boyce: one of Dr. Shoemaker's success stories.

Happily for her and many other Lyme patients, however, another key biomarker has recently entered upon the scene. Known as the “Visual Contrast Sensitivity Test,” this five-minute assay measures the brain’s ability to register visual contrast. The VCS Test is inexpensive, portable, and reproducibly reliable . . . and rarely if ever produces the “false positives” associated with ELISA and other such CDC-approved blood tests.

For the struggling Janice, a quick VCS Test was all it took to confirm the presence of neurotoxin-mediated illness - a finding which then allowed

her clinicians to quickly zero in on the Lyme toxins that were making her so miserable.

Suddenly, this exhausted patient had obtained the one thing she wanted most in life: an accurate diagnosis of her CLD.

The rest, as they say, is history. Once she knew what she had, Janice could take steps to fight it. In her case, that meant launching a regimen of daily antibiotics, in order to wipe out the Lyme bacteria and thus remove the physiological burden of additional toxins . . . followed by daily doses of a powerfully effective neurotoxin-binding medication, known as cholestyramine (CSM), according to a patented protocol.

So far, so good. But in order to win the battle against this tenacious bug, Janice had to weather two different reactions to her medications. First she confronted the unpleasant “Herxheimer Reaction,” which occurs in many neurotoxin patients when antibiotics are targeted at the microorganism producing the poisons.

Brave as always, Janice hung on through the “Herx” - and then got walloped with a second physiological response to this treatment: the dreaded “Intensification Reaction,” which occurs in about 30 percent of CLD patients who are treated with CSM, alone. Once again, Janice was forced to endure discomfort so sharp that it actually put her into a wheelchair for a few days, after her TNF-levels went sky-high.

But then her CSM treatment protocol kicked in. By taking a medication that Eastern Shore pharmaceutical rep Greg Lloyd often details to physicians (“pioglitazone,” AKA “pio”), Janice was able to turn off the “cytokine storm” caused by

the treatment and return to feeling good again.

In only three days, she felt “good as new.” And within two months or so, she felt even better . . . because the combination of the pio with the CSM and a special no-amylose diet for this situation resulted in her losing 25 pounds of fat - while shedding four inches from both her hips and her waist!

These days, Janice Boyce says she’s “never felt better” in her entire life. Only a few days ago, she catered a dinner for 100 guests, then finished wallpapering an entire floor in her recently remodeled home. She also says she can’t wait to start shopping for her (much smaller-sized) Christmas clothes.

She’s got some scars, of course. Her short-term memory still isn’t up to speed, and her joints still creak a bit in

the early mornings. And yes, she does feel just a tad bitter. (And why not? After all, the failure to correctly diagnose and treat her illness cost her dearly over the years.)

Still, the important thing is that she’s got her life back. She’s walking in the sun again! “From here on, I’m going to enjoy each day to the fullest,” she will tell you with a delighted laugh. “And I also want to get the word out.

“Somebody has to tell the world the truth about Lyme and neurotoxin illnesses and VCS testing and all the rest. I hope my story will help someone else start feeling better soon.”

See Dr. Shoemaker's article "Lyme, an Infectious Disease and a Neurotoxic Illness," under Medical Hypotheses, on page 12.

tactic to delay or prevent passage of the bill, which strengthens the Lyme Disease Advisory Committee (LDAC), a committee created in 1999 to oversee and direct the DHS Lyme disease education program. Vector Borne Disease Chief Vicky Kramer, who sits on LDAC, had requested the budget analysis, which included two extra staff positions to deal with the workload created by the bill. She also met with Joyce Isiri, Chief Legislative Counsel for the Appropriations Committee. Patient activists have tried to persuade Committee members that the bill would require no appropriation.

SB 2097 provides for nine members on the Lyme Disease Advisory Committee (LDAC); the original legislation (SB1115) called for only five, however DHS Director Dr. Diane Bonta appointed the extra four soon after the committee started to meet. Those extra costs were absorbed by the department and, according to the LDRC, should not be attributed to SB2097, since the extra members have been on board for some time. In cost-cutting negotiations with DHS representatives, the proposed reporting committee of five members was deleted and became instead a subcommittee of the LDAC. Proponents further reduced potential costs by amending the bill to no longer provide for expense reimbursements for members of LDAC, except for hardship cases. The Lyme Disease Resource Center offered to pay the expenses of its own representative.

SB2097 provides for 3-year rotating terms to add stability and permanence to LDAC. It preserves the position of two UC scientists who already serve, and preserves the patient representation on LDAC at its current level. The only new member under SB2097 is the second CMA physician from Southern California.

SB2097 will now be heard by the entire Assembly, where it is expected to be on the consent calendar once again.

Earlier this year, LDAC member

Regional News

California Lyme Bill passes Assembly on consent

Patient activists waited anxiously to hear from Lyme Disease Resource Center lobbyist Herb Dorken, PhD, about the outcome of the August 7 Assembly Appropriations hearing where, contrary to expectations, their bill was placed on the consent calendar at the last minute. Several days of activity preceded the hearing as patients faxed and emailed the 24 Appropriation Committee members in support of the bill, SB2097.

SB 2097 was passed on consent 39-0 by the California Senate on May 28, after being introduced by Senator Ortiz and unanimously passed with bipartisan support by the Senate Health and Human Services Committee. It was then referred to and passed on consent by the Assembly Health Committee on June 18. Proponents hoped that it would quickly pass in

Assembly Appropriations, however Department of Health Services (DHS) presented a budgetary impact analysis which estimated the fiscal impact to the department as \$153,426, well over the \$50,000 limit currently in effect in California due to the State’s \$24 billion budget deficit. If Appropriations Committee members believed the estimate was accurate, that would have been sufficient reason for them to place the bill on suspense, according to LDRC lobbyist Dr. Herbert Dorken. Instead, just as the Lyme Times went to press, Dorken reported that SB2097 had passed. He and others who had traveled to Sacramento to testify found that they did not need to say anything.

Proponents believe the DHS budget was deliberately inflated as a

and Lyme patient Chris Parlier and Dorken were instrumental in getting language favorable to Lyme patients included in another bill, AB2125. This bill would recognize Lyme disease,

among other diseases, under Workers' Compensation as a job injury for certain peace officers employed by the State.

and environmental experts, along with members of the public. Governor Almond also noted that with the Commission's recommendations, he looks forward to taking additional steps to protect the health of Rhode Islanders.

from page 1

Rhode Island Bill passes

antibiotic therapy for a therapeutic purpose for a patient clinically diagnosed with Lyme disease, as long as this diagnosis and treatment plan has been documented in the physician's medical record for that patient. This law defines Lyme disease beyond the CDC criteria.

In addition, after negotiations between Blue Cross/Blue Shield of Rhode Island (BC/BS of RI), Rhode Island's largest health insurer and Governor Almond's Chief of Staff, Joseph S. Larisa Jr., an agreement was reached. BC/BS of RI agreed to adopt in its policy that they may cover long term antibiotic therapy (meaning administration of oral, intramuscular or intravenous antibiotics, single or in combination, for periods of greater than four weeks) to control a patient's symptoms determined by the physician as reasonably related to Lyme disease and its

sequelae, when a physician, acting in accordance with the Lyme Disease Diagnosis and Treatment Act (R.I. Gen. Laws 5-37.5 et seq.), orders such therapy after making a thorough evaluation of the patient's symptoms, diagnostic test results, response to treatment, and physician-documented objective clinical change.

The agreement also states that neither Blue Cross nor the independent reviewer, shall contest, reverse or deny coverage based upon a physician's order of long term

antibiotic therapy solely on the ground that such treatment may be characterized as unproven, experimental, or investigational in nature. Also, during the pendency of the review, the prescribed treatment shall be covered by Blue Cross. (To read the full text of the RI law and the Blue Cross/Blue Shield of RI agreement, go to www.lymediseaseassociation.org)

First Step - the Commission

Governor Lincoln Almond, noting



Governor Almond first created a Commission and a few months later held hearings for patients, patient advocates and medical professionals.

that Rhode Islanders face a disproportionately high incidence of Lyme disease compared to other states and an increased trend toward other tick-borne infections, signed an Executive Order (01-09) on November 6th, 2001, creating the Governor's Commission on Lyme disease and Other Tick-Borne Infections. The Commission was mandated to examine the data on Lyme Disease and other tick-borne infections that lead to human disease, to hold hearings and to receive testimony from medical, public health

The panel consists of 18 members, chaired by Almond's Chief of Staff, Joseph S. Larisa, Jr. The Commission includes the Director of the Department of Health and Environmental Management, and a representative of the Coastal Resources Management Council and a member of the Rhode Island House of Representatives and a State Senator, two representatives from each category were appointed environmental advocacy groups; municipal government; University of Rhode Island Faculty with environmental tick-control expertise; practicing physicians; medical school

faculty; and individuals with experience in epidemiology and public health.

Through the Commission meetings it was decided to divide into two sub-committees. One tackled the medical aspects of tick-borne disorders and the other concentrated on the environmental aspects of tick-control. Also, two public hearings were scheduled for April,

the first hearing was held for Lyme patients and advocacy groups and the second hearing was for physician testimony.

Coalition organizing

Patients were asked to testify at an April 8th hearing at the Crowne Plaza in Warwick, regarding their history and problems that they have encountered including misdiagnosis, inappropriate treatment and insurance company denials of antibiotic therapy. Another hearing was held on April 17th at University of Rhode

Island Campus. Medical professionals from as far away as California were invited to testify on all aspects pertinent to Lyme disease, both conservative and aggressive in their standard of care. Although physicians in favor of a conservative approach to treatment submitted written testimony, they did not attend the hearing.

The Lyme Community Coalition of Rhode Island (LCCRI), with many other Lyme patients, families and friends, worked hard educating and organizing patients, advocates, wrote letters to the editor, posted flyers of hearings all over the state, posted internet notices, obtain media coverage, and lobbying of legislators throughout the process, despite the fact that most members of the Coalition suffer from chronic, debilitating Lyme disease. Neighboring activists from Massachusetts' South Coast Action Lyme Group and the national Lyme Disease Association (LDA) who had helped with the Lyme hearings in Albany also collaborated. Pat Smith, President of the LDA, gave tirelessly of herself to strongly assist LCCRI in every way throughout the whole process. She worked closely with the Governor's office to get the core physicians to testify and worked with these doctors to ensure that their testimony covered all areas about the disease and the controversy behind it. Additionally, Janice Dey of South Coast Action Lyme Group from Tiverton, RI, a Chronic Lyme patient and the mother of four children with Lyme, joined Peter Gray, a high school student also afflicted with Lyme from East Greenwich, RI, as guests on a local radio talk show about Lyme disease with host Arlene Violet.

The Hearings

Over 250 people attended the first public hearing on April 8th, with about 100 patients registered to provide testimony. LDA president Pat Smith's opening testimony gave an

overview of her organization's accomplishments in its efforts to educate officials in various states across the country about tick-borne disease. She spoke about measures the U.S. Army was taking to protect its soldiers from Lyme disease and how these measures demonstrated the Army's recognition of the seriousness of Lyme Disease. Ms. Smith then presented information,

Photo courtesy Governor Lincoln Almond's Media Office



The governor's Chief of Staff, Joseph Larisa Jr., and his sister Lisa, a Lyme patient, were instrumental in achieving passage of the Bill.

including a survey from its affiliate, Greenwich (CT) Lyme Disease Task Force, about problems with the Connecticut law, which requires health insurers there to pay for at least one month of intravenous antibiotics and two months of oral antibiotics to treat Lyme disease. The law also requires insurers to pay for longer treatment, if recommended by a board-certified rheumatologist, infectious disease specialist or neurologist. There are very few doctors who will prescribe the extended treatment. Those who do are fearful of being targeted by their state licensing board as has happened in several other states. If legislating a treatment course was to be a goal of the Commission, Ms. Smith recommended legislation that avoided placing limits on the length of treatment.

Columbia University professor Dr. Brian Fallon, director of the Lyme Disease Research Program at the NY

Psychiatric Institute, explained how he, a psychiatrist, came to be involved with Lyme disease. He said that he had a large number of psychiatric patients who were not responding to treatment, and basically he stumbled onto the explanation: persistent infection with Lyme disease. When these patients received extended treatment with antibiotics, both their mental and physical health improved. Ironically, he told the Commission, he went into the study of psychiatry because he didn't want to deal with infectious disease, but now he's found himself in the middle of it. Fallon is presently leading a major research project on chronic Lyme disease funded by the NIH.

Patient stories filled many hours. About 50 patients spoke before the Commission closed testimony at 12:30 in the morning, with the remaining allowed to submit their testimony in writing to the Commission. The last person, Virginia Burkhardt, came to testify with the help of a walker and her teenaged children. As Virginia concluded her testimony her voice cracked but was full of determination and emotion as she described how her children had to care for her during their formative years and how heartbreaking this had been for her; but when she began to get well from her aggressive treatment her children were very happy and would squeal with delight, "Mommy, you cleaned the house today! You cooked supper today! You walked to the store today!" There was not a soul who was not absolutely moved by her testimony. Virginia was indiscriminately cut off from her intravenous therapy by her insurer and afterward had regressed to her former, mostly bedridden condition. This story was clearly a call to action and a stark reminder of why the Commission was formed in the first place.

Tackling the insurance dilemma

From the answers to Chairperson Joe Larisa's questions to each person

pertaining to long-term antibiotic treatment and insurance company reimbursement, a pattern began to emerge. BC/BS of RI seemed to almost always agree to cover only one month of intravenous treatment in spite of the serious symptoms which still remained. Other health insurers were found to be less rigid, but their patients were still being denied treatment even when they are clearly benefitting from it. In all cases, patients' health worsened with this arbitrary denial of extended treatment.

Commission member Dr. Peter Brassard, formerly a physician on Block Island who had assisted LYMERix researchers with their vaccine trials, interrupted the proceedings to express his doubts about the persistence of infection and the very existence of chronic Lyme disease. He stated that he felt that chronic Lyme disease was a rare entity. At this point, Ms. Pat Smith rose and asked permission to speak. Her response: "There is a cumulative effect of having a percentage of new Lyme patients every year who, for reasons of misdiagnosis, late diagnosis, improper treatment, etc., are not cured and suffer from persistent infection. They are relegated to the population of chronic Lyme patients, which already exists from previous years. Therefore, the numbers are increasing at an alarming rate and there are high numbers of chronic Lyme patients. It is not rare." This explanation seemed to get through to some of the Commission members who had appeared to have earlier doubts. Chair Larisa asked who had chronic Lyme disease and a sea of hands were raised. By night's end, other Commission members openly admitted that they had much to learn about the seriousness of Lyme disease and had come to the hearing with inaccurate impressions about it.

Downside of Connecticut legislation

The next hearing, April 17th, opened with Karen Forschner of the Lyme Disease Foundation who told of accomplishments they are making in

the Lyme community. She then testified about the success of the Connecticut legislation. Chair Larisa extensively questioned Ms. Forschner, citing the weight of significant prior testimony to the contrary, indicating that the Connecticut law was not enabling patients to receive treatment reimbursement.

Dr. Steven Phillips, President-elect, International Lyme and Associated Diseases Society (ILADS), a doctor and researcher from Ridgefield, CT, provided reference after reference of peer-reviewed studies demonstrating the existence of a persistent infection with Lyme disease. In these studies, patients who had received extensive treatment with antibiotics were found to still be harboring the organism that causes Lyme disease, *Borrelia burgdorferi*. It has been cultured from tissues of the skin, myocardium, lymph nodes, spleen, joints, and eyes. In some of these cases, the patients were also seronegative. A physician on the Commission, Dr. Scott Hanson of Narragansett, RI, was so impressed that he asked Dr. Phillips to come to his hospital to lead a Grand Rounds.

Dr. Kenneth Liegner next presented each Commission member with a hefty folder of information. His slide show described terribly sad cases of Lyme disease. They involved patients who needed intravenous antibiotics in order to stay alive. Despite the significant improvements these patients made while on IV therapy, they were denied further treatment by their insurance companies and with all appeals exhausted, they died tragically. What made these cases even more compelling was that upon autopsy, *Borrelia burgdorferi* was cultured from the body tissues of these patients. Dr. Liegner said that

the treatment guidelines for Lyme disease of the Infectious Diseases Society of America (IDSA) were "fraudulent...The problem is chronic persistent denial of Lyme treatment, not chronic Lyme disease."

Dr. Charles Ray Jones spoke at length about the effects of the Connecticut legislation, telling how it had adversely affected his practice and adamantly asserting, "There should never be legislation to restrict the duration of treatment for Lyme disease." He explained how some defenders of the Connecticut law try to illustrate the success of that legislation by citing the fact that the number of complaints about inadequate Lyme disease treatment has gone down dramatically since the bill was passed. However, if a patient cannot get a board-certified rheumatologist, infectious disease specialist or neurologist to prescribe extended therapy beyond the maximum 90 days, the bill actually makes it impossible for that patient to file a complaint. Connecticut patients cannot ask their Attorney General to violate the law



LDA president Pat Smith, here talking with the Governor, worked with the Community Coalition and travelled to Rhode Island to testify.

and intercede for them in order to receive more treatment than what the insurance company has already provided. Under the Connecticut law, the insurance has met their obligation by providing 90 days of antibiotic treatment. Dr. Jones testified that as a pediatrician, not a specialist recog-

nized in the law, it was easier for him to get antibiotic treatment, even extended treatment, before the law was passed. Dr. Jones reiterated that any legislation proposed for Rhode Island should not restrict the duration of treatment.

Other testimonies included: David Nelson, PhD, Molecular biologist at URI, RI, who discussed in detail *Borrelia burgdorferi* in the Cyst Form; Leslie Fein, MD, Rheumatologist, NJ; Sam Donta, MD, Chief of Infectious Disease, Boston University Medical Center, on clinical aspects of Lyme Disease; Anthony Lionetti, MD, Internist NJ, about the PCR testing for Lyme Disease; Amiram Katz, MD, Neurologist, CT, Neurological aspects of Lyme. Nick Harris, PhD in immunology and anatomy, CEO of Igenex Labs, CA and Board member of ILADS spoke about the use of testing to support a Lyme disease diagnosis. The last doctor, Joseph Burrascano, testified at almost midnight. Everyone seemed energized because sitting before us was the one doctor who has been the focal point of so much controversy over chronic Lyme disease. He has authored treatment guidelines for Lyme disease, made them available at no cost, and updated them frequently. He has treated thousands of patients from all over the United States and other countries.

Dr. Burrascano related his U. S. Senate Committee testimony in 1993, and the controversy it had created in the conservative medical community by describing his success in his aggressive approach to Lyme disease, going public about his treatment protocol to the highest level of government and facing harassment ever since. He concluded that the conditions he faced in 1993 have remained virtually the same today with the federal government doing little to improve conditions for patients with chronic Lyme disease. He urged the Commission to make reform a reality.

Developing the RI Bill

Subsequent to the hearings, the Commission developed and recommended RI legislation, which landed in the Committee on Energy and Environment. The LCCRI actively lobbied the joint committee and lined up patients and Pat Smith to testify. Larisa told the Joint Committee that witness after witness had testified to the Commission that late-stage Lyme disease absolutely does exist and causes serious complications for Rhode Island residents, but few doctors in Rhode Island provide aggressive long-term therapy. The goal of the legislation is to allow physicians treat patients as they see fit. Distinguished physicians from some of the best medical schools conclude that the Lyme bacteria exists past the one to two months antibiotic treatment. Larisa told the Committee he wanted Rhode Islanders to be able to be treated by their own doctors in their own communities. After Larisa's strong remarks, the bill was immediately put to a vote and unanimously approved.

With Rhode Island Lyme activists continuing to call, fax and email their legislators, the bill passed quickly through the State House and Senate by an unanimous vote on June 4, 2002 and was ready for Governor Almond's signature.

Coalition members realize that Rhode Island could not have achieved this ground-breaking victory without our Governor Lincoln Almond's support in creating a commission solely dedicated to address all issues surrounding Lyme Disease. Governor's Chief of Staff, Joseph S. Larisa Jr. took a leadership role, chairing the Commission. His strong support, dedication and perseverance moved The Lyme Disease Diagnosis and Treatment Act through to its passage. Larisa's negotiations with BC/BS of RI resulted in an agreement to allow antibiotic therapy past 4 weeks. We owe both Governor Almond and Chief of Staff Joseph S. Larisa Jr. an

enormous amount of thanks and gratitude. We again would like to strongly acknowledge Pat Smith, President of the Lyme Disease Association, LDA for her tremendous contribution she made in bringing about such a victorious outcome. We also want to thank the RI Department of Health for drafting the legislation under the guidance of Patricia Nolan, MD Director of Health, and member of the Governor's Lyme Commission. We applaud the members of the Governor's Commission on Lyme Disease and other Tick-Borne Infections for sacrificing many hours in order to gather adequate information to make objective recommendations relating to this serious issue. We would also like to thank Sponsor/Vice Chairperson of the Joint Committee on Energy and Environment, State Senator Susan Sosnowski and Co-Sponsor/Chairperson of the Joint Committee on Energy and Environment State Representative Peter T. Ginaitt, both members of the Governor's Commission, who helped ensure that this legislation past Rhode Islands General Assembly. Our profound thanks go to the many Lyme patients, Lyme-literate physicians, Lyme medical researchers, and to Lyme advocacy groups from all over the United States who had taken time out of their busy lives to provide testimony, data, reports and other information in order to clearly illustrate the truth about Lyme disease. Rhode Island could or would not have achieved such a triumphant outcome without such a united effort.

Rhode Island ranks second in the nation for number of reported cases of Lyme disease per capita. Given the statistics, the passage of this law represents the enormity of impact this has for the state of RI. We hope it will serve as a precedent for other states throughout the country. Rhode Island looks forward to your adopting this Law and will assist you in any way it can.

Members of the Lyme Community Coalition of Rhode Island collaborated on this report.

from page 1

ICLB protest planned

20-21) and will feature a poster display and several lectures. The focus is on the clinical side of Lyme disease, according to organizers. A Lyme Times supplement containing rejected abstracts is being printed and will be distributed.

Patient activists also plan a demonstration and news conference.

According to New York organizer Ellen Lubarsky, a member of the activist group named "Voices of Lyme," they want to focus on what is lost to science when clinical doctors who treat Lyme disease are marginalized and excluded. She sees the problem as a split between academic and clinical medicine.

"Organizers of ICLB have excluded presentations by 'frontline' clinicians who most often treat chronic Lyme disease," she said, "and this conference is the poorer for it."

"We [patients] have information. We will tell you what works and what doesn't," added co-organizer Eva Haughie of Long Island. "Attendees are deprived of the most important information of all: the experience of patients treated for Lyme disease."

VOL demonstration co-organizer Jeannine der Bedrosian of New Jersey called attention to a paragraph from the NIH consensus development conference planning:

"To prevent the appearance of bias, no planning committee members, except for the panel chairperson, may serve on the panel. Planning committee members may serve as speakers at

the CDC. Disclosure of scientific bias and commercial conflicts of interest is requested of planning committee members for the record."

"I would like to see the 'record' for the IX ICLB," she said.

Patients are not the only ones to complain about one-sided presenta-

evidence that does not support their view of Lyme disease, and to silence their critics," stated one doctor who did not want to be named. A European physician wrote: "This selective acceptance does not make sense and must be publicly denounced."

The International Conference has traditionally been a forum not only for researchers from academic centers, but also for clinical practitioners and patient advocates. Before the 1992 ICLB in Arlington, Virginia, both scientists and patients raised vocal

objections, saying that certain papers were rejected for being politically incorrect. The abstracts were belatedly included in the program. That ICLB was funded in part by the CDC and NIH, however.

In the past, public funding ensured broad participation. In contrast, this year's ICLB is privately funded by corporate entities, one which is currently the defendant in a class action lawsuit, giving the appearance of conflict of interest, according to some. Many review committee members themselves have financial interests in test kits, gene patents, and other products. They were asked to recuse themselves from reviewing any paper where they perceived a conflict of interest, but no disclosures were required.

In the Rejected Abstract booklet, publisher Phyllis

Mervine makes a call for a multi-discipline patient, physician, and scientist committee including both sides of the debate for future ICLBs, and for full disclosure of all financial relationships bearing on Lyme and other tick-borne diseases.

Voices of Lyme Statement

We as patients decry the exclusion of treating clinicians as an arrogant misuse of power by Conference organizers who are entrusted with the responsibility of developing a fair, balanced and honest conference which presents all facets of Lyme disease treatment and research for consideration of merit by attendees. Instead organizers have injected personal bias and subverted the conference to advance their own tenuous position that chronic Lyme disease is seen very rarely, if at all. Conference attendees are being given a one-sided presentation and are deprived of hearing the whole truth and the opportunity to draw their own conclusions and engage in dialogue which could advance the knowledge of this disease.

We object in the name of thousands of patients whose experience, whose very existence, is being denied by this bias on which the conference rests. Our medical care and our futures are jeopardized by those who refuse to acknowledge the reality of chronic, persistent Lyme disease infection that responds to extensive treatment.

tions – some scientists and physicians agree. "Instead of dialogue, we have dogma based on inadequate information," stated one doctor who did not bother to submit an abstract, believing it would be rejected. Others made the same decision after looking at the make-up of the review committees. Some will not attend ICLB because of the perception of bias. "This is an attempt to suppress

Conferences

Greenwich LDTF organizes presentation to public school staff and teachers

On Wednesday, May 29 the Greenwich Lyme Disease Task Force, an affiliate of the Lyme Disease Association hosted an Educational Forum at Greenwich High for public school teachers and staff to learn more about the manifestations of

See photo on page 37

Lyme disease and to provide a protocol for teachers and staff to aid in early intervention. With

the support of Dr. Maria Melendez, Assistant Superintendent of Greenwich Public Schools and Caroline Baisley, Director of the Greenwich Department of Health, Greenwich educators and school nurses learned that while Lyme disease may be a short-term curable illness when diagnosed early and treated appropriately, a late diagnosis can lead to chronic neuropsychological problems which manifest in school as long-term academic, social and behavioral problems.

Panel members spoke and fielded questions concerning the cognitive, social and emotional issues which can occur in children with Lyme disease. Panelists included keynote speaker, Dr. Brian Fallon; Patricia Smith of the Lyme Disease Association; Dr. Leo Shea, clinical neuropsychologist with the Rusk Institute of Rehabilitation; Sandra Berenbaum, clinical social worker with the Family Connections Center for Counseling; and Caroline Calderone Baisley, the Director of Health for the Greenwich Health Department. The presentation was professionally videotaped, and will be available to other school districts/private schools who are interested in learning about how to help students

suffering with Lyme disease in the classroom and in developing a protocol for their teachers and staff in early intervention in cases of potential Lyme disease.

After an introduction from Sandra Waters, Chairperson, Greenwich Board of Education, Pat Smith opened her remarks with the importance of educating teachers about Lyme

“The sensitivity of the Lyme antibody tests at 3 of the best labs in the country are only 56%- 80% accurate.”

Brian Fallon, MD

disease. She commented that nine out of ten diagnosed cases of Lyme disease continue to remain unreported according to the CDC.

Keynote speaker, Dr. Brian Fallon, presented three atypical Lyme case studies which highlighted the severity, the pervasiveness, and the longevity of this illness in some cases. Dr. Fallon is the director of the Lyme Disease Research Program and an Associate Professor, Department of Psychiatry at Columbia University College of Physicians and Surgeons in New York City. He discussed the psychiatric symptoms which more than three-quarters of the pediatric Lyme patients in his study did manifest – mood swings, personality

changes and aggressive outbursts. He emphasized the typical physical symptoms of headaches, fatigue, and muscle and joint pains, along with light and/or sound sensitivity. As a result, many of these children might act in a bizarre manner in the school cafeteria, which is typically a noisy environment. He also noted that Lyme blood testing can be helpful, but not definitive in diagnosis, as the sensitivity of the Lyme antibody tests at 3 of the best labs in the country are only 56%- 80% accurate. And, because of the pattern of fluctuation and nature of Lyme symptoms and diverse manifestations of this disease, the average patient may see at least 4 doctors over a period of one year *before* receiving a Lyme diagnosis.

Sandy Berenbaum emphasized the important role of teachers and staff to be “keen observers and good detectives”. She presented a list of Lyme disease symptoms, which teachers, school nurses and guidance counselors may observe. Symptoms include moodiness, depression and anxiety; withdrawal from peers; behavioral problems; gastrointestinal problems; attention problems; poor concentration and memory, attendance problems and declining/ inconsistent school performance. She discussed a three-stage system of Lyme supports ranging from educational supports to a section 504 plan to special education classification for those students suffering from Lyme. With the proper diagnosis and school support, it is possible to avoid out-of-school placement. Sandy recommended a protocol for teachers, social workers and guidance counselors to follow where they suspect that Lyme disease may be a factor in a student’s presentation. Caroline Baisley described a protocol to be followed by school personnel when a student is identified at risk for Lyme disease. The protocol includes forms, checklists, close contact with the school nurse, and team meetings which would lead to the school nurse

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alerting parents as to the school's concerns.

In a Lyme-endemic community such as ours, this educational forum established a first-step in enabling educators to recognize manifestations of Lyme disease in order to help identify students with undiagnosed Lyme disease, and to aid students with existing disease. Enactment of the protocol will represent the second major step which is in the review process at the Greenwich School System and the Department of Health. Both departments will work closely in approving the final protocol, which will serve to oversee all students in the Greenwich Public School System. Hopefully this program will serve as a standard protocol for other school districts to review and implement throughout the state.

Number 33

For more information about Lyme disease and other tick-borne illness, please contact the GLDTF, Inc. 203-531-5090.

Due to space constraints, the report from the 2002 Lyme Disease Foundation conference will appear in the next issue of the Lyme Times. We also hope to have a report from Gettysburg.

Errata

The Winter 2001/Spring 2002 issue gave the Greenwich Lyme Disease Task Force credit for money raised for the fellowship program at Columbia to enable Dr. Jones to train medical students. The Wilton Task Force is the group that contributed to this program.

In reference to Dr. Ray Stricker's article on the LDA Conference, dentist/physician Dr. Chris Hussar specializes in head and neck pain disorders. He is not in any way affiliated with the Century Wellness Center in Reno, Nevada. He believes that antibiotics are the mainstay of treatment in any Lyme patient. The Lyme Times regrets any false impression created by our article.

Page 47

Calendar

Advanced Topics in Clinical Approaches & Environmental Issues for Lyme Disease & other Tick-borne Illnesses

**Saturday
September 14, 2002**

For more information call the Michigan Lyme Disease Association toll free at 1-888-784-5963 or email LPurdy1040@aol.com.

Speakers: Lyme Disease Foundation director Tom Forschner,

Dr. Ed Bosler, PHD Host targeted acaricidal treatments on rodents to control densities of Ixodes scapularis subadult ticks.

Dr. Sam Donta, MD - Issues in the Diagnosis & Treatment of Lyme Disease

Dr. Michael Cichon, MD - Managing IV Therapy with Lyme Disease

Representative Ruth Johnson - Michigan House of Representatives

Dr. David Blodgett, MD - Ophthalmologic Manifestations of Treating Lyme Disease

Dr. Michael Ledtke, MD - The Complexities of Treating Lyme Disease in Michigan

Dr. Joseph Burrascano, MD - Advanced Topics in Lyme Disease

Linda Lobes - President Michigan Lyme Disease Association.

If you ♥ the Lyme Times, please support us by subscribing today! See form on page 47.

Second UK Tick-borne Diseases Conference

First announcement and call for contributions

**June 21-22
St John College, York**

Following a successful first conference in Hull, 1 & 2 September 2001, the organising group agreed that further events were needed to bring together medics, researchers and patients who appear to suffer from vector-borne zoonoses. These may be diagnosed as 'Lyme disease,' but one of the aims of the conference will be to clarify the diversity and diagnoses of diseases contracted within the UK. St John College is conveniently located in the centre of historic York, UK. Basic accommodation in single study-bedrooms is available in the college, or accommodation at a range of prices and grades is readily available within a short distance. The College is disabled-friendly.

Guest speakers include New York physician Dr Burrascano; Dr Meer-Scherrer from Switzerland; Dr Marie Kroun from Denmark; Professor Roy Brown, environmental consultant with special interest in ticks and tick-borne infections.

Offers of contributions are now requested. The format of the conference is not yet fixed but will include formal papers and poster sessions. Contributions may relate to any aspect of the biology, diagnosis or medical treatment of tick-borne diseases found in Europe. The conference will be of great relevance to physicians, infectious disease specialists, bacteriologists, microbiologists, pathologists, medical researchers, veterinary surgeons,

epidemiologists, etc. Indications of interest in the conference and offers of contributions, with a title and short abstract, should be sent by 30 September 2002 to:

gilly848@ntlworld.com (plain text email preferred, but virus-free word processed documents will be accepted) OR as paper or disks to: Mrs G S Reese 4 Thorpe Leys, Lockington East Yorkshire YO25 9SP, UK

Spider Bite Study

Rick Vetter, arachnologist at University of CA Riverside, is looking for cases that fit the following criteria:

1) You were diagnosed (by a physician) as having a spider bite..and then you were diagnosed very soon after (by a physician) as actually having EM and Lyme disease.

or, and this is really where his interest lies as he is a Brown Recluse Spider expert -

2) You were diagnosed (by a physician) as having a Brown Recluse Spider bite..and then very soon after, you were diagnosed (by a physician) as actually having EM and Lyme disease.

If you fit either of these examples please contact Rick at:

vetter@mail.ucr.edu

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