Revolution in understanding bacterial diseases - page 27

Publication of the Lyme Disease Resource Center

the Lyme Times

NUMBER 27

Education, Support, Advocacy, Research

WINTER 1999

Patients are outraged over discrimination against "their" doctors

The Lyme disease community is up in arms over the recent revocation of one doctor's license and the threat of continued action against other front line Lyme clinicians. Hundreds of patients are writing and calling legislators in an effort to halt a seemingly endless series of what they view as persecutions of their best doctors.

Just before Christmas the NY State Office of Professional Medical Conduct sustained charges against Perry Orens, MD, of Great Neck, NY of gross negligence, negligence on more than one occasion; practicing fraudulently; ordering excessive tests and/or treatment; and inaccurate patient records." (OPMC, website http://www.health.state.ny.us/nysdoh/

See **Persecution** *on page 17*

Inside...

LDRC announces 1999 Distinguished Physician Award -- see page 3

Linda Finn photo

Patients protest at NIH "Astute Clinician" award ceremony

Thirty-five Lyme patients and their supporters from as far away as Michigan and Florida picketed near the Bethesda campus of the National Institutes of Health (NIH) on November 3 to draw attention to the controversy surrounding Allen Steere, MD's, guidelines on Lyme disease diagnosis and treatment. Following the demonstration, patients went to a ceremony and reception honoring Steere for being an "Astute Clinician."

Steere, who works at New England Medical Center in Boston, is credited with naming Lyme disease a quarter century ago. According to patient demonstrators, his "overdiagnosis and overtreatment" school of thought has gained such status that dissenting physicians, researchers and patients have been adversely affected. They said that patients are being turned away by physicians, denigrated publicly, and denied adequate treatment and insurance coverage. Steere and his colleagues have personally given court testimony against physicians who do not follow stringent guidelines, leading to loss of licenses to practice medicine and fear of sanctions, said patient advocates.

See **Protest** *on page 22*

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Erratum

The correct price for membership in the Lyme Disease Association of New Jersey cost $6.00. Checks and donations may be sent to LDANJ, PO Box 1438, Jackson, NJ 08527.

Letter from the Editor

Dear Readers,

It gives us great pleasure to announce that the 1999 LDRC Distinguished Physician Award has been given to Dr. Kenneth Liegner (see story opposite). A long-time patient advocate and a meticulous, caring and astute clinician, Dr. Liegner joins the ranks of Distinguished Physicians Paul Lavoie (1993), Edwin Masters (1997) and Joseph Burrascano (1998). The Distinguished Physician Award gives us an opportunity to recognize and thank those physicians who have made a great difference in the lives of many grateful patients.

As you will notice from several articles in this issue, the mood of the Lyme disease community is changing from misery and apathy to anger and activism. Reeling under the combined weights of illness, insurance and HMO woes, doctor skepticism, and now, increasingly, direct attack on their own physicians, patients have taken to the streets. Those who can't be on the front lines are writing letters and emails to their legislators and medical board members. Physicians are also starting to come together to defend themselves from the increasing strictures on their freedom to practice medicine. We are encouraged by this growing spirit.

A number of conferences and rallies are on the calendar. Please make every effort to attend to learn about the latest research. Take advantage of our bulk rate and order the Lyme Times to hand out. Nowhere else can one find so much information about the tickborne disease "scene" in one place.

On another note, let me thank all the individuals who have gone to the trouble of writing or rewriting articles especially for the Lyme Times. There are some excellent writers among us and everyone profits from their skills and willingness to contribute. The fact that the Lyme disease community is coming together in action is due in large measure to the Lyme Times and other publications which help us to maintain a feeling of interconnectedness and commonality of purpose. The internet also plays an important role, with discussion groups and many valuable websites.

> ***"It takes as much time and trouble to pull down a falsehood as to build up a truth."***
>
> Peter M. Latham 1789-1875

Keep up the good work!

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. 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 LDRC gratefully accepts tax-deductible contributions to assist its efforts.

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Lyme Disease Resource Center honors Lyme expert

by Stephan J. McLain, Ph.D.

Dr. Kenneth Liegner of Armonk, New York.

The 1999 Distinguished Physician Award, which recognizes a physician for clinical excellence, leadership, compassion, and dedication to the treatment of Lyme disease, has been awarded to Dr. Kenneth B. Liegner of Armonk, New York.

Dr. Liegner is an internist with a special interest in Lyme Borreliosis and related disorders. When he began his private practice in the mid-80s in Armonk, New York, he observed that many of his patients with evidence of Lyme disease did not fit the pattern considered typical at that time. Some patients were seronegative by currently available tests, or did not have a fully developed immune response to the Lyme organism. Some patients did not improve on the recommended short course of oral antibiotics, or relapsed after cessation of treatment. This discrepancy between the diagnostic standards and treatment protocols of the time, and what he was observing in his own patients led Dr. Liegner to question the conventional wisdom that Lyme disease is easy to diagnose and treat. By studying the literature, conferring with academic and clinical colleagues, and carefully observing his own patients, he has become one of the leading experts in Lyme disease. Sitting in Dr. Liegner's waiting room, one is likely to meet patients who have traveled a great distance to consult with him about difficult cases. He is truly a national and international resource.

Dr. Liegner is notable for the thoroughness and rigor with which he approaches the evaluation of his patients. New patient visits are scheduled to allow sufficient time for a complete physical exam, and the recording of a thorough history. He is an astute objective observer and keeps detailed written documentation of patient history and his clinical observations. Drawing on his comprehensive knowledge of tests for Lyme disease and other tick-borne diseases, he excels at obtaining objective evidence as part of the diagnostic process. He typically makes full use of the arsenal of available tests. In his treatment protocols, Dr. Liegner practices scientific evidence-based medicine relying on both the peer-reviewed medical literature and his personal contacts with other clinicians who treat difficult Lyme cases. He is at the forefront of investigating new treatment protocols in a clinical setting.

Dr. Liegner has been a forceful

advocate for patients in his public speaking engagements and regular participation in national meetings. He has attempted to "bridge the gap" that exists between academic researchers and clinicians by maintaining strong contacts with both groups, and by publishing regularly in peer-reviewed journals. His numerous publications are a remarkable achievement for a clinician with a busy private practice. His commentary article "Lyme Disease: The Sensible Pursuit Of Answers", J Clin Microbiol 1993 Aug;31(8):1961-3 is a compelling, well-documented paper arguing that the medical profession needs to consider the true complexity of this disease and the implications that complexity has on how patients should be treated. He is a coauthor of a seminal paper on the neuropsychiatric manifestations of Lyme Borreliosis. Other publications include a well documented case study of the persistence of *Borrelia burgdorferi* infection despite extended oral antibiotic treatment, and a recently published set of case studies of antibiotic responsive patients where the differential diagnosis between Lyme disease and other neurological or autoimmune diseases was exceedingly difficult.

Congratulations Dr. Liegner, and thank you for your tireless efforts on behalf of Lyme patients. From my perspective as a patient, I wish that there were many more doctors of your caliber scattered throughout Lyme country.

Letters

We do not recommend any of the doctors or treatments which may be mentioned here by writers. Patients should discuss any treatment options with their physicians. Signed letters of general interest may be printed.

Distribution of Lyme and multiple sclerosis raises suspicions

If you look at the book **Multiple Sclerosis** by Louis J. Rosner and Shelley Ross, you will see that the states with high reported cases of Lyme are the same states with the highest rates of MS-related deaths -- New Jersey and Connecticut are very high. Some states like Minnesota and Missouri reported very little Lyme but have the highest rates of MS in the country. Missouri is especially interesting in light of Dr. Masters' work and the ongoing disagreement with the CDC about Lyme in Missouri. Perhaps it is not all *Borrelia burgdorferi* but instead another spirochete transmitted by a tick in Missouri.

Since first being evaluated for MS myself, I have now communicated with over 300 people who have pursued the possibility of an untreated tickborne infection as the underlying cause of their condition. I just heard this week from a woman who was in a wheelchair prior to finding the Lyme newsgroup on the internet. After she started corresponding with me and a few other people, she demanded her neurologist (who had diagnosed MS) treat her with antibiotics to see what would happen. Today, she is out of her wheelchair.

The anecdotal evidence continues to grow, partially because the Internet allows thousands of people to converse with one another.

One of what I consider my biggest victories was with a 23-year-old woman helping me at Sears. She had very obvious partial facial paralysis; of course I could not refrain from asking her about it. She told me she had had MS since she was 15. I asked where she lived and then asked if she had ever traveled beyond her home in the city. She told me she had only left home once to go to camp in the Poconos (in Pennsylvania) the summer before she became ill. To make a long story short: her neurologist tested her for Lyme, her tests came back borderline, he referred her to a reputable Lyme doctor, she responded to treatment and her classic MS markers have disappeared.

It is stories like these that convince me that the medical community is overlooking an obvious medical discovery. Hopefully research done by the likes of Dr. Paul Ewald of Amherst will continue to gain support. He and his associates recently speculated that perhaps more diseases with "unknown" causes are actually infectious in origin. Yes, it does open the Pandora's Box of what are we going to do about that but at least then we will know what we are dealing with. This evidence must be considered by researchers with open minds who are truly interested in finding the cause of Multiple Sclerosis and other "autoimmune" diseases.

Martha Behrle
Essex Fells, New Jersey

In heart of endemic area, children are denied testing

This is like a never ending nightmare. I share your guilt over our kids having Lyme, I should have argued more with pediatrician, he claimed it's overtreated, overdiagnosed and that the kids had no symptoms (he suggested ADD). He made me feel neurotic. I told him me and hubby had Lyme, but he refused to even do a test. I know if I told him me and hubby had diabetes or heart malformation he would have tested kids. I can't understand to this day why I didn't insist on the test, after all it was just a test not intravenous drug treatment. I did find out that someone in his practice is being sued for the death of a child who was diagnosed far too late. Wouldn't you think he'd have the attitude, "Everyone in this endemic Connecticut area gets a Lyme test as part of their annual physical?". That's what I'd be saying, but no - not only will they not even test, they calmly stand in the overdiagnosed, overtreated camp. It borders on not just negligence but a severe breech in their oath of first do no harm.

One son, Greg, was misdiagnosed as having Juvenile Rheumatoid Arthritis at 6 years old, and also was told at 10 years old that he had Osgood Schlatter's disease in both of his swollen knees. Danny has had chronic hives and ear problems. After 2 years of arguing I took both boys to a LLMD [Lyme-literate doctor]. Both boys tested positive for Lyme and Greg for babesiosis, Danny for leptospirosis.

There is a saying that parents are as happy as their least happy child. In our case I believe that not only do we take on their unhappiness, but it pushes our Lyme into a more chronic state. I pray that they find a cure for this soon, but until then we will take our brews of antibiotics, herbal remedies, vitamins and any other concoction that might render us productive again. My thoughts and prayers are with you all!

Deborah Procaccini
Stamford, Connecticut

Patient seeks others trying to cope with Lyme and menopause

My health "opportunity" started in l985 and I finally found out it was Lyme in l989. Five years of antibiotics and I thought I was healed - ha ha! The new challenge is menopause. I'm having one heck of a time now in health area and finding a doctor that has a clue about those two and how they affect each other.

Are you aware of any testing or groups that are working with chronic Lyme and menopause? Have you heard from anyone in this situation? I'd love to be able to talk with others going through this themselves.

I really want to compliment you and everyone for the excellent effort in putting out the Lyme Times. It's the absolute best!

I have two e-mail addresses:
Kathieemil@aol.com and
Kathieh@Bundesen.com.

Kathie Hewko
Santa Rosa, California

Dr. Marylynn Barkley is conducting research on Lyme disease and the menstrual cycle. A report on her talk at the 1997 LDRC conference in Los Angeles appeared in the Lyme Times #19. We hope to have it on our website before too long. Dr. Barkley works at UC Davis.

Doctors ignore critical signs and symptoms

I have a 12-year old nephew in California that I had never met until last week. He has been sick for three years, suffering from joint pain, foggy thinking, skin burning, headaches, nausea, fevers, nerve pain, and twitching. He spent two months in the Stanford Hospital because he couldn't walk - his knees were swollen. He ran the gauntlet of specialists and they decided that he was a malingerer, trying to get attention. They referred him to a psychiatrist.

So he went to the psychiatrist for two years. The psychiatrist found him one of the stablest kids he had ever seen. The doctors, scrambling to find out what is really wrong with him, told him that he had fibromyalgia. My nephew went home and tried to deal with it. He was home schooled and was ostracized by friends.

So here it is three years later. I saw him last week and he was sporting two perfect bull's-eye rashes - they could be photos for the ALDF brochure. He said that they always come out just before he gets really sick. There is no question that these rashes are bull's-eyes, bright and clear.

So I talked to his mom at length. She told me that whenever he takes antibiotics, it is as if his symptoms worsen. He had had a positive Elisa but the rheumatologist said that it was a false positive.

This incenses me. This kid has been suffering for three years with what should have been a fairly obvious diagnosis. It seems like a crime. Can anyone explain the thinking that drives these dunderheads?

The body count is rising... myself, husband, and son .... two nephews... two brothers-in-law.....one sister-in-law, and mother-in-law. Is it just me or is this an episode from the twilight zone?

Amy Kelley
Rutland, Vermont

The "thinking" you refer to is often driven by the belief that Lyme is rare in the geographic area, and is therefore not considered as part of the differential diagnosis. However, in this case some important indicators seem to have been ignored.

The Michigan Lyme Disease Association has confronted this problem by collecting ticks locally and sending them to an out-of-state lab for analysis and study.

Elder encounters doctor skepticism

Thank you for your informative newsletter. I had been so ill - not knowing of Lyme. We live next to 300 acres of conservation with deer and coyotes. I always had good health and when I finally went to a clinic after circle rounds on my skin, high fever, and fatigue, the doctors questioned me why I would want a blood test - I don't think they believed me. Finally antibiotics. Live but I now have severe arthritis (a leftover). I try to keep cheerful and limp about with my seniors at the supermarket.

Myrne Riel
Barnstable, Massachusetts

Beginners' Pages

Why you shouldn't accept a diagnosis of "Post-Lyme Syndrome"

by Jonathan R. Strong

Once you get "comfortable" with a diagnosis to explain your condition, it may be tough to reconsider your position — but I would ask you to think about the following:

The "nature" of Lyme disease is still unfolding as various research projects continue. There are many possible reasons for continuing Lyme disease symptoms due to continuing infection even after extensive antibiotic treatment. Consider a few:

— A single tick might harbor hundreds of strains of the spirochete each with varying sensitivities to different classes of antibiotics. Extended treatment with various antibiotics then could conceivably be effective against some of them, and leave others behind.

— Some of the recent research suggests that the spirochete moves through three forms at various times — the common motile spirochetal form, the "L-form" and the cyst form. Each may be sensitive to a particular class of antibiotic, and resistant to others. The research suggests that it may be necessary to treat a patient with perhaps three different antibiotics simultaneously to catch all forms. Furthermore, this suggests that extended treatment with just a single antibiotic might never completely wipe out a Bb infection.

Also: remember — a "syndrome" is just a nice euphemism for "an illness whose source and nature we don't really understand." Aside from growing, receding and migrating spirochete populations in your central nervous system (CNS), what other construct could possibly explain neurological symptoms that "flare" every 3 to 6 months? If the nerves are truly damaged, how would they function properly for a few months at a time in between flare ups?

I have had, and continue to live with many symptoms. In 1992, I had these quite severely. After a few weeks of IV antibiotics, they ALL disappeared. A few years later, they returned gradually. Now they are quite bad. I have also recently had a positive blood PCR for Bb. My situation is consistent with: Lyme disease — treatment that partially knocked out the illness — a few years of symptom remission — relapse as infection reclaimed its place in my body ...and we have proof of the active infection still in me after extended antibiotic treatment.

Residual symptoms could mean either permanent damage or continuing infection that was resistant to the treatment that was used.

As I noted above, if your symptoms come and go, the odds of permanent damage being the explanation are pretty slim indeed.

In light of the research that indicates just how difficult it can be to completely wipe out a Lyme disease infection (as with syphilis, a similar spirochete which can resurface 30 years later), I suspect that patients may be doing themselves an injustice to accept a "post Lyme syndrome" label. I believe it more likely that the body reaches some kind of equilibrium between the infection and the immune system, with the active spirochete population waxing and waning over a course of months, as reflected by symptoms.

In general, unless we're discussing psychogenic symptoms, neurological problems normally associated with CNS damage just don't come and go — there is invariably a physical mechanism at work (e.g., demyelination, oxygen starvation, etc.) that is interfering with proper CNS function. If the symptoms periodically lessen, this suggests that the cause of the symptoms is NOT some kind of permanent physical damage to the CNS, but an outside agent that is able to interfere with normal function but whose presence is not constant — e.g., a Bb infection.

The whole concept of a "syndrome" strikes me as a simplistic way out for a doctor who really doesn't know what's going on. In the future, assuming that we fully understand the nature of illnesses, there will no longer be a need for the concept of a "syndrome."

How To Lick Those Ticks

by Katherine Porter

Accessible only by boat, Prudence Island is a seven-square-mile pollywog in the middle of Rhode Island's Narragansett Bay. The Island had, at last count, 118 year-round human residents and 300 white-tailed deer, each deer teeming with ticks carrying the infectious bacteria that can cause Lyme disease.

Last fall Prudence Island gained 20 new residents—all named Franklin 4. The Franklins are five-foot-high remote-sensing aerosol robots. They lure deer with a scent bait, identify the approaching animal by the deer's characteristic side-to-side jiggle, zero in on the patch of heat escaping from the top of its head, and then spray the animal between the ears with a tick-killing fungus. A naturally derived soil organism, the fungus breaks the Lyme disease transmission cycle, which runs from deer ticks to humans walking in high grass.

”Ninety percent of the ticks attach to the surface around the deer’s ears,” explains Dr. Elyes Zhioura, the University of Rhode Island entomologist who isolated the fungus. Each time Franklin 4 sprays a deer, the fungus kills off thousands of its ticks. Since each female tick produces 2,500 to 3,500 eggs, a single deer may be the nursery for 1.5 million deer ticks.

“If we hit 20 percent of the deer, you will see a 70% decline in the tick population in that region,” says David Butler, a self-proclaimed “swamp Yankee” and tinkerer, who perfected the robot’s spray mechanism. On humans, the fungus “is about as toxic as day-old bread,” says self-taught electronic wizard Gordon Salisbury, who added the heat and motion sensors.

The robots make good neighbors, says John Canario, the state’s environmental management conservation officer on Prudence Island — if they are allowed to do their job. His concern is that deer who are not hungry will not come close enough to the baited Franklin 4 sprayers.

“They will work if people stop feeding the deer,” Canario says.

Reprinted from the September 1999 issue of Yankee Magazine.

Patient stories

Lyme disease’s hidden victims

By Yvonne Abraham, Globe Staff

FALMOUTH - Two decades ago, life started to fall apart for Elizabeth Pykosz.

In 1978, she was 21 and happy, playing bass guitar in a country band, living a life with few burdens. Then, suddenly and inexplicably, the happiness drained away, and in its place arose a tide of depression that no amount of psychiatric treatment, no combination of psychotropic drugs, nor any of her 10 suicide attempts could force back down.

No matter what her doctors tried, she just deteriorated. She tried to keep up with her painting, but she seemed to be losing her skill at that, too. And she was mystified, with no idea why she had suddenly sunk so low.

Two years ago, Pykosz, now 42, discovered there was a physical cause for her illness: Lyme disease.

Though the most common symptoms of Lyme disease - rashes, lethargy, joint pain - are well known by now, the mental effects of advanced Lyme disease, which some doctors believe include anxiety, memory loss, depression, obsessive-compulsive behavior, and extreme aggression, are still a matter of heated contention.

Awareness has grown since the disease, carried by deer ticks and especially prevalent on Cape Cod and the islands, was first discovered in the late 1970s. More and more patients are being correctly diagnosed and treated with antibiotics to kill the bacteria before it does irreparable damage.

But advocates say those who suffer the mental effects of advanced Lyme disease have been left behind. Their illness, missed in its early stages, was allowed to worsen until the infection reached their brains.

Doctors estimate there are thousands of patients like Pykosz, suffering crippling psychiatric problems and taking heavy doses of psychotropic drugs, not knowing that Lyme has caused their illness or that they might be helped with antibiotics.

“If I’d been diagnosed earlier, all of this could have been avoided,” Pykosz said of her years of psychiatric illness. “I’ve gone through an awful lot, and it makes me mad.”

Patients like Pykosz, say their advocates, are stranded on the frontier in a war against a disease that is still mysterious.

But they’re also caught in a crossfire between those who believe Lyme disease is widespread and those who believe Lyme disease has become the disease du jour, overdiagnosed and overtreated with dangerous doses of antibiotics. While one group of doctors sees a clear connection between the illness and psychiatric symptoms, another believes the connection is tenuous at best and that psychiatrists may be harming mentally ill patients with antibiotics.

“I think in all too many cases what’s being called psychiatric disease due to Lyme disease is not and that other forms of treatment than prolonged antibiotic therapy would be more effective for these people,” said Dr. Allen Steere, chief of rheumatology and director of the Lyme Disease program at New England Medical Center.

Those who care for Lyme patients with psychiatric symptoms say Steere refuses to acknowledge a public health crisis.

“What we’re starting to learn should be a huge wake-up call to all mental health professionals,” said Dr. Paul K. Ling, a psychologist and advocate for patients with mental symptoms of Lyme disease. “Otherwise, a whole lot of needless human suffering will be the result."

Some doctors liken the situation to earlier thinking on other physical illnesses that were first thought to be psychological.

"There were people in insane asylums who were found to have thyroid disease and syphilis and lupus," said Dr. Sam T. Donta, professor of medicine at Boston University. "History tells us there are causes for these illnesses. They're not due to evil spirits."

Greg, who asked that his last name not be used, grew up near Lyme, Conn., the town for which the disease is named. He said he had battled mental illness since childhood, but that his problems worsened a decade ago, when he became a stockbroker. He was diagnosed with bipolar disorder, but he also complained of exhaustion and joint pain.

"No one ever questioned my diagnosis; no one ever tested me for anything physical. It's amazing," he said.

Several years ago, he tested positive for Lyme disease. If he had been correctly diagnosed earlier, Greg said, his illness would have been "a bump in the road of this life, instead of going off a cliff."

Though he conceded that he still feels paranoid, Greg said he has been much improved since he stopped other medications, opting for antibiotics alone. He now holds a part-time job doing maintenance work.

Pykosz said that since she began antibiotic treatment for her illness and jettisoned her other medications - at one point she was taking 14 medications a day - she has been vastly improved. She said she doesn't think of suicide any more, and her paintings, which years ago hung in several Cape galleries, are finding showings once more.

Both Pykosz and Greg have medical charts as thick as phone books and have taken a long succession of drugs that, they say, left them in a permanent fog. They also lived with the stigma of mental illness.

"To have people around you shamed by your mental state, and then to find it's a physical thing, it's very liberating," Greg said. "It's so much easier to accept the fact that some parasite made me ill. It gives me a chance."

Nobody can say how many other patients like them there might be. According to the Massachusetts Department of Public Health, more than 700 cases of Lyme disease were reported last year, but advocates say that figure is far short of the actual number, since some people carry the disease without knowing it and not all patients who have it test positive using the current tests.

Some psychiatrists say the number of Lyme patients with mental symptoms runs into the thousands: Dr. Robert Bransfield, a psychiatrist and associate director of the Riverview Medical Center in Red Bank, N.J., another Lyme hot spot, said he has seen a thousand of them.

Advocates argue that there should be an aggressive public awareness campaign to educate doctors and the public about the hidden side of Lyme disease. Ling and his colleagues also want the state Department of Mental Health to start screening its clients. Blood tests for the disease cost less than $100, but brain scans, which some psychiatrists say are more reliable, cost more than $2,000.

Others say that is alarmist.

Steere, who first named the disease in 1978, does not see such strong connections between the disease and mental illness. He will go only so far as to say that Lyme disease can give rise to "a subtle neuropsychiatric picture in which subtle memory deficit is the most common manifestation."

"A lot of what has been described as Lyme disease, and attributed to Lyme disease, would not stand up to the scrutiny" of peer review, he said.

Unfortunately, it's a debate without clear answers, and the argument promises to stretch on for years.

Meanwhile, advocates say, patients like Pykosz will get lost in the system.

"I don't know if they're filling up mental institutions," said Donta. "But there are more ordinary people who are walking around who have those symptoms and have gotten themselves in a vicious downward spiral and have just accepted that it's their lot to be depressed."

This story ran in the Boston Globe on 08/09/99. Copyright 1999 Globe Newspaper Company. Reprinted by permission.

Many different treatments do not cure patient completely

by Lou Ellen Gooding

My Lyme story started in the spring of 1991. Every spring I would go mushroom hunting in rural Illinois. I never found an attached tick or had a bull's-eye rash but that year I had the "flu" three times and severe knee pain which I thought was related to an injury.

In the spring of 1992, over a period of three days, both arms and legs began to tingle. Initially it was one-sided and my physician ruled out a stroke since I was only 34 at that time. My physician sent me to a neurologist who very quickly wanted to diagnose me with MS.

We as a Lyme disease support group have found the specialist you see determines your diagnosis. I was able to convince the neurologist to try me on the antibiotics for Lyme as I felt I had more symptoms of Lyme than MS. With the antibiotics I had the classic Herxheimer reaction where my symptoms became much worse for a few days, then I began to improve. By then my symptoms included fatigue, headaches, nausea, weight loss, joint pain, dizziness, muscle aches and blurred vision.

In September 1992 I had a short course of IV antibiotics. I then switched doctors as the neurologist would not treat me further until I went to Iowa City Hospital or Mayo Clinic to confirm the diagnosis as three blood tests were negative. I was involved with the Quad Cities Lyme Disease Network and knew neither of these medical facilities give a fair evaluation for Lyme disease.

I stayed on oral antibiotics until the spring of 1993 when my symptoms became much worse. Again my physician began to talk about MS and I had a MRI, which was normal. My Lyme tests were still negative. I found a Lyme clinic in Indiana, 6 hours away. My Lyme test confirmed Lyme disease and I was put on 21 weeks of IV antibiotics. I improved and went back on oral meds, but then I again relapsed. I could no longer see the doctor in Indiana but found a doctor in Missouri. My physician told me he was at the end of believing I had Lyme disease. This was while I was sitting in his office looking like death warmed over. I was extremely ill at that time and he offered no help except giving me my records.

The physician in Missouri tested me for Lyme and I had a very positive test. He changed my antibiotic and for the first time someone addressed possible yeast problems.

In the fall of 1994, I started the Mississippi Valley Lyme Disease Network. We have drawn people from Missouri and Iowa who have similar stories; most of us go out of state for treatment. Most physicians in Illinois do not recognize Lyme as a problem, even though the Illinois Department of Public Health has identified ticks with the Lyme bacteria since the late 1930s.

In the fall of 1994 I went off antibiotics but was not symptom free. In the spring of 1995 I began to have problems again and went back on antibiotics. The symptoms settled down and by January 1996, I was off antibiotics.

I did well until the fall of 1996 when my symptoms returned with a vengeance. I tried three different oral antibiotics and none of them worked. I tried IM shots of Bicillin and had an allergic reaction. So again I had a central line inserted and several weeks of IV Vancomycin. I still was only doing fair. By February and March 1998 I had heard of the hyperbaric oxygen study in Texas. I did not meet all of the criteria for the study and did not want to wait to see if I would receive treatment. Two other individuals and myself went to Tampa and received hyperbaric oxygen treatments. We were the first Lyme patients they had treated. I received 48 treatments over five weeks with significant improvement. I returned to Tampa for 48 more treatments over four weeks in October and November; I was slipping by that time. Both times I was on IV antibiotics during the HBOT. The second set of treatments helped and I feel the best I have felt in seven years. I really feel if I was able to receive 2 or 3 months more of HBO I would be cured of Lyme. I can not afford more HBO and I have used up all my sick and vacation time for the last two trips to Florida.

I have been lucky that my insurance has paid for IV antibiotics when I needed them and for my oral antibiotics without question. But my insurance is changing and I hope I do not have to test it again.

I have spent a lot of my money on alternative treatments for Lyme; some have helped and some haven’t. But I do not believe mainstream medicine has all the answers to Lyme disease unless they treat early. I have changed local physicians 5 times as they tend to lose interest when you do not get well on schedule. My current physician is supportive of my Lyme treatment and does not object to the alternative treatments and I pray he does not lose interest as the others did. I still go to Missouri to see a doctor for Lyme as he has treated hundreds of Lyme patients.

Over the years a fraction of my symptoms have included: fatigue, headaches, sinus problems, blurred vision, ringing ears, fluid in the ears, neck pain, joint pain, hurting head to toe, arthritis, knee problems, dizziness, nausea, weight loss, yeast problems, ankle/foot pain, abdominal pain, memory problems, sleep disorder, numbness/tingling, tooth pain, choking problems, low body temperature, palpitations, sweats/chills, depression, irritability and colitis. The changes in lifestyle, loss of some friends and lack of understanding by others goes without saying.

I will never give up until I am totally symptom free. I continue to have a lot of support from my family, my church, my faith and my friends. Never give up as there are caring medical professionals who are willing to help. Join a support group as they can be a wealth of information and support.

Lou Ellen Gooding can be reached at P.O. Box 568 Roseville, IL 61473 Tel.(309) 426-2339

In Memoriam

Dieter Gossel
of Hamburg, Germany
Jan. 1, 1934 - Dec. 25, 1999

after a long decline, of heart disease complicated by Lyme disease.

Patient Support

Meeting With Your Member of Congress

The most effective thing you can do as a citizen to influence policy is meet with your Member of Congress. Elected officials and their staff regularly meet with people to hear their views on an issue. However, the majority of their visitors are paid lobbyists representing industries and corporations. Your citizen meeting with your Member is critical to counterbalance the paid lobbyists and to remind Members of Congress who their constituents are and what issues you are most concerned about.

You can approach your Member of Congress by yourself, or with a group of friends, co-workers, or other people who share your interests. The wider spectrum of people supporting an issue, the more weight your position will carry.

You can arrange a meeting with your Member of Congress or their staff when he/she returns to their home district/state, or you visit their Capitol Hill office in Washington, D.C. The most important thing to remember is that anyone can request a meeting.

Here are a few tips for you to follow before, during and after your meeting with your Member of Congress to make it more successful:

Before the Meeting

Make an appointment. Simply call your Congressional office and tell the staff member that you are a constituent and you'd like to a meeting with your Member of Congress. If it seems unlikely that you'll get an appointment with your Member, ask to meet with a staff member working on the issue you are concerned about. Remember that these aides advise and make recommendations to their bosses about legislation. Members of Congress are very busy and their schedules are packed. If a meeting is not possible at the time you are calling, be persistent! You might need to follow up at a later time. You can call the U.S. Capitol switchboard to get your Member of Congress' telephone number.

Put together a delegation. Try to go beyond the usual suspects by finding unlikely partners that are diverse enough to suggest that a wide range of voters are sympathetic to your cause. For example, pair taxpayers and environmental advocates, or religious and business leaders. If you are having trouble confirming a meeting, broaden your delegation and try again.

Preparing for the meeting:

· Establish your agenda and goals. Determine exactly which issues you want to address. It is best to focus on one or two issues. Decide what kind of commitment you are asking for. For example, decide whether you want your Member to vote for a specific bill, ratify a treaty, take a leadership role on an issue or co-sponsor legislation.

· Research your Member's stance prior to meeting. It is key that you know your Member's position and arguments so that you can present your stance more effectively and have an intelligent discussion. On some issues your Member of Congress may not have stated his/her opinion, in which case, you can gather that knowledge during your meeting.

· Set up a pre-meeting with the entire group. It is important to have a good idea of what each person plans to say during the meeting. Select someone to act as the group leader and make a list of points to be made and questions to be asked by each person. Acting out a few role plays would be useful. Try to do this within a day of your meeting so your rehearsal stays fresh.

· Prepare materials. You may want to bring a packet of materials to your Member of Congress. This may include: fact sheets from various organizations, supporting op-eds, editorials, and letters to the editor or news items which illustrate your issue. It is important to include your name and phone number in the packet so your Member of Congress will have a contact for more information.

During the Meeting

Be on time for your meeting. Members of Congress and their staff are very busy. You probably won't have much time for your meeting, so you don't want to waste it.

Be concise and diplomatic. Keep your presentation short and to the point. Make clear exactly what action you wish your Member to take. It is important to listen to your Member of Congress even if his/her view differs from your own. Don't be argumentative or confrontational.

Be a good listener. Look for indications of your Member's view and watch for opportunities to provide useful information in order to strengthen or counter particular views.

Put a local and personal angle on the issue. Stress why this issue concerns you and other in your district or state. Clarify how your Member's actions affect the people he/she represents. And be specific. For instance, cite local statistics, give examples of communities that will be most affected by this issue, or mention who supports your issue locally such as business, community leaders, local politicians, etc.

Press for a commitment. Don't let your Member of Congress evade the issue or change the subject. Ask specifically for their position on the issue.

Don't be intimidated. Your Member of Congress is in office to serve you. It is important that you have a general knowledge of the issue, but you don't need to know every little detail. Chances are, you will know more about the issue than your Member of Congress of their staff. If he/she asks a question that you do not know the answer to, simply say that you don't know, but that you will find out. Get a fax number and a follow-up contact and be sure to provide the necessary information as soon as possible.

After the Meeting

Write a follow-up letter. After your visit, write a letter thanking your Member of Congress for his/her time and his/her support for your issue. This will give you a chance to summarize the key points you made during your visit and include any information you promised to provide. You may also want to write to any staff members that were present. They can be important allies.

Share the knowledge you learned. Be sure to tell colleagues, organizations, and individuals what you learned. This is particularly important if your Member stated an opinion that was previously unknown.

Stay in contact with your Member. Remember, you are there to strengthen or build a relationship. Keep your Member in touch with your concerns and thank him/her for any key positions, votes, or statements he/she made on issues of concern to you. When you write or call, remind your Member of your visit.

Reprinted by permission of 20/20 Vision from their website at http://www.2020vision.org/meeting.html. Located in Washington, DC, 20/20 Vision watchdogs Congress and makes grassroots activism simple, quick, and efficient for busy people Sign up for their once-a-month alerts on vital issues. Tel. 1-800-669-1782.

Distinguished Lyme physician urges political action

by Joseph Burrascano, MD

In 1993, Senator Kennedy hosted a hearing on the current status of Lyme disease in this country. It was clear then that things were not good. The many promises made since then have not come to fruition. In fact, in many ways the status of Lyme, as far as the patient is concerned, is much worse!

I very strongly suggest that all with an interest in Lyme send a message to the Senate. Tell the Senators that you want them to reopen the hearings on Lyme, and insist that every effort be made to reveal the true plight of the Lyme patient — problems with many MDs and insurance companies denying the diagnosis, many MDs and insurance companies denying treatment for Lyme, and unethical actions and conflicts of interest by many government and insurance company professionals. There is a need for meaningful research done at the community level, with the input of patients and treating MDs. Everything else that must be addressed at the federal level should be mentioned.

To do this, first contact Senator Kennedy and Senator Frist (the only MD in the Senate). Then contact your own Senators and all those who have an interest in public health, government corruption, and those from states where Lyme either is a big problem, or those where Lyme does exist but awareness is lacking.

You can contact them by going to http://www.senate.com. This lists their web sites, email addresses, phone numbers and mailing addresses.

Emphasize that Lyme is a major public health issue that must have Federal input.

If you are willing, send a copy of your letter to me at 139 Springs Fireplace Road, East Hampton, NY 11937.

Reprinted from Dr. Burrascano's website. Regular letters are said to be more effective than emails.

Websites offer information and support

After a year of planning, the upgrade of the LymeNet site is now underway, according to editor Marc Gabriel. The network connection was upgraded to a SDSL line 7 times faster than the old line, and site "look" is being revamped to get rid of the much maligned frames.

Interested people are invited to check out the new site at http://www.LymeNet.org.

Yale alumnus Douglas Dodge provides the patient community with up-to-date and lively commentary on the latest anti-patient articles and statements on his website www.lymetruth.org.

The America On Lyme Newsletter is intended to reach out and share knowledge, educate, personalize our plight though our experiences, hopes, and community happenings. Together we CAN make a difference!

This newsletter can be accessed at http://www.angelfire.com/ny/lymedisease/newsletters.html.

Clincal picture varies among children of one family

by Nancy Berntsen

Are you the parent of a teen or preteen who has or has had Lyme disease? Sometimes it is difficult to distinguish Lyme disease from other problems common in adolescence.

Below I've briefly summarized 4 cases of juvenile Lyme I'm very familiar with. I'm an RN with Lyme, and mother of these four boys.

The oldest, Joel, and the youngest, Peter, (now ages 17 and 10) had the classic early symptoms and got prompt, apparently effective treatment. A year later, my oldest was still waking up stiff and had trouble getting up in the morning due to fatigue. He began treatment again under an excellent doctor's care. He had elevated liver enzymes, negative for hepatitis and likely from Lyme. His symptoms were the least clear. His tests for Lyme were negative but he had enough symptoms to warrant treatment. After a few months of antibiotics, his liver enzymes returned to normal and he discontinued treatment because he was feeling fine.

My youngest was reinfected the following spring but did not have symptoms until he was farther along: slight fever, swollen glands, fatigue and headaches mainly. He responded well to about 3 months of antibiotics. He was again bitten by ticks this past summer but was asymptomatic until this fall when he had headaches and "wooziness" (his own words) that recurred every 3-4 weeks. Upon taking a closer look, I found he also had some word-finding difficulties he never had before. I regret I did not have the bites treated prophylactically. The doctor started him on antibiotics before test results were back. He tested positive for later stage Lyme disease and thankfully is now asymptomatic following several weeks of antibiotics.

My second born, Ben, at the age of 12 started complaining of stiff shoulder, neck, and jaw (TMJ). He also had some memory problems affecting math and speech. He was treated for several months with oral antibiotics until symptoms resolved. Because of his symptoms, I realized I probably got Lyme in my youth. I wasn't diagnosed till I was 36 when I may have been re-infected.

Ben had a recurrence of Lyme at age 14 while vacationing. TMJ was so bad he had to get on a muscle relaxant in addition to antibiotics. He's doing fine now.

My third son, Tim, has a high tolerance for pain. He would very occasionally complain of a severe headache, a stiff wrist or achy knee: "I got out of bed wrong today and hurt my knee..." and stiff finger joints. All along he had brain fog, as long as I can remember. This was written off as ADD. He was oversensitive, sluggish and often depressed. Routine Lyme tests were negative, but I had my doubts.

Finally the summer of 1998, an extensive exam indicated he had other Lyme symptoms but his high tolerance for pain had minimized what he was really experiencing. He began oral antibiotics for Lyme in September, 1998 and has made slow, gradual progress. His mind is sharper; he's more alert, less emotionally sensitive, and doing better with his schoolwork. He's got a hereditary syndrome besides (Aspergers) which makes it harder to know what is causing his symptoms, but he clearly has been improving since he started antibiotics.

An increase in antibiotics resulted in an emotional outburst and his feeling all out of sorts the following day. He has gone through periods of speech errors and memory problems, as had I. Feeling worse before you feel better is not at all unusual as the antibiotics kick in and start killing off bacteria. Toxins released by the bacteria cause more symptoms. This is called the Jarisch Herxheimer response.

It's very important that you find a competent doctor regarding Lyme. It is all to easy to be convinced it's just growing pains, or that only a couple weeks of antibiotics is enough. Undertreatment leads to advanced Lyme which these same doctors have no idea how to handle.

I now believe it is a mistake to wait after a tick bite to see if there are any symptoms when early prophylactic treatment can keep this potentially disabling disease from taking root. It is also advisable to have ticks tested and have your child tested for other tick-borne illnesses.

Unfortunately, the best Lyme doctors are under the scrutiny of frugal insurance companies and their supporting doctors. Treatment for Lyme disease has not been standardized and diagnostic testing is not reliable enough to rule out Lyme disease. Treating Lyme properly has become very political in the medical community, causing division and heartache.

As parents of children with Lyme disease, we often have to go the extra mile to get competent health care for our children. Lyme disease should not be treated lightly. As advocates for our children and their future, we must speak up for them and insist on getting the care they need.

Nancy Berntsen, RN, BSN, is a graduate of University of Bridgeport. She is a wife and mother of 4, and currently a home educator and coordinator of TRISHA, a Lyme support group in eastern Connecticut. She may be reached by email at berntsen@altavista.net.

"Grievin' On A Lyme Train"

by Jeannine Der Bedrosian

Dedicated to the New York OPMC Protest 12/8/99, the start of the New Millennium - Time for Lyme. Sing to the tune of "Leavin' On a Jet Plane"

Well my bag was packed with plenty of Flagyl,
Zithromax and Doxy because I'm fragile,
Sunglasses for my light sensitivity,
Got the meds for pain and arthritis,
Is that a taxi horn or just tinnitus?
Took Xanax for my Lyme anxiety.

Kiss me and smile for me,
Share my Lyme disease fate with me,
Hold me as my IV Bag does flow,
'Cause I'm a'Grievin' on a Lyme Train,
Don't know when I'll have a doc again.
Doc Orens, why must you go?

There were so many times I made the rounds.
Of every doctor in every town,
They couldn't figure out what was wrong with me,
They said "It's Just Stress, or Multiple Sclerosis,
Fibromyalgia - That's our diagnosis!
It's All in Your Head, or maybe its ADD."

Kiss me and smile for me,
Share my Lyme disease fate with me,
Massage my veins so that the blood will flow,
'Cause I'm a'Grievin' on a Lyme Train,
Don't know when I'll have a doc again.
The last one let me go....

When my arteries began to harden,
I remembered a Tick-Bite in the Garden,
ELISA and Western Blot were POS (+) for me,
"Thirty Days of Antibiotics will be a Breeze,
That's All That's Needed for Lyme Disease,"
Docs told me that were wrong as they could be.

Kiss me and smile for me,
Share my Lyme disease fate with me,
'Cause I'm a'Grievin' on a Lyme Train,
Don't know when I'll have a doc again.
Is Burrascano the next to go?

I finally found a Lyme Literate Doc,
In the middle of treatment - what a shock,
He's suspended by New York OPMC,
"He's overprescribing, he's overdiagnosed,
We'll lift his license, his clinic is closed,
Charge fraud against this compassionate MD"

Kiss me and smile for me,
Share my Lyme disease fate with me,
Hold me as my symptoms start to grow,
'Cause I'm a'Grievin' on a Lyme Train,
Don't know when I'll have a doc again.
Doc Orens, we love you so....

There's so many after our Lyme Doc Friends,
Insurance companies refuse to spend,
"It's 'Not Lyme Disease,' you're 'Really Not Sick,'
It's just your body playing a trick,"
Said the doctor paid by the Insurance Company.

Kiss me and smile for me,
Share my Lyme disease fate with me,
Hold me as my Spinal Tap does flow,
'Cause I'm a'Grievin' on a Lyme Train,
Don't know when I'll have a doc again.
Now they're after Burrascano?

They need to fund a Lyme Cure faster,
Our Lyme disease children are a disaster,
So many affected neurologically,
Can't concentrate, they quiver and quake,
With jerks and tics their bodies shake,
Their problems make them sad as they can be.

Kiss them and smile for me,
Share their Lyme Disease Tale with me,
Hold them as our children's tears do flow,
Cause I'm a'Grievin' on a Lyme Train,
Don't know when they'll have a doc again.
Doc Jones, please don't go?

We're under attack by A'Stupe Clinicians,
We must involve the Politicians,
Together there's a message we must send,
Persecution of Lyme Docs - must cease,
Fund Long-term treatment for Lyme disease,
Until that time this song will have no end??

Kiss me and smile for me,
Work to stop the Conspiracy,
Help us so the Lyme Disease Truth will flow,
'Cause I'm a'Grievin' on a Lyme Train,
Don't know when I'll have a doc again,
Guess I'll go to Mexico........
(whisper) Grievin' on a Lyme Train.......
Grievin' on a Lyme Train.....
Guess they'll give me
hope in Mexico.....

Jeannine Der Bedrosian, aka online as MisTick or Songster lives in East Brunswick, New Jersey. See her account of the demonstration in Bethesda on page 23.

"Not a dry eye" video on kids with Lyme

Special video on children with Lyme Disease titled "Dr. Charles Ray Jones and the Children of Lyme Disease" is available in public libraries in Fairfield County, Connecticut, and can be purchased directly from Dolly Curtis, address below.

Eight other Lyme disease videos are also available from TV producer and Lyme patient Dolly Curtis. Please see order form at www.dollycurtisinterviews.com or write to:

Dolly Curtis
35 Flat Rock Rd
Easton, CT 06612
or Fax 203 372 4511

Book Reviews

Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability

A new view for men who parent the one in ten children with a disability

"I wrote *Special Children, Challenged Parents* to deal with issues that no other book about disability deals with, especially a major male dilemma: Men, including myself, have a hard time facing things they can't fix," says Dr. Robert A. Naseef. "Men feel powerless, inept, sterile. We can't simply work harder to fix our child's disability. Instead, as we struggle with the grief and darker side of what it takes to face our broken dreams about our child, we must deal with our powerlessness." According to Dr. Naseef, "Fathers as well as mothers can go through a process that leads from grief to hope, from isolation to relatedness, from emptiness to fullness, and from shame to pride. This process can be long and arduous, but it can also be heartfelt and inspiring."

Special Children, Challenged Parents is a singular book because it offers the views of a man who is a psychologist and the father of a child with autism. This volume addresses the issues of all parents with special-needs children, and it focuses specifically on the issues and needs of fathers. *Special Children, Challenged Parents* not only helps men to open up in their own way, it also helps women to get a glimpse inside the psyche of men. Couples can also use this book to connect and communicate better when their marriages seem ready to crumble from strain.

In the words of James May, Project Director, National Fathers' Network: "With enormous insight and eloquence Bob Naseef blends his understanding as a psychologist with his real life experience of raising a son with autism. The result is a book which moves and teaches us at the same time—an intelligent, authentic, and impressive achievement." Joan F. Goodman, Ed.D., University of Pennsylvania Graduate School of Education and author of *When Slow is Fast Enough*, had this to say: "Never have I read a book that combines so profoundly the experiences of a father—agonizing, embarrassing, frustrating, exhilarating, sometimes even blissful—with the insights of an experienced therapist and the wisdom of a scholar."

The book is receiving praise from many disability organizations. The National Psoriasis Foundation wrote that "the honesty and compassion with which it is written translates easily to any condition."

For more information about *Special Children, Challenged Parents* you are invited to arrange an interview or to request a press pack, respond to this message or contact the author. The book is available through your local bookseller, or from Carol Publishing at 1-800-447-BOOK (X2665).

Yoga for the Special Child, A Therapeutic Approach for Infants and Children with Down's Syndrome, Cerebral Palsy, and Learning Disabilities, by Sonia Sumar.

Price $19.95; 256 pages.

Yoga for the Special Child, a comprehensive hands-on instruction manual for parents and professionals, is now available at bookstores across the country.

This book presents an innovative program of yoga techniques designed to increase cognitive and motor skills at each stage of the special child's development.

Yoga is far more than just a slow-motion calisthenics routine or stress reduction method. It is a teaching method which enhances coordination, muscle development, body awareness, and concentration. Its success as a remedial program in the education of special children has been documented in studies published in American Education and psychology journals.

YSC is currently the only full-length work on this important subject. With over 200 photos and illustrations, this comprehensive and easy to understand guidebook gives the reader a clear and compassionate look into the future of special education.

In praise of the book:
"An excellent therapeutic program—clear, comprehensive, and compassionate. I was particularly impressed by the profound transformation in Sonia's students, which came as a direct result of their practicing yoga."

—Dean Ornish, MD, author of Love and Survival

A Holistic Newsletter is available from Yoga for the Special Child.
Address Route 1, Box 1559,
Buckinham, VA 23921

Toll free 1-888-900-YOGA, Tel. 804-969-2668, Fax 804-969-1962, email: info@specialyoga.com, website: www.specialyoga.com.

Regional News

Lyme disease triples in Virginia- high among children

The December 5, 1999, Washington Post reported that the number of Loudoun County, Virginia, residents testing positive for Lyme disease more than tripled this year, baffling health officials and raising concerns, especially among parents of young children.

Of 55 reported Lyme disease cases so far this year, half were among children younger than 15, according to preliminary figures. In 1998, there were 17 such cases in the county, and only nine in 1997.

The county Health Department is considering what steps they may take, although they still appear to be uncertain that there actually is more disease than usual.

Diana Helentjaris, the county's health director suggested several factors that could be contributing to Loudoun's sharp increase in reported cases of Lyme disease, including rapid population growth, more accurate diagnosis and improved reporting procedures.

"When you get a larger population in what was once a rural area, there is a likelihood of increased contact with wildlife," she said.

The Washington Post reiterated the frequently heard misinformation that 90 percent of Lyme disease cases resolve themselves without serious long-term complications when treated promptly with antibiotics. Many medical journal articles emphasize the considerable longterm morbidity associated with Lyme disease, especially when it is not treated early. Public health agencies are noted for trying to present a rosy picture in an apparent effort to allay peoples' fears.

Michelle Dunne, who lives in Loudoun's fast-growing Cascades neighborhood, is convinced that the county's growing deer population contributed to her 8-year-old daughter contracting the disease last month. Seven years ago, when the family first moved into its town house near Algonkian Regional Park, members saw seven or eight deer walking in the woods.

Lately, Dunne said, she has seen 30 to 40 deer roaming nearby, some within yards of a children's playground between the town house complex and the park. She is concerned that some neighbors might be contributing to the problem by putting food out in their yards for the deer.

Dunne said she thinks it was at the playground that her daughter, Bridgit, was bitten by a tick a month ago. Bridgit, whose illness included severe headaches and loss of muscle control in her face and legs, is on antibiotics and is expected to make a full recovery.

"It was frightening," Dunne said. "For weeks, we couldn't figure out what it was because she never had the classic bull's-eye rash that everybody talks about."

Doctors say the disease is difficult to diagnose because symptoms mimic those of other illnesses such as influenza, mononucleosis and arthritis. Blood tests are often inconclusive and cannot be used to rule out Lyme disease.

In Florida the Lymed are leading the Lymed

After their experiences with the doctors in Central Florida "who know disgustingly little about Lyme disease," said Terri Hundeby, she and Marvina Lodge decided this year that Florida needed a state organization to pull together and support all support groups and individuals living in Florida. They took their own money and formed the Florida Lyme Disease Network. Their first meetings were held in Orlando, adding new members despite hurricanes Floyd and Irene.

"We were also concerned with the fact that people were very disconnected, living cities away and never having any contact with other Lyme patients except through email," said Hundeby. "Down here, it can feel like you are the only one in the state with Lyme, and none of one's neighbors or coworkers will have any understanding of what one goes through."

Hundeby and Lodge are currently working on their nonprofit status paperwork and hope to achieve nonprofit status before the end of 1999. They are also working on an 800 number. Their ultimate goals are to conduct regular speaking engagements to various groups, physician seminars, and fund-raising activities geared toward a medical treatment grant fund. Their motto is, "The Lyme Leading the Lyme."

Many Florida patients originally lived in the Northeast and moved south to find there were no doctors in their area who understood Lyme. According to Hundeby, some had previously been diagnosed and some did not exhibit major symptoms until after living in Florida for some time.

"However, we can attest to the fact that people are also being infected in Florida," she stated. "When that occurs, if they are fortunate enough to be aware of

Lyme disease, as not many are in Florida, a negative ELISA can mean that treatment will not be made available without visiting several doctors, and even then, if the patient does not contact us, they are likely to receive 10 days to three weeks maximum of low-dose antibiotics."

Hundeby is disturbed that none of the public education that is happening up north by the noted experts ever comes to the South.

"People are in real trouble here, because doctors are more likely to diagnose a mental illness than to test a patient for Lyme," she said.

Lodge added that no state wants to recognize that Lyme disease or Lyme-like diseases could possibly be endemic because it would be harmful to the tourist dollars. Florida is particularly vulnerable on that score.

"It is absolutely amazing how many people we find here in Florida with Lyme," said Lodge. "So far we have helped prevent numerous suicides related to Lyme depression. Others have responded in tears just to know they are not alone with this disease. We are finding persons with *Borrelia burgdorferi*, Babesiosis, Ehrlichiosis, and Rocky Mountain Spotted Fever," she added.

Hundeby creates an email newsletter to send to members before each meeting. Interested people who wish to subscribe to the free mailing list for announcements should use FL-LymeDiseaseNetwrk-subscribe@onelist.com or email Hundeby.

For more information contact the
Florida Lyme Disease Network
Marvina Lodge, President
(407) 839-0200 (407) 839-0974 fax
email: lovey38@juno.com
Hours: 9 am-9pm EDT

Terri Hundeby, Vice President
407) 381-9177 email:
MiKidzMom1@aol.com

Angry Texas mom forms Lyme Coalition to help other families

Dr. David Dennis at the Centers for Disease Control and Prevention (CDC) in Fort Collins, Colorado, thinks that Lyme disease "is practically nonexistent in Texas" but Julie Rawlings, MPH, epidemiologist in the Infectious Disease Epidemiology and Surveillance Division of the Texas Department of Health in Austin disagrees.

The June 7, 1999, Austin American-Statesman describes the battle Lisa Johnson had to get treatment for her son Hunter. He made 14 doctor visits in 10 months, passed out on the school playground and eventually couldn't make it through a full day of school. His joints hurt so badly that at one point he was using a wheelchair.

"I just felt sick and tired," Hunter, now 9, said.

Johnson thought Lyme disease was something you caught only while hiking in the Northeast. The doctor told her Lyme wasn't an issue, so she put it out of her mind.

More than $60,000 in medical bills and dozens of doctor visits later, Johnson is convinced the bacterial infection spread by ticks is a threat to residents of Central Texas. She never saw a tick on her son, but says Hunter developed flulike symptoms that wouldn't go away.

"If he wasn't on antibiotics, I couldn't keep him well," she said.

Johnson finally took Hunter to Connecticut, where he was diagnosed by a specialist. He still takes weekly injections of antibiotics — and could on and off for the rest of his life.

She has sought out other families affected by the disease, formed the Texas Lyme Coalition and even lobbied the Texas Legislature to form an interim study committee to examine the issues of insurance, diagnosis and treatment that Lyme sufferers face in Texas.

"Doctors weren't as knowledgeable as they should be," Johnson said. "What's important to me about Hunter's situation is it could have been prevented."

She is fighting a tough battle. Even though Texas Department of Health officials say 50 to 100 cases of Lyme are reported in Texas a year, and about three times that many suspected cases are noted in the state annually, many doctors never consider Lyme disease when they encounter symptoms such as rashes, joint aches and fever.

Dennis, for one, says true Lyme, which is spread by the black-legged (or deer) tick, is practically nonexistent in Texas. The CDC's standards for reporting a case are stringent, and Dennis says Texas patients may suffer from a similar rash illness carried by the Lone Star tick that also can be treated with oral antibiotics.

"Children who are ill, their parents are desperately seeking help," said Dennis. Lyme often becomes a convenient handle because it is a new and emerging disease that's treatable with antibiotics."

But Julie Rawlings says Lyme can — and does — occur all over Texas.

She says the Lone Star tick, which lives in grass on ranchland, around lakes and at parks but usually not in urban backyards unless brought there by a pet, carries the bacterium that causes Lyme disease.

"It is our most prevalent tickborne disease, and there are people having problems getting treated," Rawlings said. "It's something people should be aware of. If it takes awhile for disease to become diagnosed, it can become chronic, and you can spend a lot of dollars."

New support groups form in Pennsylvania and Maine

A new support group has been formed in **Pennsylvania**. Members of the group have already gotten some of their stories printed in local newspapers. They have hopes of organizing a local rally, an educational event for medical personnel, and are looking into renting billboards. They can be contacted at:

Gettysburg Lyme Disease Support Group
2389 Chambersburg Rd.
Biglerville, PA 17307
717-334-6339
Attn. Lovette Mott
e-mail smott@netrax.net

The organizational meeting of the Eastern **Maine** Lyme Disease Support Group (EMLDSG) was held Friday, Nov. 5th, at Eastern Maine Medical Center (EMMC). The meeting had 15 attendees, including people diagnosed and being treated for LD, those who thought they might have LD, and spouses. The personal histories were heart wrenching, and a repeat of all the stories we have heard before. This initial meeting was a time to get to know each other, to get comfortable, and to decide where to go from now. The next meeting will be held Monday, Dec.13, 1999 at EMMC

489 State St.
Bangor, Maine 04401.
Happy Dickey
207-862-2444
email: hapsquilt@aol.com

Persecution of Lyme doctors raises patient ire

continued from page 1

opmc/main.htm) Fraud is defined on the OPMC website as “conduct intended to deceive.” Medical fraud is defined as a physician making “false and intentionally misleading statements to patients.” Orens had an impeccable 40-year record until his return from retirement to treat Lyme patients after his daughter, who had contracted the disease, was allegedly misdiagnosed and mistreated at SUNY. Patients held a demonstration on his behalf in front of OPMC New York City headquarters (see p. 21).

In the meantime, after undergoing a lengthy investigation, East Hampton, NY, physician Joseph Burrascano was informed that the OPMC intends to prosecute him in a formal administrative hearing. There is a strong probability that Burrascano will have his license to practice medicine revoked, suspended, or restricted (i.e. cannot treat Lyme patients), and face a possible fine. The cost of legal defense may run as high as $100,000.00.

OPMC accepts conservative guidelines

New York doctors may be playing against a stacked deck. In a December letter sent to NY Senator Moynihan, Dr. Marks, executive secretary of the OPMC, stated that the OPMC follows the conservative Lyme guidelines of the American Lyme Disease Foundation and the recommendations of the Medical Letter.

“Rarely, if ever, have the published guidelines indicated that anything more than that two-three weeks of antibiotics are required to cure Lyme Disease,” he wrote.

Patients and doctors claim that the OPMC position is contradicted by numerous research articles in peer-reviewed biomedical journals. Accumulating evidence indicates (a) that many Lyme patients are not cured by 2-3 weeks of antibiotics, (b) that some of those are cured after months or years of antibiotic treatment, and (c) some are never cured. The National Institutes of Health is currently funding research on patients in categories (b) and (c).

NYU Professor Doris Aaronson, PhD, thinks the problem is that the conservative researchers use very restrictive criteria for the category of patients that can be used, and then inappropriately generalize their research results to all Lyme patients, including many who do not meet the restrictive criteria.

“Every text book in either introductory statistics or research methods warns that false conclusions can be made based on inappropriate generalization from a research sample population to other populations with attributes that differ from the research sample,” Aaronson said. “One can observe the flawed logic by reading some of the publications of the Lyme researchers who support Dr. Marks’ theory, and by discussions with knowledgeable physicians who are familiar with the Lyme research.”

Possible conflicts of interest

Patient advocates are raising issues of financial vested interests. They allege that two prominent national science advisors of the American Lyme Disease Foundation are paid consultants of the health insurance industry, and regularly testify in court on behalf of insurers and against patients.

“There is a clear conflict of interest when the OPMC is investigating doctors for professional medical misconduct using standards from an organization whose advisors have financial ties to the insurance industry,” stated patient Steve McLain, PhD, of Delaware.

Others point out that SUNY physician Ray Dattwyler, MD, who testified against Orens, is a principal in Brook Biotechnologies, a privately held company devoted to the manufacture of new ELISA diagnostic kits for Lyme disease. According to information published online at the SBA and at NIH, Brook Biotechnologies has received at least $800,000 in government awards. Leading Lyme clinicians claim that more than 60% of patients with chronic Lyme test negative on ELISA, undermining arguments for the utility of the test.

"Should we file complaints against Dr. Dattwyler and others in this camp alleging medical fraud for misleading us to believe that Lyme can be cured with 4 weeks of antibiotics ?" asked Massachusetts physician Lynn Shepler. "For making false and misleading statements that the CDC two-tiered protocol adequately reflects the biological realities of the disease? It's desirable that better diagnostic kits be developed," she continued. "However, it becomes problematic if physicians and scientists who have nominated themselves as 'authorities' issue twisted versions of this disease to fit it into something that can be milked for commercial reasons."

Other researchers are investing their time in trying to find antigens that can be patented. According to Kathleen Dickson, cofacilitator of the Southeastern Connecticut Chronic Lyme Disease Support Group, New England Medical Center researcher Allen Steere has an NIH grant to study tickborne pathogens in Russia.

"Clearly it is for the purpose of international patents for vaccines and test kits for the new strains of Borrelia and other new pathogens he finds there," Dickson stated. "The recognition of the abuses inherent in regional DNA patenting is emerging," she explained. "If you then go to the US patent office, you will see who owns the majority of the patents related to *Borrelia burgdorferi* to license diagnostic means and vaccine candidates. It is the same people who say Lyme is overdiagnosed and overtreated."

Lyme patients becoming politically active

Against this complex background, Lyme patients who see their doctors being investigated and disciplined are becoming increasing frustrated and angry.

"Dr. Allen Steere's views have gone beyond making life hell for Lyme disease patients; they are now actively endangering other doctors who have been nothing but beneficial to Lyme disease patients and their families," said James Martin of Euless, Texas.

Many patients and doctors have written letters; others have joined demonstrations. Some are working behind the scenes for political change, passing legislation to mandate health care coverage of treatments, as happened in Connecticut earlier this year.

The Lyme Alliance of Michigan has set up a legal defense fund for Dr. Orens similar to the one they set up for Michigan doctor Joseph Natole several years ago. Dr. Burrascano urges patients to write to their senators. He thinks that patients are much worse off now than they were when Senator Kennedy hosted hearings in 1993.

Dr. Orens Legal Fund

Send checks to Lyme Alliance, Inc. P.O. Box 454 Concord, MI 49237

Please make checks payable to Lyme Alliance and make sure you mark "for Legal Fund" or for "Dr. Orens Legal Fund". Mark this also on the envelope. You may also go to the web site http://www.lymealliance.org/ and make a donation using Visa or Master Card.

"Tell the senators that you want them to reopen the hearings on Lyme," Burrascano said, "and insist that every effort be made to reveal the true plight of the Lyme patient — problems with many doctors and insurance companies denying the diagnosis, many doctors and insurance companies denying treatment for Lyme, and unethical actions and conflicts of interest by many government and insurance company professionals."

Patients seem to agree that if Dr. Burrascano is convicted and disciplined by the OPMC, not only will his patients suffer, but thousands of other patients whose doctors learn from his publications, will also suffer.

In a letter to NY State Department of Health Commissioner Antonia C. Novello, MD, MPH, Massachusetts Lyme Disease Coalition State Coordinator John Coughlan wrote, "Many physicians, in contrast, do NOT have the courage, commitment or compassion to even consider treating patients with more advanced or entrenched Lyme disease."

A lobbyist from the Foundation for the Advancement of Innovative Medicine (FAIM) has been hired to contact New York legislators on behalf of Burrascano and other doctors currently under investigation. Patients are being encouraged to visit the FAIM website (http://www.faim.org) and become members, thus helping the campaign. FAIM's toll free number is 877-634-3246.

Patients are also being encouraged to continue writing letters to their own legislators and the people listed below. Many people have expressed the opinion that what is happening in New York affects patients everywhere.

Write to:
OPMC
Attn: A. Marks, MD

Continued on next page

New York State Dept. of Health
510 Penn Plaza
New York, NY 10001

Antonia C. Novello, MD
Commissioner of Health
Corning Tower
Albany, NY 12237

Hon. Kemp Hannon, Chairman
Senate Health Committee
Room 609 LOB
Albany, NY 12247

Hon. Richard Gottfried, Chairman
Assembly Health Committee
Room 822 LOB
Albany, NY 12248

Hon. Sam Colman
NY Assembly
Room 946
Albany, NY 12248

Governor George E. Pataki
State Capitol
Albany, NY 12224

OPMC committee appears to ignore expert testimony

In a letter dated November 18, 1999, the NY Department of Health ordered Perry Orens, MD, to deliver to the OPMC his license to practice medicine, either by certified mail or in person. Their decision was based on their interpretation of the testimony offered by Dr. Raymond Dattwyler of SUNY Stonybrook as the State's expert, and Boston University professor of medicine Sam Donta, MD, who testified on behalf of Perry Orens at the July 19, 1999 administrative hearing with the OPMC. The hearing was held before a panel consisting of Administrative Officer Hon. Marc Zylberberg; Dr. Frank Iaquinta, Panel Chair; Michael Gonzalez, PA; Dr. Sethi; and Leslie Eisenberg, Esq., Bureau of Professional Medical Conduct.

According to the official transcript of the testimony, and in response to leading questions by defense attorney Ira Maurer, Donta emphasized that there are no treatment standards for late, chronic Lyme disease. He claimed that it was impossible to say that treating chronic or persistent Lyme patients for more than 28 days is a deviation, because there is no standard. Ray Dattwyler, MD, who testified for the prosecution, maintains that up to four weeks treatment is the standard.

“But there is no information that he can supply, or anybody else,” argued Donta, “that that treatment is curative in that period of time, and that people are not left with significant treatment problems, because they are left with significant treatment problems, and,” he continued, “I think the issue is, do you belittle or disregard symptoms such as pain and fatigue, things you can't really assess on physical examination very well, and do you then substitute and say you had a fever, you had a big swollen joint, we treated the joint, the swelling started to go down, and even though you have some aches and pains and fatigue and numbness and tingling, that that is post Lyme disease. There is nothing ‘post’ about it,” he added.

Donta went on to explain how rheumatologists, who were early experts on the disease, tended to be more interested in the immunopathogenesis of disease, whereas as an infectious disease specialist, he himself is more interested in whether there is a persistent infection driving symptomatology. Different specialties understand different aspects of the disease.

“I think those are all legitimate ways to do it, but we do not have an adequate understanding upon which to make definitive opinions about standards of diagnoses and standards of treatment,” Donta said.

Donta thinks that there has historically be too much emphasis on “objective findings,” such as swollen knees and not enough on symptoms of fatigue, numbness, joint aches.

“Lyme disease is symptom rich and objective finding poor,” he said. “The so-called standards of Lyme that have been brought up by a small group of people have focused on those that have objective findings, and have basically ignored the other group, and I think this is the large group of people that constitute, in my opinion, the majority of Lyme disease.”

“What do you do about all these other people?” Donta asked. “Do you let them go and keep referring them to a psychiatrist and neurologist, and keep testing for other diseases? You don't find any other diseases,” he stated.

Later, Donta explained that sometimes patients require extended treatment periods, and while he prefers oral antibiotics, sometimes he uses intravenous antibiotics. He expressed the opinion that some physicians “may have gone too far in some directions.” He referred to a survey he conducted with Martina Ziska, MD, of physician preferences, which showed that different medicines were being used.

“I think it reflects an attempt by the doctors to improve the patients,” he said. “They hear some rationale, or some experience, somebody said I had a good experience with this, so somebody else says, let me try it.”

The panel questioned both Donta and Orens about certain records from Orens’ practice. Donta testified about his own procedures, what he would include in a physical examination of a patient, what tests he would order, and what types of notations he would record in charts. When the panel looked at some of Orens’ charts, there was some confusion about the exact sequence of events when going back in the charts to try to reconstruct how the patient had been treated and the rationale for the treatments chosen. Orens himself apparently could not figure out what he had done with a particular patient based on review of the chart.

The panel also questioned why Orens decided that a patient had Lyme disease when the test result from Stony Brook fell into the indeterminate category.

Orens responded, “As you know, I do a lot of testing. This is... almost six years later, and... there is a ton of stuff here. To go through every single one to find that report it matters very little, because there are other unequivocally positive tests on this patient for Lyme disease, and we have already established that we don't treat laboratories, we treat people.”

The November 18 letter summarized the findings of the OPMC panel:

“Unfortunately, Dr. Donta did not testify directly about the patients in this case nor did he render an opinion about Respondent’s medical conduct based on the specific records or patients in this case. Dr. Donta testified that although he previously reviews the records in this case, it was a long time ago, he did not write a report regarding his review and he did not remember much about the records. Dr. Donta testified that in any respects his own practice differs from Respondent’s medical practice. For instance, Dr. Donta treats patients with oral medications, not parenteral therapy. Moreover, Dr. Donta repeatedly stated that he could not render an opinion about Respondent’s records because he is not an expert on medical records. Dr. Donta’s testimony was of little value to the Hearing Committee.”

No mention was made of Donta’s extensive testimony about the complexity of Lyme disease diagnosis and treatment.

Dr. Orens may appeal.

California creates new Lyme Advisory Committee for public and professional education

On Friday, October 8, California Governor Gray Davis signed a bill creating the Lyme Disease Advisory Committee. The new group will be responsible for developing and establishing a state outreach program on Lyme disease.

Sponsored by state Senator Wesley Chesbro (D-Arcata), the new bill becomes effective on January 1, 2000.

“Lyme disease is a serious threat in my district, specifically in Mendocino, Sonoma and Humboldt Counties,” Chesbro said. “This Advisory Committee will provide the leadership we need to eradicate this disease, which has debilitated so many people.”

The text of part of the bill is below:

Article 2.5. Lyme Disease Advisory Committee and Information Service

104190. As used in this article the following definitions apply:

(a) “Disease” means Lyme disease recognized by the presence of the spirochete (*Borrelia burgdorferi*), a spiral-shaped bacterium, in the human body.

(b) “Lyme Disease Support Network” means the groups organized through hospitals and volunteer organizations to counsel and provide support to those individuals who have contracted the disease.

104191. (a) There is hereby created in the state department the Lyme Disease Advisory Committee composed of seven members as follows:

(1) Two from the University of California conducting research into Lyme disease.

(2) Two from the department.

(3) One from the Lyme Disease Resource Center.

(4) One from the Lyme Disease Support Network.

(5) One from the California Medical Association.

(b) Members shall be appointed by, and serve at the pleasure of, the director but shall be selected from recommendations of the represented entities.

(c) Members of the committee shall serve without compensation, but may be reimbursed for travel and necessary expenses incurred in the performance of their duties on the committee.

104192. (a) The department shall do all of the following:

(1) Establish a public information service that prints and distributes pamphlets on the disease, its diagnosis and treatment, along with telephone information numbers to the general public and medical community.

(2) Provide detailed information regarding Lyme disease and its treatment to physicians and surgeons in affected areas.

(3) Create a Lyme disease telephone hotline service for the affected areas of the state. The telephone service shall provide information on the disease, chances of contracting it, the use of vaccines to prevent the disease, symptoms, and locations of treatment. This telephone service may make use of a prerecorded information message, but shall also list a telephone number for further information.

(4) Identify, in consultation with the Lyme Disease Advisory Committee, those segments of the population who are especially at risk of contracting Lyme disease and may provide workshops, with detailed information on the disease, for those individuals, if recommended by the committee.

(5) Provide information to the Occupational Safety and Health Standards Board about which types of employees are at risk for the disease. The information shall include, but not be limited to, recommendations for those employees who should be required to receive the vaccine as a condition of employment, in order to reduce the potential liability of the employer and protect the health of the employee.

104193. The Lyme Disease Advisory Committee shall recommend to the department the content of, areas for, and amount of distribution of, the information pamphlets, and shall make recommendations to the director concerning how best to provide the telephone hotline service to the general public in California.

Political Action

Patients picket outside Madison Avenue headquarters of the Office of Professional Conduct to protest recent prosecutions of Lyme doctors.

Stephanie Gail Lavender Parke photo

Patients protest doctor harassment at NY OPMC

Over 100 Lyme disease sufferers rallied in support of their treating physicians outside the Office of Professional Medical Conduct (OPMC} in New York City on December 8. Attendees represented the East Coast as well the Midwest and the South. Support and organization were national in scope.

Protesters indicated that harassment through investigations and sanctioning of physicians who treat Lyme disease in ways that do not conform to very stringent guidelines has accelerated during 1999. Although this has gone on silently for years, physicians who are leaders in open-minded approaches are now being targeted. A total of 17 doctors are being investigated on the East Coast. Accusers in many cases are anonymous, as are the initial charges filed against the physicians.

Dr. Perry Orens of Great Neck, NY, had his license revoked on November 24. Charges against him indicated that he “overdiagnosed,” “overtreated” and “overtested” for Lyme disease. The key to these charges is the belief that Lyme is cured in about 4 weeks of antibiotic treatment. Protesters strongly disagree, citing research ignored by OPMC.

The Lyme community publicly protested the OPMC’s position on identifying, harassing and severely sanctioning Lyme disease doctors based on stringent guidelines. The guidelines used for sanctioning doctors are obsolete, biologically unfounded and ethically suspect, they contend. They demand recognition of open-minded approaches. They called for the reinstatement of Dr. Orens’ license and exposure and investigation of those individuals responsible. A massive national write-in and call-in campaign occurred concurrently with the event.

Protest organizer Lisa Smiley stated, “Investigation and sanctioning of physicians who deviate from conservative Lyme protocols is a bully tactic used to maintain predominance of a belief system that cannot be sustained in the light of current research, clinical experience and patient perspective.”

Report prepared from a Voices of Lyme (VOL) press release.

Poem

canonize me doctor
and with all this suffering
who knows
maybe even
saint

Lyme patient on newsgroup sci.med.diseases.lyme

Scientific debate stifled, patients claim

Protest, cont. from page 1

“Steere’s ‘overdiagnosis and overtreatment’ guidelines remain predominant primarily due to political and historical directives, and not from rational science, clinical experience and patient perspective,” said Rita L. Stanley, PhD, West Coast organizer and coordinator of a support group in Portland, Oregon.

Another patient commented that open exchange and discussion would have made the “media stunt” unnecessary.

“The Steere gang continues to promulgate their own viewpoint by stifling the open dissemination of information that contradicts them. This is pretty pathetic behavior in a field that is supposed to be a ‘science,’” stated New Jersey patient Jonathan Strong.

Steere has been confronted by picket lines at previous lectures and the presence of a heavy security presence was noted.

“They were very, very nervous that something embarrassing might happen to him. I’m sure he and they were embarrassed that it was even an issue that they felt he needed protection from a group of sick people on canes and a wheel chair,” said Marleen Oetzel, a patient advocate from New Jersey.

Florida veterinarian M. Alexandra Stowe, who attended Steere’s lecture, was pleased that Steere did not seem to overstep his area of expertise.

“He limited his presentation to the small subset of patients he recognizes as having Lyme disease, that is, those who have a significant arthritis in a large joint and positive blood tests (at his lab),” she stated. “Unfortunately, since Steere is acknowledged as a leading expert on Lyme disease, those patients who do not present with arthritic symptoms (a majority) and/or test negative on his tests, are left undiagnosed and go on to become severely incapacitated by their infection,” she added.

Stowe thinks tests should be modified to identify other strains/ species of Borrelia which currently are not detected by tests done at New England Medical Center.

Protestors indicated that they expected demonstrations to continue at other sites where Steere lectures. The next one is planned on January 19 in Ventura, California, to coincide with the Gordon Research Conference on Biology of the Spirochetes.

Patients plan May March on Washington

According to spokesperson Marvina Lodge of the Florida Lyme Disease Network, a March on Washington (MOW) is being planned for Wednesday, May 3, 2000, to increase America's awareness of the harassment of physicians who are aggressively diagnosing and treating Lyme disease.

“I find it impossible to understand how the National Institutes of Health, the Centers For Disease Control, and the respective Offices of Professional Medical Conduct could blatantly single-out those doctors who are trying their best to aid their

Continued on next page

Linda Finn photo

Pennsylvania mother holds sign at NIH protest.

patients to have a better quality of life," stated Lodge.

She is inviting people to participate in the March. Organizers are also seeking any individual or support group in the Washington, DC area who would be willing to act as host for housing, publicity, transportation, media coverage and other aspects of the event. People wishing to support the March are asked to contact Lodge at email LoveyOnLyme@aol.com or telephone 407-839-6016/407-839-0200.

"I would encourage anyone from any state with any tickborne disease to join those of us who suffer the most from disseminated borreliosis and coinfections caused by tickborne pathogens," Lodge said.

Patients must refuse to go along with "Politics of Denial"

An eyewitness account of Bethesda protest

by Jeannine Der Bedrosian

The Politics of Denial of Lyme Disease brought me to National Institutes of Health in Bethesda, Maryland on November 3, 1999, to protest against the award of "Astute Clinician" status to Dr. Allen Steere. Due to his "Overdiagnosed/Overtreated" philosophy on Lyme disease propounded so far and wide, it took over **three years** from my initial infection, before any doctor in New Jersey would test me for Lyme disease, and then it occurred only by "accident" (to protect the innocent I will not elaborate).

At the time of diagnosis, I was almost dead, barely functioned around four children's school schedules, and slept the other 20 hours. Three years of having my symptoms and physical distress trivialized by doctors had left me overmedicated ("all in your mind") and overwhelmed with the burden of my "mental illness."

After testing "highly positive," including coinfection with Erlichiosis, from April to November I burned. How had so many doctors managed to avoid this small act of writing on a script pad, "Test for Lyme Disease," when I presented with over 30 characteristic major symptoms.

November brought a focus and clarity to my anger – I could assuage it (I thought) by travelling to Bethesda and standing to be counted outside NIH with other Lyme disease protesters.

I could barely stand or walk, huffing and puffing, stopping every 25 feet. I traveled by public transportation to Washington D.C. – first driving to a parking lot in South Jersey, abandoning the car and travelling by trains and subways and free shuttles to my Arlington, Virginia hotel. I could not have accomplished this on the same day as the protest. I brought my little fold-up stool as I can not stand for very long, or wait in lines while stationary. My little stool goes everywhere with me.

The next day I arrived by Metro at NIH campus shortly after 11:30, with the opportunity to meet other fellow Lyme disease sufferers as they arrived. One of the first had driven in from Michigan, on behalf of her sister who was institutionalized with Lyme disease while still raising young children. Gena had tried to persuade the sister's husband to test her young-looking sister for Lyme disease, even tried to obtain a court order requiring it, but had been unsuccessful and her sister still languishes in an institution. Gena abandoned her car in Ohio when it broke down and the good folks there drove her to obtain a rental to continue her important mission.

Protesters came from nearby Maryland and Virginia, and as far away as New York, New Jersey, Florida and as mentioned, Michigan.

Continued on next page

Patients with canes and wheelchairs joined protesting group.

Linda Finn photo

We were a decrepit bunch, all in all. There were over 40 of us, altogether, including a few who came from NIH on their lunch hour and waved signs. Some patients needed canes, a wheelchair, a walker. Patty and her son came on behalf of the other son and her husband, a physician who was no longer able to practice; all have Lyme disease. Two attendees were participants in the NIH Chronic Lyme Disease study. They both wore shirts with ticks and other slogans. One of these participants had tested negative in Dr. Steere's lab but – much later – positive in several others. She would have been ineligible for this study if she had been correctly diagnosed and adequately treated in the beginning, much like myself.

One sign was littered with medication containers. A large board carried the multitude of names of victims of Lyme disease.

Immediately as we congregated in front of the Metro entrance next to NIH campus, a contingent of security guards arrived with fanfare, and the Chief of Security spent approximately. ½ hour explaining the follies and penalties of protesting there, including a night in the county jail. We were instructed that there could be no demonstrating on NIH property, no signs, no distribution of literature, not even wearing of the green ribbon, and as it was government property we could and would be arrested. A Washington attorney and Lyme sufferer moved one "giant step" over onto the public sidewalk and asked if it was still federal property. When the Chief shook his head, everyone took a giant step sideways and we continued.

The camaraderie grew quickly, so many faces from on-line matched up with names and screen names. Story after story rolled off of our tongues, comparison of symptoms, exchanges of remedies and tips. That day was more instructive to me in learning to cope with Lyme disease than several previous doctor visits.

Meanwhile two squads of security continued to observe us from a side street and a third contingent followed our actions from a truck on hill just above our protest – more room in that paddy wagon!. A fourth security vehicle circled us around…and around… and around! Every time it stopped at the traffic light, Lyme patients generously volunteered a wealth of information to the officers. All in all it was a courteous and elegant protest.

So naturally one would wish to continue this affair with attendance at Doctor Steere's honorary lecture, wouldn't one? But it was quite a hike, perhaps a mile from where we were protesting. As other NIH employees came out and conversed with the protesters, I noticed an ambulance was sent from NIH campus to the hospital just across the street. Security was unexpectedly attentive then and when the ambulance came slowly back and continued up into NIH campus. I had an odd feeling of premonition that Dr. Steere had just arrived in his "limo," to avoid recognition when passing by the protest.

My curiosity piqued, I noticed an NIH government minibus discharging passengers at the Metro Stop. I told my neighboring protesters, "Come ON, we pay taxes, this is our government and our property and that's our bus. Let's get on our bus and go to the lecture." So we did, putting away our signs (mostly). The minivan driver courteously guided us to the correct building. Inside, in the ladies room, I rolled my eyes at the female security guard there, "So many security people in one building!" "Well you know those Lyme protesters are out by the gates," she began to say more and a protester more mannerly than I let her know we were some of "those protesters." She was curious as to our motivation and very receptive to our explanations. I was wearing a picture of my family whom I am no longer able to adequately care for, my 4 young daughters, my mother-in-law with Alzheimer's disease, and my husband.

Because we were timely in our arrival, many of us had our choice of

Linda Finn photo

NIH officials, perhaps fearing mobs of unruly protesters, called out a strong security force to contain the demonstration. Their fears proved unfounded. Here demonstrators confront NIH security personnel.

aisle seats near two microphones. When Dr. Steere was being introduced, the speaker referenced the Controversy over the Lyme Disease Issue and acknowledged “as evidenced by the presence of protesters just outside our gates.” No one bothered to correct him that we were now inside of his lecture hall.

Dr. Steere’s lecture was disappointing, focused solely on a historical panorama of his experiences with Lyme Arthritis, with a bit of vaccine information thrown in. I was dismayed to see that failure rates of the Lymerix vaccine were attributed to “subsequent infection” by a tick, with no thought that, as I have heard anecdotally, the vaccine itself appears to actually **cause** the manifestations of Lyme disease in many recipients. This was not touched on or ruled out.

The turnout from NIH employees was quite sparse, so Dr. Steere was expectant when two long lines formed at the microphones at the conclusion of his talk. One astute speaker stated to Dr. Steere that in view of the negative climate for Lyme sufferers and the impact he had produced in frightening doctors, cooperating with insurers against doctors and patients, and inhibiting research which differed from his own, it seemed that the only hope was to look outside the U.S. to France and Germany for a cure.

After a few more questions from Lyme disease patients which were answered by Dr. Steere in a dissembling and ambiguous manner, the speaker abruptly terminated the session and announced Dr. Steere needed to attend his reception, which of course, piqued my curiosity – “our tax dollars” = “**our**” reception!

But first I approached Dr. Steere and his security contingent parted for me, perhaps thinking me a reporter in my suit with pad and pen. I stood a foot away from this mild man and spoke to him of how difficult it was for those of us who could not obtain even testing, let alone adequate treatment, and that his influence had resulted in denial of needed care to thousands. He apologized several times, but repeated that he was not responsible for how doctors or institutions chose to interpret his studies. I asked him what he would prescribe for treatment of someone like me, highly positive after his stated three weeks of antibiotics, in fact I was in my seventh month of full symptoms despite antibiotics.

Dr. Steere’s answer was vague. He objected that it depended on the symptoms and how they manifested and it was a complicated picture. So I refined the question.

I asked, “Suppose your own child, Dr. Steere, was undiagnosed for three years and now presented with chronic, long-term neurological symptoms and after 30 days of antibiotics, still suffered with positive test results and symptoms for Lyme disease. Could you name me ONE doctor or institution you would send her to?”

Two things immediately happened: security hustled him away, and he seemed to say, “Here.”

I obtained directions to “our” reception and passed them along to other Lyme patients. I understand many attended and also spoke with Dr. Steere and that it got quite heated and he left abruptly. I had to miss “our reception” due to the need to catch the train returning to Philadelphia. Thus I returned home by Metro, Amtrak train, Blue Line subway, Speedline, and finally a long drive in my own car, musing over the day. I was still angry.

Eventually it came to me that the Politics of Lyme Disease are far more serious than AIDS – due to AIDS, in fact, as was pointed out by my pediatrician. While Lyme disease came slowly into national consciousness despite the gravity and numbers of patients afflicted, AIDS stole center stage for those years. Their lobby was active, publicly outraged and united in their demands. Prominent spokespersons assisted the recognition and drama – even when treatment regimens began to prolong lives and improve health of AIDS patients.

Meanwhile an establishment centered on a rigid philosophy and narrowly defined treatment protocol of Lyme disease became entrenched in NIH and in state medical bodies. One catches Lyme disease from a tick, not nearly as sensationalist as the routes of transmission for AIDS, with apologies for cynicism. As a body we cannot or have not been able to attack those who disagree with our need for broader and longer treatment as “LymeOphobes, and thus an element of defensiveness is lost.

Finally, we are for the most part heterosexual, often overburdened with family responsibilities or job responsibilities or isolation from people who were once more involved with our lives. Long term illness isolates and there doesn’t seem to be a period where Lyme patients are well enough to care for their sicker brethren until their turn comes. And we can not accuse our employers or insurers of “discrimination” if we are let go from jobs or turned down for treatment. The entrenched establishment has set the rules for the Politics of Denial of Lyme Disease. My anger continues, but it continues outward. I refuse to turn this anger inward, into a debilitating depression.

Thus I patiently sewed my black MisTick costume and attended the OPMC demonstration in New York, and have written a few hundred letters since that time.

Our only hope is to make The New Millennium – Time for Lyme. We must become determined as a group that this year the Politics of Denial of Lyme Disease will become significant as history only, that we refuse to accept these politics any longer. We must set our mission to make every day count by our actions, and I truly believe that we will thus bring significant change in the way our disease is diagnosed, treated and – yes – cured.

Senators seek $125M for under-treated Lyme disease

by Robert Miller

Lyme disease in the United States is reaching near-epidemic proportions in some regions. Yet the disease is still grossly under-reported and, some doctors say, woefully under-treated.

“The standard of care for Lyme disease is more than a medical issue,’’ said Dr. Kenneth Liegner, speaking last weekend at a two-day conference on the disease at a conference at Bard College at Annandale-on-Hudson, N.Y. “It’s an international human rights issue.’’

In recent years, Lyme disease has been identified in a wide band across Europe.

Hoping to remedy at least some of those inadequacies, the state’s two senators, Christopher Dodd and Joseph Lieberman, on Monday proposed the government spend $125 million over the next five years to improve surveillance and treatment of Lyme disease and education about its cause and symptoms.

The bill the Lyme Disease Initiative of 1999 is cosponsored by the two Connecticut Democrats and Sen. Rick Santorum, R-Pa. If Congress approves the bill this month, it would receive funding next October.

The bill, along with promoting better detection of the disease, also would require all federal agencies involved with Lyme disease to “substantially improve’’ coordination of their efforts. In a press statement yesterday, Lieberman said the initiative represents “our most comprehensive effort yet’’ to fight Lyme disease, the nation’s most common tick-borne illness.

The first symptoms of the disease resemble the flu -- a fever, backache and headache -- only without any stomach upset or respiratory infection. Some people also develop a large, red rash around the tick bite. If people begin antibiotic treatment of the disease at this stage, they usually recover without complications.

But, if the bite goes undetected or sometimes, even after treatment infection from the Lyme spirochete can cause a bewildering array of problems: Neurologic ailments; insomnia; severe arthritis-like pain; fatigue; memory loss, depression and anxiety; vision and hearing problems; and heart ailments.

> ***“What’s being promoted as a standard of care for Lyme disease, especially chronic Lyme disease, is medical neglect.”***
>
> **Ken Liegner, MD**

Dr. Carmine Sorbera, director of cardiac electrophysiology at New York Medical College in Valhalla, N.Y., said at the conference last weekend that researchers are finding the Lyme spirochete may interfere with the heart’s ability to pump blood strongly throughout the entire circulatory system. That, in turn, causes dizziness and fatigue.

“It’s not hocus-pocus anymore,’’ he said.

It’s also possible the spirochete may be able to survive in the bloodstream for several months or years before reproducing and causing what some doctors call chronic Lyme disease.

More often than not, it is a multisymptom disease. Some patients go from specialist to specialist trying to treat the different symptoms without being treated for the spirochete that is the root cause of all of them.

What’s made treatment of the disease even tougher is the lack of an easy, reliable blood test for Lyme disease. Tests can show whether a patient has developed antibodies to the spirochete, but not whether the spirochete is still present in the body.

There are two diametrically opposed camps within the medical community. Some academic researchers and U.S. government health officials have publicly questioned whether chronic Lyme disease even exists; in turn, they’ve questioned whether people should be treated for several months with antibiotics to cure a phantom condition.

But many patients who have the symptoms of chronic Lyme disease and the doctors who have to treat them say the health establishment is ignoring the reality of the disease and the one option antibiotics that’s shown success in ridding people of their symptoms.

“It’s an unsatisfactory approach,’’ Liegner said at the conference, acknowledging that overuse of antibiotics can cause bacteria to mutate and become resistant to the drugs. “But it’s the best treatment we have.’’

“Galileo’s colleagues refused to look through his telescope for fear of seeing something that would upset their view of the galaxy,’’ Liegner said. “I think the same thing is happening today with Lyme disease. What’s being promoted as a standard of care for Lyme disease, especially chronic Lyme disease, is medical neglect. That will change, but only from the ground up, not from the top down.’’

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Conference Reports

The Bacteria Revolution

by Colman Jones

Part One of The Bacteria Revolution begins at the 12th International Conference on Lyme Disease and Other Spirochetal and Tick-Borne Disorders in New York City, where about 350 people have gathered to review the latest information about Lyme and other tickborne diseases.

The conference is sponsored by the Lyme Disease Foundation, headed by Karen Vanderhoof-Forschner, who was bitten by a deer tick in 1985. She didn't think much of it at the time, but upon becoming pregnant, she experienced a series of multisystem disorders, including loss of taste and smell, irregular heartbeats, and profound fatigue, although it was hard to relate these diverse symptoms to her earlier tick bite. When her son was born, however, he had evidence of a brain infection, and was later found to have Lyme disease. Forschner and her husband decided to form the foundation, hoping it would find solutions for their son. It didn't, alas: he died in 1991 at the age of 5.

Lyme disease is one of several diseases spread by insects called deer ticks. Others include human granulitic and monocytic ehrlichiosis, and babesiosis, which Dr. Gregory Bach of Colmar, Pennsylvania, calls the "brother of malaria". Babesiosis, he says, causes not only fatigue, but what's been called "babesiosis rage". Bach reports that one woman with babesiosis actually took a chain-saw to her furniture, and notes these exaggerated reactions have been implicated in suicides, even certain crimes.

Sorting out all the various symptoms caused by tickborne diseases is no picnic, and both the detection and the treatment of Lyme are surrounded by controversy. As Dr. Kenneth Liegner from the New York Medical Center in Armonk, New York, points out, many academicians have staked their reputations on the view that Lyme disease is easily diagnosed and cured. Liegner is convinced, based on many years of clinical experience, that many patients are difficult to diagnose and there may be no way of curing this infection with currently available methods.

But the notion that Lyme disease can persist in a chronic form - even after treatment - has been hard for some researchers to accept.

These uncertainties are front and center at the New York conference, which is chaired by Professor James N. Miller, of the Department of Microbiology and Immunology at the University of California at Los Angeles School of Medicine. Miller agrees that there's not a clear consensus with respect to how to diagnose Lyme disease. He points out there is no unequivocally perfect test for diagnosing the disease in people without a characteristic rash. Many develop atypical rashes, or none at all, and enter into a "latent" state - which may be short or long - where there is nothing visibly happening.

"Because some of the clinical manifestations in early Lyme disease can be very subtle, generalized and referable to other diseases", he says, "this makes it difficult to diagnose," adding the blood tests for Lyme have problems in terms of their specificity, sensitivity and reproducibility.

This uncertainty over the blood tests makes it hard for doctors to say whether a patient really has the infection or not. Dr. Charles Ray Jones works in pediatric and adolescent medicine in Hamden, Connecticut, with a practice of 1500 children with Lyme disease, ranging in age from 1 day to 18 years old. "Judging from the pattern of presentation, I feel that it is way under-diagnosed and way under-treated," he says, meaning that many cases are never identified by doctors. Even among those people who do receive treatment, many still go on to suffer a variety of ills, ranging from headaches and depression to arthritis, but it's not clear whether this hodgepodge of symptoms is due to the Lyme disease or something else.

Lyme disease got its name from the towns where it was first identified - Lyme and Old Lyme, Connecticut. In 1975, unusual arthritis cases were being reported in children. A type of bacteria, known scientifically as *Borrelia burgdorferi*, was subsequently isolated from deer ticks, and later confirmed as the cause of the illness. Recently, using high-tech DNA amplification techniques, researchers have found evidence of this bacterium dating back to Paleolithic times. Even though this agent was not even known to exist until recently, Liegner is confident it has been affecting people for millennia. The conditions it induced were called by other names, he suggests, without anyone suspecting these illnesses had an infectious cause. He adds we still don't know the range of symptoms this bacterium - and others like it - might cause.

But the notion that Lyme disease can persist in a chronic form, causing all sorts of problems for patients - even after treatment - has been hard for some researchers to accept. When Dr. Sam Donta, a leading Lyme specialist who works at Boston University's School of Medicine, first went to workshops held by early experts on the disease, he was told it only needed to be treated for two to four weeks. Yet when he saw patients start - but not finish - getting better, he looked back at the original recommendations, and discovered they were being advocated without scientific foundation.

Donta says one cannot conclude that there is no infection if blood tests are negative, and speculates the Lyme bacteria may have instead gone into hiding someplace. "People were interpreting the absence of the organism in those body fluids as meaning there wasn't any infection," he notes, "but if you think about it logically, you cannot conclude that."

Donta began comparing the standard blood tests for Lyme disease with more sophisticated tests, and soon started to question the conventional wisdom on Lyme, established by the American government's Centers for Disease Control (CDC). He began to put the picture together, and when the CDC criteria for the lab diagnosis were established, it was clear to him that those were not accurate criteria. "The shame of that now", he says, "is that physicians are still relying on a negative test as meaning that a person doesn't have Lyme disease."

While Dr. Donta and his colleagues work to uncover the true extent of Lyme disease, others downplay the very notion of chronic Lyme. The insurance industry, for example, is often reluctant to pay for better tests or lengthier courses of treatment, without clear evidence that patients are still infected. Karen Vanderhoof-Forschner says, "There is a lot of money out there to be made by having expert witnesses at trials for insurance companies say who does and who doesn't definitively have Lyme, so there is money to be made for those who feel they can clearly and easily separate those who have the infection from those who are disease wannabees."

There's no shortage of patients who have joined coalitions, like the Lyme Disease Foundation, to agitate for more research. Donta recognizes that because patients aren't dying right and left with Lyme, there isn't the support there is with AIDS, but from his perspective, Lyme is pervasive. Liegner suggests there are so many different manifestations that we're going to find that Lyme disease has a role in a lot of things that we do not yet accept or realize.

Indeed, there may be overlaps with diseases like fibromyalgia, chronic fatigue syndrome (CFS) - even Gulf War illness. Donta says "We're dealing with a whole new set of disorders, and people haven't stretched their mind to think of a different model. We've been spoiled with our antibiotics to treat acute disorders that come and go rapidly, and since there are often no objective signs [of Lyme infection], you tend to dismiss it, you say the person made it up or it's psychosomatic."

Psychosomatic illness is a label often used by doctors when they just can't figure out what's making somebody sick.

Psychosomatic illness - originating not from external influences but in the mind of the patient - is a label often used by doctors when they just can't figure out what's making somebody sick. But now that doctors have better techniques for zeroing in on hidden infections, they're finding Lyme bacteria in all kinds of patients - even those who don't show the typical symptoms of Lyme.

For example, Dr. Martin Freid recently presented evidence of infection with the Lyme germ in patients with Crohn's disease, an inflammation of the bowel which affects some 50,000 Canadians, and whose precise cause has eluded medical researchers.

Dr. Gordon Greenberg, Professor of Medicine at the University of Toronto and head of the Division of Gastroenterology at Mount Sinai, says it's not clear exactly what causes either Crohn's disease, or another inflammatory bowel disease called ulcerative colitis. He notes, "There has always been the concept that a single infectious etiology might be the cause of Crohn's or ulcerative colitis, but to date no single bacterium or virus has been linked with either disease. What is clear, however, is that bacterial flora within the gut, at least in a secondary way, perpetuate the inflammatory process in Crohn's."

Greenberg cites several lines of evidence, including studies from his own center, on the effect of specific antibiotics, which he's found to be particularly effective in helping to control the inflammation of Crohn's disease. His initial data suggest improvement or remission in up to 63% of Crohn's patients treated with antibiotics. "More and more the concept is emerging that bacteria do play an important role, and that selected antibiotics are quite helpful in the management of patients with Crohn's disease," Greenberg notes.

Dr. Freid recently saw an 8-year-old girl with blood in her stool, a typical symptom of ulcerative colitis. He prescribed medicine to calm the inflammation, but he also sent a tissue biopsy off for analysis. Surprisingly, it revealed an active Lyme infection. He put the girl on antibiotics for a month, and she made a complete recovery. "That's not the nature of ulcerative colitis, which would come back. But an infection would go away if treated properly. I thought it was fascinating."

Neither Dr. Fried nor Dr. Greenberg is sure just what's going on in their patients, but the evidence certainly points to a role for bacteria. This uncertainty over causation extends as well to mysterious problems like chronic fatigue and fibromyalgia. Some think the Lyme bug may be to blame for a lot of cases, others suspect another organism called a mycoplasma - it’s going to be a while until we know for sure.

Professor Garth Nicolson, chief scientific officer at the Institute for Molecular Medicine in Huntington Beach, California, works on a variety of diseases, including CFS, fibromyalgia, Gulf War syndrome, rheumatoid arthritis, and a number of autoimmune diseases, including MS, ALS (Lou Gehrig’s disease), and Graves’ disease. These are for the most part interrelated disorders, Nicolson says, particularly CFS, fibromyalgia and Gulf War syndrome, but there are certain unique characteristics that typify the disorders: fibromyalgia symptoms include muscle pain, aching and tenderness all over the body, as well as a number of secondary symptoms that overlap with CFS.

The origin of these diseases has been open to speculation, with suggested causes including genetics or environmental exposure to chemicals. Nicolson and colleagues have been very interested in the role of infectious microorganisms like mycoplasmas, and bacteria known as chlamydia, in the progression of these diseases, and have found chronic infections in the majority of patients suffering from them. For example, approximately 70% of Nicolson’s fibromyalgia patients have mycoplasmal infections in their blood, which he says go deep into tissues and are responsible for much of their sickness. When appropriately treated with long-term antibiotics, these patients can apparently recover, although this is dependent on a number of other factors, including other infections and chemicals in their systems. Nicolson and his institute have convinced the U.S. Department of Defense to conduct an $8 million clinical trial, testing the effects of various antibiotics in patients with Gulf War syndrome.

But it’s going to be long time before this kind of research effort is brought to bear on patients suffering from what is thought to be chronic Lyme disease, because no one seems to be able to prove they’re still infected with the Lyme bacterium. All that may change, however, with a bombshell discovery published in the November/December 1998 issue of the prominent medical journal Infection (vol. 26, p. 364-367). In a controversial paper entitled “A Proposal for the Reliable Culture of *Borrelia burgdorferi* from Patients with Chronic Lyme Disease, Even from Those Previously Aggressively Treated,” American researchers describe a complex technique with which they can find previously undetectable Lyme bacteria in the blood of patients with chronic disease.

> ***“If you are able to culture the bacteria, then no one can doubt the diagnosis any more, especially in the chronic late stages, which the controversy is about.”***
>
> Neurologist Hamid Moayad

Dr. Hamid Moayad, a neurologist from Fort Worth, Texas, first heard from Phillips in 1997, through their joint association with Lida Holmes Mattman, a Wayne State University microbiologist well-known for her work on stealth pathogens, and who now runs a private lab in a suburb of Detroit. Mattman says the Infection paper developed because Moayad and Phillips both had many Lyme patients, and supplied her with blood samples, out of which she allegedly grew the Lyme bacterium in laboratory cultures, where it could be studied indefinitely.

The material used to grow the Lyme bacterium - the culture medium - has to be ingeniously designed. Lida Mattman’s recipe includes sugar, starch and a variety of laboratory chemicals (along with Detroit tap water). Using this special culture medium, the Phillips research team claims to be able to grow the Lyme bacterium from the blood of patients with suspected chronic Lyme disease - patients who had been missed by the standard tests.

Culturing a disease organism from a patient is seen as the gold standard by which all other tests are judged. The publication of the Phillips paper -allegedly proving that patients with chronic Lyme disease are still infected with the Lyme bacterium - opens up a Pandora’s box for patients and researchers alike. “This would actually be the gold standard for diagnosis of Lyme disease”, ventures Moayad, “because if you are able to culture the bacteria, then no one can doubt the diagnosis any more, especially in the chronic late stages, which the controversy is about.” This article, he says, “proves without a shadow of a doubt that it is a chronic infection - chronic Lyme means chronic infection.”

But the paper has come under fire from both patients and scientists alike, who question its conclusions. Rita Stanley first contracted Lyme disease many years ago, and went on to start several support groups for Lyme patients in the Northwestern part of the U.S. She remembers the excitement that initially greeted the Phillips paper. Stanley recalls, “This is exactly what the doctor ordered - we need a test like this, but as in everything else, things aren’t cut and dry, especially in science. One has to have an eagle eye to ask the question: is this valid?”

James Miller would like to see the work reproduced before he can accept it. “It was a very, very provocative study, one that is very important, but because it is so provocative and so important, it needs to be reproduced.”

Controversial test would revolutionize understanding of Lyme

The problems faced by the Phillips paper represent a good illustration of the problems faced by any revolutionary finding in science - problems that have been well described by historians like Thomas Kuhn. When a paradigm-shattering discovery is presented, most people reject it because it doesn’t fit with their picture of the world. But how can there be so much controversy over a paper that’s appeared in an eminent, peer-reviewed, journal like Infection. It must be correct, right?

Not necessarily. Even the editor of the journal tells me he’s not sure if Phillips is right, since other labs still haven’t been able to reproduce the results, at least not yet. Dr. Walter Marget, speaking from Munich, says “Our reviewers are very, very skeptical, and personally, I am not very enthusiastic about this study.” Marget cites experienced Lyme disease researchers in Germany who have tried to reproduce Phillips’ results - but to no avail.

One of those researchers is Dr. Dieter Hassler in Heidelberg. “[To] my knowledge, nobody worldwide has found so much borrelia in culture like Phillips has,” Hassler says, “and we don’t know exactly why. I can’t believe that so much borrelia survives, but I’m not sure, and I spoke to Dr. Marget and I told him ‘we have to discuss it, we have to try it... if other work groups are able to find the same, it would be sensational.’”

You might be surprised that science articles get published before they’re reproduced and verified. But publication is often an invitation to other researchers to try and duplicate the discovery; and so far no other Lyme researcher has been able to reliably cultivate the Lyme organism from the blood of patients allegedly suffering from the late stages of the disease.

A number of concerns surfaced in interviews with other prominent Lyme researchers at the New York conference, including Dr. Richard Tilton, who is medical director at Boston’s BBI Clinical Laboratories, as well as serving as editor-in-chief of the Journal of Clinical Microbiology. Tilton says “If the work can be corroborated, then it is truly remarkable. However, based on the paper that was published in Infection, we will have a very difficult time repeating that work.” He says he tried unsuccessfully to grow a standard laboratory strain of *B. burgdorferi* in the Mattman medium, but was later told he had the wrong recipe.

Moayad insists the culture technique developed by Dr. Mattman is a very reliable culture for this bacteria, a technique he says took her 5 to 6 years to come up with, and he’s confident it will be reproduced soon.

Other experts can’t understand how the Lyme bacteria could still persist in the blood of patients who have been aggressively treated with antibiotics for months, even years. The answer may lie in a very important idea that surrounds the work of Phillips and colleagues: disease-causing bacteria may be able to transform themselves into something that’s resistant to standard treatment and invisible to the body’s immune system.

Mounting evidence that bacteria may form cysts

Dr. Moayad says the Lyme bacteria may take a form different than the usual coiled spiral shape characteristic of the spirochete family to which it belongs. There’s a lot of evidence, especially from the older syphilis literature, that suggests spirochetes - (syphilis is caused by a spirochete, like Lyme) can form what are called “cysts”, containing tiny granules that may form the basis for new “daughter” spirochetes.

The discoverer of the Lyme-causing spirochete *Borrelia burgdorferi* is Willy Burgdorfer, after whom the spirochete is named. Dr. Burgdorfer, a microbiologist and editor-in-chief of the Journal of Spirochetal & Tick-Borne Diseases, gave the keynote address at the New York conference - The Complexity of Vector-borne Spirochetes (Borrelia spp) - which explored the idea of spirochete cysts “hiding” in the human body. Burgdorfer notes this was once called “granulation theory” and was considered as the organism’s mode of reproduction. He’s not sure whether the cyst forms represent a true propagative mechanism, but he is confident they represent a complex defense mechanism of the organism in a human host.

Asked what implications this way of looking at spirochetes has for the diagnosis of Lyme disease, Burgdorfer says “It’s probably the answer for the difficulties we have in diagnosing Lyme and other spirochetal diseases, in that we can demonstrate these cysts by microscopy, and once they are in the tissues of the patient, we can no longer detect them. It is quite possible that this material that we cannot see by microscopy is responsible for producing prolonged and chronic disease.”

Burgdorfer is asked whether he’s seen the Phillips paper, which purports to have reliably identified this same “cyst” - or “bleb” material, as it’s called - from the blood of late-stage Lyme patients. He hasn’t seen it, but when shown a copy, responds immediately: “This is exactly what I’m talking about”.

He points to the electron microscope photographs included in the paper. “Here you see blebs, and these are shed by the mother spirochetes, and they are thought the germinative units out of which the daughter spirochetes develop. I personally believe that the significance of these blebs as the agent responsible for prolonged and chronic disease is very important, and it may be the answer to the diagnosis of these chronic diseases such as Lyme disease - because that's what we are looking for: something that produces diseases long after the initial treatment, and then relapse occurs after several months - or years - and the question is: where did this relapse come from? Well, it may come from these surviving crystals or bleb material that is in the tissue, and it stays there until the antibiotic or immune pressure is gone, and then when the conditions are right for its further development, they develop into typical spirochetes again."

It is very difficult, he says, to see these blebs or these morphologically atypical spirochetes microscopically in tissues. "You don't see a typical long spirochete - all you see is granules, and atypical material, and to demonstrate that this is actively living material is very difficult."

Dr. Burgdorfer and I proceed back to the conference, where we bump into Moayad, one of the coauthors of the Phillips paper. Burgdorfer reminds him the notion of a spirochetal life cycle was first proposed in the syphilis literature long ago, which described how the syphilis organism (*Treponema pallidum*) is not only present as a classical, beautiful spirochetal structure but it may also adopt "cyst-like" forms. Liegner notes "one couldn't even recognize these as having anything to do with syphilis or spirochetes unless one had made a very detailed study of the nature of the syphilis organism in tissues under various conditions."

In other IDEAS programs, we've heard about how the syphilis spirochete may be causing a lot of what we call "AIDS", despite remaining undetectable on blood tests (see What Causes AIDS? A Second Look, aired November 6 & 7, 1991, and Déja Vu: AIDS in Historical Perspective, aired January 9 & 10, 1996). It's possible it might elude detection by turning into these cyst-like forms. (see "Implications of the recent Lyme culture technique for the diagnosis of syphilis", a paper by John Scythes and Colman Jones, presented at the Lyme conference).

Debate favors existence of cyst forms

James Miller, who has worked for nearly half a century with the spirochetes of both Lyme and syphilis, says, "There's never been any definitive proof that the so-called cyst-like forms of *T. pallidum* occur in vivo, either in an animal or human." He notes that when the fluid from lymph nodes of syphilitic rabbits - in which he could not find any organisms - were injected into rabbits who had never been exposed to the disease, the newly-infected animals developed the disease, complete with classic spirochete organisms. But he can't say whether there were cyst-like forms present in the lymph nodes of the original rabbits, or simply very few spirochetes that he could not detect.

Does Burgdorfer think that everything that he's told me about Borrelia would apply to Treponema as well? "Of course. As far the ability of *T. pallidum* to undergo development into cyst forms, that has already been proven."

"And of course, in the old literature, these formations of the spirochetes were considered to be a degeneration process due to the fact that spirochetes cannot survive under these conditions and therefore they will eventually die and no longer develop. But in those days all the investigators had was the ordinary microscope to investigate what the spirochetes looked like. And then once the spirochete developed into these cyst forms, they were no longer detectable by the ordinary microscope. So, for them, that was the end of the spirochetes and they called it degeneration."

"Yet there was that other group of scientists who said, 'No, all these are a phase in the complex development from a mother spirochete to a daughter spirochete'. Still today, both theories have a lot of supporters. A lot of scientists say it has nothing to do with the further development, it has nothing to do with the immune process, and these are organisms that degenerate and are no longer able and capable of reverting to actively developing daughter spirochetes. Yet there is now mounting evidence that this complex development, and the ability of the organism to withstand unfavourable conditions, that this is true."

At the University of Massachusetts at Amherst, biologist Lynn Margulis is famous as one of the leading proponents of the Gaia Hypothesis - the idea that the earth as a whole acts like a gigantic living organism. Her concepts of symbiosis - the natural coexistence and co-development of different organisms - have transformed the study of evolution.

Part of Dr. Margulis' work involves looking at microscopic spirochetes found in the natural environment. Margulis says that free living spirochetes set a precedent, in the sense that they can survive desiccation. She has gone into their natural habitat and removed muds for as long a period as a few years - muds which look to the naked eye to be dry.

"We put that mud material back into supportive media for spirochetes and we see spirochetes come out - the spirochete form; which suggests that spirochetes are hiding in a form that's not the swimming spirochete.

Bacteria form cysts for self-preservation

"Now, if we take those spirochetes that look fine and healthy, and we put them into any kind of media that is threatening to them, they immediately round up, they pull in their bodies. And this is active: this is not a falling apart, like when you hit them with alcohol or something like that. It's not a lysis, it's not a falling apart, it's not immediate death like you could easily cause immediate death by lots of negative conditions, like too much acid and so on. It's not the extreme that you see in immediate death but quite the contrary: you see active cells ballooning out their membranes, actively pulling in their bodies."

A videotape of spirochetes called Spirosymplokos (found in the hindguts of desert termites) shows the vigorous recoiling of the organisms into little balls, a remarkable behaviour to watch in real time as Margulis explains what we're seeing.

"Making these membranous structures, that is making these non-spirochetal type morphologies, is a normal part of the life history of spirochete bacteria. It's likely that organisms like Borrelia and Treponema that have been found in human tissue can burrow into tissue and make the same kind of resistant bodies, and wait and come out when conditions are suitable twenty years later. I mean, I've got a couple of years in mud, why not in human bodies?"

In a paper published in the Proceedings of the National Academy of Science ("Composite, large spirochetes from microbial mats: Spirochete structure review", Proc. Natl. Acad. Sci. USA, vol. 90, p. 6969, August 1993), Margulis and colleagues note that confusion concerning the identification of spirochetes, especially *Treponema pallidum*, persists even among scholars who should be better informed. A recent book exacerbates the problem: "Syphilis has long fed on an hysterical panic that has ill-served the cause of prophylaxis .... Nowadays, by contrast, syphilis feeds on the carefree disdain of the general public. Can penicillin vanquish it? Of course, but one still has to know that one is contaminated. The treponema is a tiny fragile thing, a vulgar protozoan, not even a virus. But this fragility, which has so far made it impossible to culture in vitro and thereby gain a sufficient understanding of its modes of operation, assures its survival."

In her lab just outside of Detroit, Lida Holmes Mattman, Professor Emeritus at Wayne State University, has spent many decades studying all the different forms that bacteria can take, publishing a textbook entitled Cell-Wall Deficient Forms, published by CRC Press LLC.

Mattman says the first course on microbiology teaches everyone that bacteria have only a few shapes - balls, either in ones, twos or in chains (streptococci); rods or sticks (the well-known *E. coli* bacteria), and snakes (spirochetes and other spiral-shaped organisms).

L-forms are normal part of bacterial life cycle

But Mattman has discovered there are odd forms too, including what are called "L-forms" of bacteria.

"I first realized there was such a thing as an L-form when I held in my hand a test tube that was very cloudy with broth. I had put some staphylococci in there, but when I made a smear of it, and heat-fixed it, I didn't see any organisms. Yet I could take a few drops of that and put it in fresh broth that wasn't cloudy, and in a day it would get cloudy. But I didn't get any of these gummy colonies you can see with the naked eye. Then I realized there was something there I was missing, and I have been looking at those missing things ever since."

Mattman says it's a terrific misconception that L-forms are only produced by abnormal situations. "On the contrary, this is a normal way that bacteria grow, often 10 times more this way. It's as if you only recognize a man if he has a tuxedo on! Most of them go around very casually, and without a name-plate!"

The only way to definitely identify these odd-shaped bacteria, Dr. Mattman says, is by using very sophisticated biochemical techniques. Mattman says there's a misconception that these cell-wall deficient organisms are harmless - not so, she insists.

"They're causing all sorts of problems." How does she know? "We find them in autopsies. We can also put them in animals and prove they make people sick."

I ask Mattman if there is something different about this lab that allows her to see these L-forms. "Maybe as a teacher I had a little more time than I did as a clinician, because someone was telling me how many stains he has to look at in one hour... we spend twenty minutes on one smear, so it's a matter of time."

The kind of research Mattman is doing isn't exactly familiar to most of the doctors I spoke to, who hadn't heard of this work. Garth Nicolson says much of the new molecular microbiology is not present in medical training today, and none of this was presented to physicians who received their training 10 or 20 years ago. But now, he says, there's an emerging awareness of the role of these infections in a variety of different diseases, and it will only increase with time.

Indeed, as new research is showing, there may be a lot more to bacteria than we thought. Tilton says "As we are in the midst of a revolution in information technology, I think we have a similar revolution before our eyes with regard to the role of microorganisms in diseases of humans."

This article is excerpted from "The Bacteria Revolution," a 2-part radio documentary series by Colman Jones, broadcast on the Canadian Broadcasting Corporation (CBC) Radio program IDEAS on May 28, 1999 and available on the World Wide Web at http://radio.cbc.ca/programs/ideas/bacteria/index.html

Bard conference focuses on new findings, neuro-Lyme

by Stefanie Ramp

As one of the fastest-growing infectious diseases in the United States, and reaching near epidemic proportions in the Northeast, the tick-borne Lyme disease continues to plague the medical community. Because it can be difficult to diagnose and treat, Lyme has engendered an unparalleled acrimony amongst physicians, researchers and patients while definitive answers remain evasive and people suffer in the interim. Conventional wisdom about diagnosis and treatment of Lyme has been recently questioned and in many cases found faulty, and though many doctors have adjusted their approach in accordance with new findings, many others are unacquainted with Lyme's myriad and wily symptoms, particularly in the disease's advanced stages, which can cause serious neurological effects.

With the goal of educating healthcare professionals and local community, several Westchester County physicians organized a weekend-long conference held at Bard College in Dutchess County, NY, earlier this month. The conference attracted about 250 attendees each day from all over the Northeast, including a considerable number of Connecticut's patient advocates, along with more than 40 physicians and a respectable assemblage of allied healthcare workers.

One of the event's organizers, Sandy Berenbaum, a psychotherapist in private practice in Wappingers Falls, N.Y., noted in a recent interview that the conference was very well received and accomplished most of what it set out to do. However, Berenbaum was disappointed with the lack of response from area physicians, particularly since Dutchess County has the highest rate of Lyme disease in the nation aside from Block Island, RI.

The conference drew doctors from all over the Northeast, Washington D.C., and the West Coast, and even a member of the NASA space program. Many of Lyme's leading figures, including Connecticut physicians Dr. Charles Ray Jones, Dr. Amiram Katz and Louis Magnarelli, PhD, a researcher at the Agricultural Experiment Station, lectured on all aspects of the disease from tricky diagnosis to pediatric cases to the sometimes deleterious effect of menstruation on chronic Lyme. SmithKline Beecham supplied Dr. Michael Caldwell, Dutchess County's Health Commissioner, to speak about the pharmaceutical company's Lyme vaccine, LYMErix, which has prompted great concern from much of the medical community, including most of the conference speakers.

According to Berenbaum, Caldwell was unable to assuage many anxieties or answer questions raised by attendees, which further disconcerted physicians as well as the community at large—particularly since SmithKline Beecham plans to file for FDA approval of LYMErix for children by year's end.

Berenbaum spoke on Lyme's psychological manifestations, which can be serious enough to cause psychotic episodes and suicidal and homicidal tendencies. Berenbaum's practice, the Family Connections Center for Counseling, focuses on adolescents and family conflict, and she has encountered an increasing number of adolescent Lyme cases in the past 13 years. Because in children Lyme often first presents itself as behavioral and learning problems, Berenbaum believes that mental health professionals should be vigilant and consider themselves the first line of defense against undiagnosed Lyme. She and her partner Lynne Canon developed a system dubbed "The Berenbaum/Canon Screening Protocol" which is fast gaining popularity and which helps determine the possibility of Lyme.

Conference co-director Dr. Steven Lipidus, a Westchester County plastic surgeon, became involved with Lyme education nearly 10 years ago when he diagnosed himself with Lyme after 14 colleagues missed the diagnosis. He organized his first conference in 1990, and this, his second effort, is the first of its magnitude in the area since then, according to Berenbaum. Dr. Kenneth Liegner, a respected pioneer in chronic Lyme treatment, also co-directed the conference and was joined by his partner Janice Kochevar, a board Certified Nurse Practitioner specializing in adolescent Lyme in Armonk, N.Y.

Willy Burgdorfer of the National Institutes of Health, the scientist who discovered the Lyme pathogen, gave the keynote address. Berenbaum hopes to make the conference an annual event.

From the Fairfield Co. Weekly's website 11/25/99

Bard tapes and syllabus available

Video orders are being taken by the Lyme Disease Association of New Jersey. Send a $25 check for a set of three tapes to:

LDANJ
P.O. Box 1438
Jackson, N.J. 08527

If people are interested in having a copy of the conference syllabus, email LymeConf@aol.com or contact the Lyme Times editor. If there is enough interest, another printing will be ordered. Cost will be in the $20-25 range.

Michigan conference changes ideas about Lyme

by Kim Weber

Reprinted with permission from Tick Talk, newsletter of the Michigan Lyme Disease Association.

On September 25th, the Michigan Lyme Disease Association, hosted a conference for clinicians with full capacity of over 120 attendees who expected to hear about diagnostic and treatment modalities of Lyme disease. However, it became quickly apparent that there is a quiet revolution going on in the arena of tickborne diseases. Six guest speakers at the Ashman Conference Center in Midland, Michigan presented surprising and insightful findings on the wave of technological advances and increasing clinical studies.

In recent years, new discoveries have begun to broaden the scope of focus for Lyme research. This conference reflected the increasing trend of Lyme disease sharing center-stage with emerging tickborne diseases such as babesiosis and ehrlichiosis. With the knowledge that a patient can acquire more than just Lyme disease from the bite of one tick, the physician's understanding of this disease has dramatically changed. Therefore, patient diagnosis and management is now more complex than ever.

For decades, the reliability of lab testing has been debated; but, new methods are being more widely utilized for earlier and more reliable results. This important information will help back up the crucial clinical diagnosis. Even with progress in serology, clinicians are counseled not to rely solely on lab results for determination of disease. The importance of taking a careful history and thorough exam is still emphasized for diagnosis.

Patient management is changing as therapy becomes more tailored to the individual disease(s). Armed with knowledge from other infectious diseases such as HIV, the speakers concurred that patients may require a 'cocktail' of medicines to control the symptoms of Lyme disease and that patient compliance is imperative to prevent drug resistance or relapse of disease. In light of these findings and new information coming in at a faster pace than in previous decades, the importance of physicians being current was underscored by the guest speakers. Their unwavering commitment to learn and work toward solutions for these insidious diseases is reflected in the following synopsis of these respective speakers' presentations.

Ed Bosler, PhD, of Stony Brook, New York. Entomologist and member of the research team that discovered the bacterium, *Borrelia burgdorferi*, that causes Lyme disease. As moderator, Bosler set the tone for the conference with his emphasis on newly recognized tickborne diseases. His field studies are tracking coinfection in deer ticks (*Ixodes scapularis*) with Babesiosis and ehrlichiosis. This reflects a trend in endemic areas in the Northeast, showing up to 80% coinfection rate with Lyme disease. With this in mind, Bosler recommended that those people without a spleen or who are immuno-compromised, limit exposure to endemic areas of the Northeast. In these cases, contracting Babesiosis could cause severe illness or even death.

The assumption that deer commonly transmit infection of ticks, was corrected by Bosler. He clarified that the deer fit into the scenario by maintaining the tick population that is needed for the cycle of Lyme disease. However, it is the white-footed mouse or other small rodent that is responsible for transmitting the infection to the larvae and nymphal ticks. This is the crucial stage where the infection is acquired by the tick.

Bosler briefly commented on the 1997 veterinary research study tracking canine Lyme disease in southeast Michigan. Although an overall 3.4 percent positive result is not remarkable figure alone, it is the increase from .1 percent in 1991 that has caused Bosler to take notice.

According to Bosler's field studies, within one summer infection rates can triple in ticks. He has observed areas with few ticks can become endemic within five short years. Bosler's observation has led him to conclude that this region has the proper wildlife to support a continued increase of infection.

Steven Phillips, MD, of Ridgefield Connecticut is on the Medical Advisory Board for the Lyme Disease Foundation and has conducted research on Lyme disease and ehrlichiosis. Acknowledging that diagnosis is still mainly clinical, Phillips feels that much of the traditional lab testing is not reliable. With the knowledge that spirochetes can evade the patient's immune response and resist antibiotics with antigenic shifting, he has taken a novel approach to screening for Lyme disease.

"This disease is always being looked for in its classic form [corkscrew shaped], and this is why it is so often missed," said Phillips. He elaborated that spirochetes can and will often change shape when being challenged in a hostile environment. Antibiotics will cause this phenomenon as well as the patient's own immune response. This explanation can account for the resistance to antibiotics. Also, the conversion of the spirochete to a cyst form (L-form) along with other forms mentioned, will not only render certain antibiotics powerless, but will also cause an increase of false negative lab results. Understanding this phenomenon may help the physician determine how to more effectively treat the patient.

Leonard Schuchman, DO. of New Jersey serves on numerous medical boards and his practice is dedicated to Lyme treatment. Schuchman sees patients who are mainly in the chronic stage of Lyme disease. Since his group practice is a treatment center, most of his patients are “someone else’s failure.” Many of these patients already have a thick chart and have had extensive serological testing. However, Schuchman is now favoring and relying on PCR testing (polymerase chain reaction) to aid his diagnosis. This particular test looks for the “genetic fingerprint” based on replicating the actual DNA of the bacteria. Previous concerns of false lab results due to contamination have been assuaged with the development of better controls. Now with PCR, Schuchman is confident that a positive result is a reliable indicator of infection with *Borrelia burgdorferi* (Lyme disease). However, he warned against using a negative result to conclude that a patient is cured. PCR testing is recommended monthly for up to one year to determine if the infection actually has cleared. Intravenous therapy can be continued while testing with PCR. Schuchman mentioned a preference for Rocephin over Claforan due to problems occurring with white blood cell count falling dangerously low.

Michael Cichon, MD, is a consultant for Department of Infectious Disease, Florida. In private practice for 25 years, Cichon enumerated the challenges for physicians who see a patient with Lyme disease for the first time. For example, he is seeing a growing number of patients presenting with symptoms of chronic fatigue and arthritis. He observed that these symptoms, and others, overlap with Lyme disease making it difficult for a physician to know what disease he is actually treating.

Cichon elaborated that the attending physician might also find treatment a challenge when the differential diagnosis is fuzzy. What will work for one illness, may not work for another illness with similar symptoms of different etiology. For example, alleviating autoimmune symptoms with steroids would cause a bacterial infection to run rampant as in the case of Lyme. Cichon also acknowledged that physicians my be wary of treating Lyme disease because of the problems associated with antibiotic induced colitis or yeast superinfections from *C. difficile* toxin. However, he noted that this can be avoided with adjunctive therapies such as daily doses of acidophilus and plain yogurt. Using Dr. Horowitz’ protocol for treatment of Lyme disease, Cichon is seeing good results with doxycycline and flagyl (metronidazole). He also recommends B vitamins, immune gamma globulins (IGG). In conclusion, Cichon commented, “If you don’t look for a disease, you won’t find it.” He observed that this is especially true with Lyme disease and may account for the main reason why patients are having such difficulty being diagnosed.

Richard Horowitz, MD, of Hyde Park, NY, has been a Lyme disease clinical researcher since 1992. Being in practice eight years with over 2000 patients, Horowitz has found coinfection with Lyme disease in his more chronic patients. These patients have tested positive for babesiosis and/or ehrlichiosis. A patient who is coinfected will need different therapy than with Lyme disease alone, stressed Horowitz. Whether a patient has one or more of these diseases, he recommends using a combination of drugs for the most effective therapy. Also, optimal and consistent doses are imperative to prevent drug resistance. Horowitz has witnessed better and sustained improvement with patients who adhere to these guidelines. He compared Lyme disease to syphilis, pointing out that these organisms are heat-sensitive. He noted drug therapy is more effective with raising the body temperature daily to 102 degrees for a period of time. Horowitz also introduced an old drug for new therapy with Lyme disease. Flagyl is now being used by physicians who are consulting with Dr. Horowitz. He reported there has been appreciable improvement with some patients. For babesiosis, he advises doing serial assays with PCR testing. When the patient is positive, he uses antimalarial drugs and artemesia (herb) with Lariam. Persistent symptoms have been dubbed by some physicians as “post-Lyme syndrome” characterized by an autoimmune response; however Horowitz referred to studies siting reasons for chronic illness - suppressed immune response, ability of bacteria to hide from antibiotics, and antigenic shifting of the organism itself. It was noted that patients will continue to slowly improve on antibiotic therapy and would refute “post-Lyme syndrome.” Duration is different for every patient. For some that could mean several years before endpoint of therapy. In every case however, Horowitz will treat the patient until symptom-free for two consecutive months.

Michael Ledtke, MD, is a family practice physician in Michigan. He has acquired much of his knowledge from international conferences and personal experience with family members with Lyme disease. Ledtke finds that many of his patients have already been diagnosed with Lyme disease before seen by him. After a short initial treatment these patients are basically given up on by other doctors, maintains Ledtke. Often these patients were never ill before contracting Lyme disease and then suddenly their illness was dismissed by physicians who treated them like hypochrondriacs. These patients often require more time than many physicians are willing to give.

"Treating Lyme is definitely not profitable," said Ledtke. "It takes commitment and patience. When treating Lyme disease, you can't just write a prescription and send the patient home."

Upon the initial visit, Ledtke devotes up to 90 minutes for examination and taking patient history. The office visit involves educating the patient about adjunctive therapies and a healthier lifestyle. Dr. Ledtke finds that using a symptom chart to evaluate the patient on each visit helps to determine his treatment regime. These charts have also revealed that when there is stress, the patient's progress suffers. This finding underscores the need for treating the whole patient, not just the disease.

A positive patient outcome require time and commitment on the part of both physician and patient. However, Ledtke asserts that long-term therapy, is cost-effective by giving the sedentary patient back a job and personal life. He notes that listening to the patient is important and can be a good learning experience for the doctor.

Noting that he is inundated with patients from Michigan and surrounding states, Ledtke invites other doctors take up this challenge.

For detailed information on treatment guidelines, please have your physician contact the MLDA for referral to above speakers.

For information, contact the MLDA 1-888-784-LYME.

Washington, DC MOW Rally planned for Wed. May 3

The Lyme Disease Foundation and Marvina Lodge are working together on the MOW rally (see article on page 22).

Honorary Chairs: Senator Christopher Dodd (CT) and Congressman Christopher Smith (NJ)

The schedule is tentative and subject to change.

11:00 - 11:45 - Marching, media interviews (senate swamp)

Noon - 12:30 - Press Conference Senate Swamp (Northeast side) in front of the Capitol Building (Driveway area). Senators, Representatives, and others will speak. Media will be attending. Your attendance will demonstrate the need for improved diagnosis and treatment methods. You should carry a poster.

12:30 pm - 4 pm - Personal visits with Senators & Representatives

Wear a Bell & Green Ribbon to Help WAKE-UP WASHINGTON! Wear a cow or sleigh bell to let others know you are there as you walk through the halls of the Capitol! Make sure the bells are removable - so you can go through security.

Your poster should be bright and large. Include your state, name and photo of patient, cost of the disease (medical bills, lost job time, etc.)

The law prohibits the use of sticks with signs. Everyone must go through security when entering Congress.

Free buses are being arranged from Philadelphia & New Jersey.

All patients and advocacy groups welcome!

For more information contact the Lyme Disease Foundation, 1 Financial Plaza, Hartford, CT 06103 tel. 860-525-2000 or email Lymefnd@aol.com or Marvina Lodge (see Calendar, page 40).

Patient help needed for educational outreach project

The Lyme Disease Resource Center is dedicated primarily to education, and the Lyme Times is our main educational outreach effort. Patients can easily assist this effort by making sure their local libraries have a Lyme disease file, filled with brochures, newsletters, medical journal articles, and the Lyme Times. We are making a special offer to get you started - five back issues for $10 to cover shipping and handling, plus a free one year subscription to the library of your choice. *Only two people took advantage of the gift offer in the last issue of the Lyme Times.* It will take a century to educate the public at that rate.

We also have a Lyme Times bulk distribution policy. This is designed for special events like rallies, workshops and conferences. The rates are reasonable, and we will negotiate if finances are a problem. For large orders (over 500) it is best to order before an issue goes to press, so plan ahead and order early.

An application form for bulk Lyme Times is available from the LDRC secretary, PO Box 707, Weaverville, CA 96093, tel. 530-623-3227, or email LDRCsec@snowcrest.net.

We hope that more people will order the Lyme Times for their public libraries, where they will benefit many readers. The Lyme Times is the premier publication of the Lyme disease community, with in-depth coverage of up-to-date issues. Help us to help others by distributing the Lyme Times and taking advantage of these special offers.

Yes! I'd like to give a year of the Lyme Times...

Please begin a one year subscription of the Lyme Times for $25*...

- as a gift • for myself • Special Offer • this is a renewal
- I enclose an extra $10.00 for a packet of back issues for my library (see special gift offer).
- I enclose $_________ as a tax-deductible contribution to the LDRC.
- Enclosed is my check for total amount of _________________. *Please make your check payable to LDRC and mail with this form to LDRC, PO Box 707, Weaverville, CA 96093.*

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*Annual rate for the US. Canada and Mexico add $10.00, other foreign countries add $15.00 for air mail. US funds only, please.

Special Offer! We will send a free one year Lyme Times subscription to your library. Check the box “Special Offer,” fill out the “Gift For” section, and send it to us. Please check with your librarian before ordering to make sure your gift is welcome. For an extra $10, we will send a packet of 5 back issues to help your library start an educational Lyme file.

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- I enclose $_________ as a tax-deductible contribution to the LDRC.
- Enclosed is my check for total amount of _________________. *Please make your check payable to LDRC and mail with this form to LDRC, PO Box 707, Weaverville, CA 96093.*

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*Annual rate for the US. Canada and Mexico add $10.00, other foreign countries add $15.00 for air mail. US funds only, please.

Lyme Disease Foundation Conference information

For contact information and prices, see Calendar on back page.

Program Agenda Saturday, March 25, 2000 (8am -5:15pm)

· Keynote: Richard Blumenthal, Attorney General of Connecticut ·

· West Nile virus - Epicenter to epidemic and expectations in 2000: McNamara

· West Nile virus in Connecticut: Anderson

· Overview of human ehrlichioses and Rocky Mountain spotted fever in the US: Padduck

· Coinfections: Magnarelli

· Lyme disease in the South: Oliver

· Analysis of Southern Borrelia: James

· Babesiosis: Krause

· Preliminary in vitro and in vivo findings of hyperbaric oxygen treatment in experimental *Borrelia burgdorferi* infection: Pavia

· Immunity against host-adapted Bb in the rabbit: Miller

· Immunologic aspects of Vlse, a Bb antigenic variation protein: Norris

· An Immunodominant peptide of Bb Vlse: Role in diagnosis and pathogenesis: Philipp

· Antibiotic treatment of Lyme borreliosis: A review of results with dogs: Straubinger

· A *Borrelia burgdorferi* repetitive antigen that confers protection against experimental Lyme disease: Skare

· Use of borreliacidal assay in the serodiagnosis of Lyme disease: Schell

· Lyme neuroborreliosis: Role of PCR and culture in the diagnosis and in the confirmation of relapse after antibiotic treatment: Oski

· Laboratory testing panel: Tilton, Shah, Schell, Golightly, Mordechai

Program Agenda Sunday, March 26 (8am - 5pm)

· Keynote: W. Burgdorfer, PhD, MD

· Characterization of an immune evasion system in Lyme disease spirochetes: Marconi

· Environmental regulation of gene expression in Bb: Samuels

· Matrix metalloproteinases in Lyme disease pathogenesis: Perides

· Interleukin-10 regulation during acute Lyme arthritis in dogs: Straubinger

· T-cell response: Marques

· Protection against tick-transmitted LD in dogs vaccinated with a multiantigenic vaccine: Frey

· OspA vaccine update, including serologic results and range of EM rashes: Parenti

· Atypical EM and acute Lyme disease: Masters

· Neurologic Lyme disease in children and adolescents Pietrucha

· Cognitive deficits in children with chronic Lyme and the public health/educational implications: Rissenberg

· Neurologic Lyme disease in adults: Coyle

· Neuroimaging in neuropsychiatric Lyme disease: Uses, abuses, and the future: Fallon

· Pharmacologic properties of antibiotics and their relevance to Lyme disease: Donta

· Treatment Roundtable: Fein, Leigner, Donta, Pietrucha, Burrascano

Order Lyme Times in bulk for your rally or conference!

Professional organization will support Lyme docs

The International Lyme and Associated Diseases Society (ILADS) will have its first meeting for physicians and professionals on April 29, 2000. The meeting is associated with the Lyme Conference of Central Pennsylvania, near Hattisberg.

Lyme specialists facing investigations have turned to the Foundation for the Advancement of Innovative Medicine (FAIM) for support. Observers have felt for some time that the situation was ripe for the formation of a society to focus on the problems doctors who treat tickborne diseases are facing.

“FAIM can provide the political connections, but I think the existence of a professional society dedicated to Lyme and associated diseases is absolutely essential,” said IGeneX Laboratory president Dr. Nick Harris, who is also an officer of ILADS. “While it is true that there are other better known Lyme organizations that are in the public’s eye, these are primarily consumer and patient advocacy organizations.”

Harris stated that it is hard to change medical ideas and prejudice with out the strength of a professional society backing it.

ILADS welcomes professionals (M.D., D.O., D.C., D.D.S., Ph.D., P.A., N.P.). to the meeting.

The ILADS web site should be up by February 4 at http://www.ilads.org. For more information about the meeting, contact Dr. Harris at 1-800-832-3200.

Central Pennsylvania conference on chronic Lyme

For contact information and prices, see Calendar on back page.

Speakers at the conference will include:

Attorney Michael Schoppman

NJLDA president Pat Smith - the Lyme Disease Initiative- what's in it for you and the ticks

Dr. Gregory Bach, clinical practice specialist in tick borne diseases

Dr. Virginia Sherr psychiatrist - on panic and Lyme disease

Dr. Richard Horowitz - how to treat long term tick borne diseases; a nuts and bolts description from success with patients

Dr. Nick Harris - what tests to order for direct and indirect evidence supporting a diagnosis of tick borne diseases

Dr Teresa McKnight - symptoms and signs of tick borne diseases are not vague. A presentation with study documentation of the organ manifestations to seek and detail for patients with long terms tick borne diseases.

Dr. Harold Smith - introduction to the problems of chronic tick borne diseases and how to help many victims misdiagnosed as other disorders.

Patient testimonials- Three nurses who are also patients will present their terrible illness and its cure. Ten patients will go to stage and read a 2 minute summary of how Lyme disease affected their lives, each emphasizing a specific aspect such as delayed diagnosis, misdiagnosis, belittling the disease and doctors caring for it, response to long term treatment etc.

Lyme specialist asks for patient feedback on website development

by Robert Gasser, MD

To all Lyme patients:

Our borreliosis Study Group, which was set up in 1988 at the University of Graz, Austria, has received thousands of requests of all different kinds from patients all over the world and, in particular from the USA, concerning treatment and diagnosis of Lyme disease, which we have answered as much as we could. Our main subject has been chronic Lyme disease. Over the years we have collected various types of questions and problems discussed and now we intend to set up all the answers on the Internet.

We are on the point of establishing a page which will answer most questions by mouse click, since many are repetitive and we are not always able to answer all letters. However in order to complete this task, we welcome any suggestions from patients concerning Lyme disease and connected problems which they think should be addressed.

Please send your questions to:

Prof. Robert Gasser, MD, PhD
The Borreliosis Study Group
LMED, University of Graz
LKH-Auenbruggerplatz 15
A-8036 Graz Austria
FAX 43 316 385 3733

Thanks to all supporters. Best wishes for 2000.

The Second Battle of Gettysburg

A rally will be held in the middle of the Square of Gettysburg from 1pm to 4pm on Saturday, April 8th. Rally organizers plan to print up and sell T-shirts for the event with a logo suggested by James Martin of Texas:

T.O.F.U. - Ticked Off and Fed Up

The shirts will be sold for cost plus shipping.

At 2pm there will be a media event, and at 4pm an indoor symposium on Lyme disease.

Senator Rick Santorum may present information on his Lyme Initiative in the US Senate. Other local/state politicians will be invited for the media event and symposium.

Patients are urged to come and to bring friends and family who are well.

"Just because you may not have Lyme doesn't mean you can't come and help us swell our numbers," said organizer Lovette Mott. "Gettysburg is a very small town, so any number over 100 is going to look HUGE and may gain national attention. We're going to alert all of the media, and they are likely to show up if our US Senators are going to speak."

For further information, call Lovette Mott, at 717-334-6339 or e-mail Arconic@aol.com.

Join the fight against Lyme disease - subscribe to the Lyme Times!

Calendar

13th International Conference on Lyme Disease and Other Tick-Borne Disorders

Saturday, March 24
Sunday, March 25
Hartford Marriott
Farmington, Connecticut

Sponsored by the Lyme Disease Foundation. Clinical Management & Research Update.

This conference is designed for clinical professionals (including but not limited to Primary Care Physicians, Nurse Practitioners, Physician Assistants, Public Health Officers, Researchers and Veterinarians) and for other health professionals (medical directors, risk managers) who wish to enhance their knowledge of Lyme disease and other tick-borne disorders.

Registration: $275 before March 21. March 22 to on-site $325. Poster Presenters $160 - contact LDF for forms. Graduate Students with University validation letter. Reception only $60.

For hotel reservations call 800-228-9290. Cost $79 and up, single or double occupancy.

For travel arrangements call Huntington Hay Travel at 800-783-9783

Registration includes attendance at scientific sessions, book of proceedings, lunch and breaks on both days, and receptions Friday (3/23) and Saturday (3/24) night.

For more information, contact the Lyme Disease Foundation, 1 Financial Plaza, Hartford, CT 06103, tel. 860-525-2000.

See page 38 for conference program.

Central Pennsylvania Conference on Chronic Lyme Disease

Saturday, April 29
12 noon to 6pm
Shikelamy High School Auditorium
Sunbury, Pennsylvania

The conference will present a wide range of topics aimed at educated community members, including fibromyalgia, multiple sclerosis, and ADD support groups, sportsmen, health care providers, scouts, pain therapists, farmers, veterinarians, etc.

For more information contact Harold Smith, MD, at 570-275-4464.

For program details, see article on page 39.

March On Washington (MOW)

Wednesday, May 3
Washington, D.C.

Patient advocates plan to march the halls of Congress with cowbells and have a rally at a site to be announced. For more information or to help out, please contact: Marvina Lodge (Loveyonlyme@aol.com)

Phone 407-839-6016 direct

407-839-0200 message

407-839-0974 fax

The Lyme Disease Foundation is also promoting the March. For more details see articles on page 22 & 36.

Send Calendar announcements to the Editor.

International Lyme and Associated Diseases Society (ILADS) Meeting

Saturday, April 29
9am to noon
Sunbury, Pennsylvania

In addition to an open discussion on treatment, a well known attorney will consult with professionals on how doctors can protect themselves from investigations and fight back. For details, see article on page 38.

The Second Battle of Gettysburg

Saturday, April 8
Gettysburg, Penn.
1pm to 4pm

For further information, e-mail Arconic@aol.com or call Lovette Mott, at 717-334-6339. For more details see page 39.

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