

the **Lyme Times**

NUMBER 29

Education, Support, Advocacy, Research

SUMMER 2000

Patients' Vigil to "dishonor" Dr. Steere

New York City - On June 1 over 300 people converged at the Hotel Pierre at 61st St. and 5th Avenue for a peaceful, early evening "Vigil." The demonstration was a patient protest against the honoring of Allen Steere, MD, for his work on Lyme disease, at a gala event sponsored by the New York-based American Lyme Disease Foundation (ALDF). Many in the Lyme disease community think the ALDF acts counter to the best interests of Lyme disease patients and is controlled by special interests.

According to The Vigil spokespersons, the Lyme patients with their friends and families assembled to express publicly their contempt toward this physician whom they feel has caused suffering in so many lives and has hindered Lyme disease treatment and cure. Most came from the Eastern seaboard, although a few came from as far away as Los Angeles and Kansas City to attend.

See **Protest vigil** on page 24



LDA President Pat Smith addresses MOW rally

Patients march on Washington

Washington, DC - Lyme disease patients from throughout the New England and the mid-Atlantic states converged on our nation's Capitol on Wednesday, May 3, for MOW – March on Washington. Parading with green ribbons and posters in front of the Capitol building in the "Senate Swamp" the patients met to call attention to the Lyme Disease Initiative (Bills HR-2790, S-1905, see article below) currently languishing in committee.

Free buses were provided by the Connecticut-based Lyme Disease Foundation and self-appointed organizers cor-



Judy Swartzman photo

MisTick (Jeannine Der Bedrosian) poses near the Capitol during MOW.

See **MOW** on page 26

Lawmakers call for GAO investigation

Washington, DC - Senators Pick, Santorum and Chris Dodd and New Jersey native and Lyme Disease Association president Pat Smith have joined Representative Chris Smith in supporting Smith's legislation, HR 2790, The Lyme Disease Initiative, as well as calling upon the General Accounting Office [GAO] to conduct an investigation into the possible mismanagement at the Department of Health and Human Services.

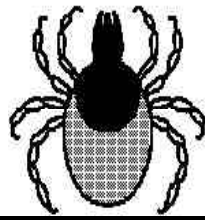
"Lyme disease is a serious health

concern throughout the Northeastern United States," said Congressman Chris Smith (NJ-4) at a press conference at the Capitol. "The Lyme Disease Initiative contains a package of desperately needed reforms, combined with additional resources totaling \$125 million, to help combat this emerging public health threat," added Smith.

Smith noted that this legislation represents the means of forging

See **Lyme Bill** on page 24

NUMBER 29
SUMMER 2000



the

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In this issue...

- 3 Guest Editorial
- 4 Letters
- 5 Opinion
- 7 Commentary
- 8 Front Lines
- 10 Beginners' Pages
- 12 Patient Stories
- 18 Patient Support
- 27 In Memoriam
- 28 Action Alert
- 30 Research
- 31 Subscription Form
- 32 Calendar

From the Editor

Dear Readers,

This issue of the Lyme Times is once again dominated by news of political activity in the patient community. Letter-writing campaigns, marches and protests seem to us to be appropriate responses to the politicization of Lyme disease by the health professionals. Increasing numbers of patients are becoming involved. New leaders are emerging. More activities are planned in upcoming months, so keep an eye on local newsletters and internet message boards for the latest information.

We hope you find the image of MisTick (page 1) as delightful as we do. The creation of Jeannine Der Bedrosian, MisTick made her debut at NY OPMC Rally in December, 1999, and has appeared at every major patient event since. If you can envision a role for MisTick in your community, Ms. Der Bedrosian would be delighted to consult with you about costume and accoutrements. She plans to purchase eight Lyme ribbon pins, one for each leg. A western version of MisTick – Frantick – is making her appearance at the Democratic National Convention in Los Angeles.

As we all become more aware of the great need in many parts of the country for more education and outreach efforts, we become more aware of the limitations of acting

alone, and the power of groups. As the Lyme Disease Resource Center enters its tenth year, we are looking for new people to help guide the organization into the future. We are seeking energetic and dedicated volunteer activists who are skilled in business administration, financial management, and legal matters. If you are interested or if you know someone who might be interested in joining the LDRC Board, please contact one of our board members or the editor. Applicants should be capable of travelling to Santa Rosa, California, two or three times a year. If board duties do not seem right for you, committee work is always a possibility. There are numerous tasks which go undone because there is no one to do them. People who are serious about creating positive change for the Lyme community need to step forward to accept responsibility. Check the LDRC mission statement at the bottom of this page. If your project idea fits one of the categories, it is likely that we can figure out some way to make it happen. Please get in touch, if not with us, with your own local Lyme group. Be part of the solution.

Remember, many hands make light work!

Phyllis Mervine, Editor

Features

- 5 Two-tier testing system must go, by Harold Smith, M.D.**
- 20 Dominion Life Foundation helps patients, by HG Antonio DiGiovanni**
- 22 Seven strategies for making the most of your doctor visit, by Sheree Parris Nudd**
- 28 Action needed for Burrascano OPMC hearing**

The Lyme Times belatedly thanks Wendy Feaga, DVM and the Ellicott City [Maryland] Animal Clinic for a generous grant permitting Dr. Raphael Stricker to attend the Road Back Foundation conference which he reported on in the last issue.

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

the Lyme Times Staff

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Guest Editorial

Patients must start demanding accountability from public health officials

by Jeannine Der Bedrosian

Dr. Perry Orens, a 73-year old compassionate doctor who was extending his medical knowledge of a difficult and little known disease in the hard times of Lyme Disease Denial, steadfastly continued to treat Lyme disease patients - instead of lounging in the Caribbean in retirement. He did not back down. He was notified the day before Thanksgiving that his license was being revoked. Think of the hundreds of thousands he would have saved in legal and appeal costs if he had just backed down.

Dr. Joseph Burrascano, another who does not back down, advocates a more realistic approach to Lyme Disease by doctors, patients, political officials, government officials, and government bodies. He is currently being investigated.

Just as our caring doctors are being scrutinized and held accountable for *adequately* treating the disease and the patient, it is time for government officials, NIH, state medical and regulatory agencies, and politicians to be well scrutinized and held accountable for what they have and have not done with respect to Lyme disease, now the nation's leading infectious disease. This scrutiny is an activity of top priority which we, as challenged Lyme patients, must engage in whenever we are able in the months ahead. Key Word=ACCOUNTABILITY!

These officials and agencies are publicly funded by us, and they are accountable to us - for negative, perverse, and unresponsive activities in opposition to their given charge of protecting the public health.

It is not enough anymore to write email letters and even snail mail letters, letters to the editor, or post gripes to the Lyme Internet. Lyme patients and their supporters everywhere must vociferously call for an investigation at the highest level. Absolute insistence must begin now and continue.

We must question why a small American Lyme Disease Denial-Mafia (ALDDM) of academicians, insurers, politicized state "public health" officials and others, are in fact *hindering* public health. We must question why these individuals are actively engaged in a deliberate, concerted effort to perpetrate the nation's fastest growing infectious disease upon growing numbers of citizens. There must be accountability here!

Think of the consequences of this group (ALDDM) being wrong – as they are – and the truth coming to light that an intentional and concerted effort has been made by multiple individuals to sicken and kill citizens through disease. Then one begins to understand why their voices are so loud and shrill, their denials so insistent, their trivialization of Lyme disease in mass media so defensively emphatic, widespread and frenetic.

This racketeering for political and personal profit must end. It is time for the ALDDM to stop playing "The Emperor's New Clothes" with Lyme disease and with the Public Health. We, as patients, together with supporters and friends of Lyme disease sufferers, must call for an active investigation and accountability at the highest level, and must call without ceasing!

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.

British patient strives for recognition

My French Lyme friend says that the problems there are at least as bad as ours. Not even the papers will print her story! At least here I got my story in a Woman's magazine last year and a very large article in a newspaper. Then last week I got a piece on a BBC TV news programme. The TV crew were so horrified at my story that they are going to ask the BBC if they can do a documentary for us. Lastly, another story about how I'm helping Lyme patients on the internet is to go out in 'Woman' mag on 22nd May, all being well.

I wish a few more Lyme patients worked as hard as I do, I think we'd soon win in this small country! At least nobody would be able to say that they have never heard of it, or that it's 'very rare.'

Gillian Reese
Lockington, Yorkshire, UK

Patient wants to tell children's story

A reporter from our local TV station has been in contact with me. Her story has gotten personal. It seems her own 2 year old may have Lyme. Her baby has been experiencing severe joint pain in her legs, pain that wakes her up during the middle of the night crying. The reporter is coming to my home with a TV crew. I told her I want no personal publicity. She said that since she is a TV reporter and not a newspaper reporter, she needs people to get involved so she can get the true story. I'm planning to have my IV home health care nurse here so she can tell the story of the little kids she has treated with Lyme disease. I

Page 4

believe enough stories have been told about us adults. I've asked her to tell the story about what is happening to the children of Lyme.

I told her how some people testify in court or for insurance companies for a fee that WE are malingers ... but KIDS? What are they guilty of trying to get out of? Trying to avoid watching Sesame Street or to get out of preschool? She agreed that would be a better way to go storywise — but she said I have to provide her with the names and phone numbers of the children with Lyme from the area.

I now think that I could also provide her with a list of names, ages and states of ALL kids with Lyme. How's that?

Marleen Oetzel
Claymont, Delaware
LymeFightr@aol.com

If you are not online, send your child's name, age, and address to the editor and the Lyme Times will pass the names on to Ms. Oetzel.

Lyme seminar at non-Lyme meeting draws interest

Here in Maine I have had success getting my Lyme lecture on the rooster of already scheduled annual meetings of area organizations. Naive doctors are generally receptive, and although they may not have shown up at a "Lyme" seminar, they are generally open minded when a Lyme lecture appears on the schedule of a meeting that they were already planning to attend. I am always surprised at the number of positive responses I get, although I must admit not everyone is complimentary.

Terri MacKnight, DO
Andover, Maine

Lyme Catch-22

Some private insurance companies won't pay for full Lyme treatment because they say chronic Lyme doesn't exist but some insurance companies won't give you insurance if they think you have chronic Lyme. I don't know they're the same companies, but I bet they are!

Jentri Anders
Humboldt County, California

HMOs use Chronic Fatigue diagnosis to avoid treating patients

Did you know that the rapid growth of Chronic Fatigue Syndrome (CFS) is directly proportional to the growth in HMOs, both over the years and in certain regions of our country?

Both the National Institutes for Health (NIH) and the Centers for Disease Control (CDC) have published guidelines for ruling out other (treatable) causes of the same symptoms before making a CFS diagnosis.

A California HMO I used to have told me I had CFS, but refused to follow NIH or CDC guidelines in ruling out other possible causes (I have their refusal to recognize NIH and CDC guidelines in writing and my complaint is filed with the DOC).

The HMO pressures on doctors to avoid running tests of any kind (even ones endorsed by published NIH and CDC guidelines) has made it much easier for a doctor to just say the patient has CFS (or any disease that is not treatable).

Most of these patients would be back to work and lead productive lives, if the most meager effort would be made to find the underlying cause. This is a criminal waste of human lives and a horrible burden on the government systems for the disabled.

When a patient formally asks an HMO (in writing, with references) to follow a published NIH or CDC

Summer 2000

guideline, the HMO should not be able to refuse this request.

Robert Lessman
Gilroy, California

Dog trained to help disabled Lyme patient

We got "Keeta" a Belgian Sheepdog, as a puppy in August, 1993, to herd on the farm or assist our disabled (congenital Lyme daughter), Shone. A month later I came down with tertiary Lyme symptoms, so she grew up learning how to help me. She pulls my wheelchair, when I need it, helps me walk, arouses me out of daily paralysis seizures, and alerts me before the grand mal seizures occur. She also protects my head during the self injury phase of this seizure.

Keeta has developed arthritis after the last 2 Lyme vaccines, 2 years ago. I am training another Belgian, 13 month old, Shannon-Unci, to assist Keeta in her daily care giving.

I rely on Keeta to be independent in my community--she is constantly by my side, watching me, ready to assist.

Kathy Cuddeback
Brighton, Iowa

Ms. Cuddeback and another of her self trained service dogs, Seneca, were on Breed All About It on the Animal Planet channel in March.

Dogs get better treatment

My doctor is not familiar with Lyme since it is "not in my area." I do know he is familiar with the controversy though. His words were, "Don't tell anyone I am checking you for Lyme and don't put my name on the internet."

He might send me to an infectious disease specialist. Right now, I'd take a veterinarian although I am human but I understand that dogs get better treatment.

Rick Vargo
Scranton, Pennsylvania

Number 28

Opinion

Report to VAERS illness that may be caused by vaccine

by Ira Auerbach

A serious potential risk from the Lyme vaccine has been downplayed. Up to 30% of the general population is genetically predisposed to "autoimmune" disease (incurable Lyme like arthritis, etc.) from LYMERix. When the FDA released this vaccine with "guarded endorsement" it recommended long term follow-up studies due to this (JAMA June 24, 1998 "Guarded Endorsement of the Lyme Vaccine"). There is currently a class action suit against SmithKline Beecham about this issue.

This week my wife, coordinator of the Hudson Valley Committee for Lyme Disease Patient Advocacy, received a call from an individual who was inoculated in March and developed arthritis and other problems that were very likely caused by the vaccine. Neither the person nor her physician were aware of the risk. Reporting is critical otherwise there is no way that illness caused by LYMERix can be tracked. The FDA/CDC have a Vaccine Adverse Event Reporting System (VAERS) available at 1-800-822-7967 or <http://www.fda.gov/cber/vaers/vaers.htm>.

www.fda.gov/cber/vaers/vaers.htm.

I don't understand why [Health Commissioner] Dr. Caldwell has not disseminated this important piece of information to our local physicians when so many in Dutchess County have been vaccinated. Anyone can use the VAERS reporting system, including the patient. If you have had the vaccine and experience health problems, even if it is after quite some time, it is critical that this be reported. It should be left to the FDA/CDC to determine the relationship to the vaccine.

The vaccine will NOT protect anyone from the many other serious diseases carried by ticks in Dutchess County (Ehrlichiosis, Babesiosis, etc.) In addition, it is only 78% effective which is quite low for a vaccine.

Ira Auerbach of Poughkeepsie, New York, is the husband of Lyme activist Jill Auerbach, whose article appears on the following page.

This letter appeared in The Poughkeepsie Journal, Monday, April 3, 2000.

Two-tier testing system must go

by Harold Smith, MD

In a perfect world, we would use a test with high sensitivity to pick up all cases and then a specific test to confirm. It's a good theory but in practice the two-tiered scheme – an ELISA and then a Western blot – recommended by the CDC has never worked. The articles presented in support of the CDC criteria at the Dearborn Michigan meeting in 1994

by Dressler and Engstrom, and still quoted today, demonstrated that one third of the chronic victims of tick-borne diseases were missed by the system. In the Engstrom study, 20% of victims were missed. This is a terrible testing system by any standards.

For most of us who have studied and suffered from Lyme disease,

these two tests make no scientific sense, no practical sense, no ethical sense, and no common sense.

They don't make scientific sense since Lyme disease is not a disease of free antibodies circulating in the blood stream waiting to exceed a cutoff value below which one doesn't suffer from Lyme disease. The borrelia are in the tissue and the antibodies are attached. The patient is lucky if what is left over is high enough to detect.

What is more, whenever direct testing is available for the study population, there is even less correlation. Victims who are growing borrelia out of tissue biopsies, spinal fluid and blood are NEGATIVE by the ELISA and Western blot testing time and again. If you look at any study done by the proponents of the two-tiered system which starts with a group of samples which are all positive by culture or PCR and then checks how the two-tiered system matches, the correlation is very poor. The one study reported by Bakken found that 2/3 of children with culture confirmed borreliosis would be missed! Time and again at the International Conferences on Lyme Disease (Stockholm), culture positive patients are detected about 50% of the time. Case after case is reported in the medical literature of patients negative by ELISA and Western blot testing, who go on to suffer and even die due to the failure to diligently search for additional laboratory information. The CDC itself admits that the two-tiered and clinical testing outlined results in 90% of the victims not being reported. We suspect that 90% also aren't being diagnosed and treated since so many authorities use the same criteria.

Other scientific reasons for the failure of this testing is that the microbe in the neurological compartment is quite different from that expressing antigens in the systemic compartments. Furthermore, borrelia changes its outer surface coating in response to many stimuli and over

time – yet the tests try to match the patient against one strain. In addition, borrelia exists intracellularly, mimics the hosts' own antigens, and forms cystic structures without a wall containing outer surface proteins.

In the Dressler-Steere study, the control (that is like in NORMAL) group was made up of patients with chronic fatigue, systemic lupus, multiple sclerosis and rheumatoid arthritis. Many consider that these idiopathic diseases have a possible microbial origin. The most fascinating part of this study was that so many of the control patients had 3 (three) positive bands. Open-minded thinkers might find this exciting – not that the test was any good as a screen for Lyme victims – but that their control population was positive for Lyme disease!!

Interestingly, when the ELISA test was negative in the study, these samples were confirmed by a lymphocyte proliferative cell test – and weren't matched against the Western blot results. The two didn't check out here. Someone needs to explain the math for us in this study, please.

Practically it makes no sense to do these two tests – since if the ELISA is negative it means nothing, and if positive, the patient is told to get more tests.

Ethically it makes no sense because the world of diagnostic testing for Lyme disease has moved well beyond an arbitrary system of indirect testing that can't be repeated from lab to lab or specimen to specimen. Ethically we are compelled to keep up with knowledge in the field of diagnostics – and the content of knowledge about Lyme disease has moved years beyond the hopeful but terribly flawed guidelines from Dearborn. Ethically the tests make no sense.

Finally, it makes no common sense to use the ELISA test and the Western blot. In common sense, we learn from our errors. This testing fails time and again. So we aren't learning

from past mistakes. This bespeaks a lack of common sense.

Imagine that your child has the summer flu. Months later he becomes profoundly fatigued, has constant headaches, fails in school, develops secondary rashes, sleep disturbance and cardiac rhythm disturbances. The ELISA test is 0.8 with 0.9 being required to be indeterminate. So the child doesn't have Lyme disease and goes on to suffer for years as the disease spreads through organ after organ. If the test had been 0.9 then magic! Now it is time to do a Western blot. Now your child has 4 bands. Not 5!! So there is no Lyme disease. Wait a few years and then there will be multiple sclerosis, attention deficit, systemic lupus or juvenile rheumatoid arthritis, all of which would have been prevented by diligent laboratory pursuit of the multitude of testing now available. But it wasn't done because the two-tier testing lab plan is believed by so many.

So far we have little science to support the two-tier testing promoted by the CDC. The issue is so vastly empty of dialogue that perhaps Emily Dickinson can help the proponents of the "sensitive" ELISA and Western blot:

This Science [*World in her poem*]
Is Not Conclusion

This science is not conclusion
A sequel stands beyond,
Invisible as music,
But positive as sound.
It beckons and it baffles;
Philosophies don't know, and
through a riddle, at the last,
Sagacity must go.
To guess it puzzles scholars;
To gain it, men have shown –
contempt of generations – and
crucifixion known.

At present in North America, the victims of Lyme disease are being crucified by the false teaching of the ELISA and Western blot testing.

Dr. Smith is a regular contributor to the Lyme Times. He lives in Pennsylvania.

Commentary

Lyme is full of contradictions

by Jill Auerbach

Syphilis and Lyme are both caused by the same type of bacteria, a spirochete, and share the same stages, including dormancy and many of the same symptoms. This should demonstrate the seriousness of this disease which is the fastest spreading infectious disease next to AIDS.

YET—

In a survey by medical entomologist Richard Falco, PhD of residents in areas endemic for Lyme disease, 26% of households had at least one member who had contracted Lyme disease; 18% within the previous year. YET can you imagine the uproar if that had been syphilis? The suffering of those with chronic symptoms is trivialized and they are often told to go to a psychiatrist rather than be given appropriate treatment.

Doctors treat acne and rosacea for years on end with the same antibiotic (tetracycline) that is often used for Lyme disease, but limit treatment for Lyme to an arbitrary 28 days or less rather than going by each individual's symptoms. YET there is no scientific evidence that the spirochete that causes Lyme is eradicated in that time, but there is a multitude of peer reviewed scientific studies that provide proof that this is not a sufficient length of time in all cases.

After reading an article in the New England Journal of Medicine, some people in the medical field are disseminating as fact that there is only a 1% chance of acquiring a Lyme infection from a tick bite. YET that study does not reflect what really occurs in nature. The ticks in that study were not engorged (not attached long enough to have taken blood into their bodies from the person they were attached to). They were not attached long enough to transmit Lyme disease, other than in a **Number 28**

very small percentage. Also, in many endemic areas the tick infection rate is many times greater than the ticks mentioned in that article. The 1% statement just does not make common sense; if it took almost 100 bites to produce a case of Lyme disease we would not have a Lyme disease problem! How can anyone accept that statement? This inaccuracy leads to a false sense of security by individuals and by physicians, potentially resulting in untreated serious late stage Lyme disease.

Microscopic worms (nematodes) are sold to citrus growers to protect their crops, YET the USDA researcher who is trying to provide them for the protection of people cannot get sufficient funding to complete her studies.

The inaccuracies of tests for Lyme disease produce false negative and false positives at an unacceptable rate. The CDC states that the two-tiered blood tests (Elisa and Western blot, the most commonly used) are for “national reporting of Lyme disease, it is not intended to be used in clinical diagnosis.” The FDA and CDC both emphasize that the diagnosis is to be based upon risk of exposure and the clinical symptoms; the serologic (blood) tests are merely one tool to aid in the diagnosis. YET many physicians still rely on these tests rather than their clinical judgment, potentially causing patients to develop late stage chronic disease, which is more difficult and costly to treat. Many patients would not be ill today had their physicians been alert in detecting the clinical signs and symptoms and had treated them early in the course of the illness.

The abundance of ticks has been increasing like wildfire during this past generation. YET money is being spent on vaccines, and given to researchers who trivialize the disease.

These researchers are making money hand over fist through grants, and speaking engagements for pharmaceutical and insurance companies, which deny sufferers of the disease a proper cure and treatment. The money would be better spent by supporting research to reduce the numbers of ticks. Instead we allow Lyme and other tick-borne diseases to proliferate, infecting, re-infecting and co-infecting our children and ourselves! According to an Annual Review of Entomology article we've managed to find solutions for agricultural pests—of course there's money to be made by increasing food supply—but apparently not in protecting humans.

According to Dr. Dennis Parenti of Smith Kline Beecham, one finding from the LYMERix vaccine trials of 11,000 individuals was that only 60-65% of those who contracted Lyme disease presented with a rash, and that a large percentage of those were not the classically described bull's-eye. YET because this information is not being passed along to the medical community, many physicians still believe that the bull's-eye rash is the most common symptom of Lyme disease and are reluctant to treat patients without that symptom.

In 1999 a three year old little girl had 23 ticks pulled off of her body during a bath the evening after visiting a park in Dutchess County. YET there are no signs posted in county and some town parks warning people of the presence of ticks. It has been said that this is to protect county tourism. And unaware tourists may go home ill without a clue as to what is causing their illness, when knowing to do a tick check might have prevented this.

Dutchess County, New York, which has the highest per capita incidence of Lyme disease in New York State and is second in the country, had a \$5.1 million budget surplus last year. \$1.5 million profit was from the LYMERix study. \$372,000 has been allotted to avert the West Nile virus, YET in spite of a raging

Lyme disease epidemic there, *none* of that profit is being used for tick control research. This is despite the fact that a renowned ecological research institution, The Institute of Ecosystem Studies, is located in that county and is a perfect place for the county to fund this research.

A research physician testified for an insurance company against a patient who wanted to be paid for longer term therapy. The patient's physician testified on behalf of the patient's need for the therapy and the insurance company lost, YET this researcher was called as a New York State Office of Professional Medical Conduct (OPMC) expert witness against this physician. Do you think that this is a conflict of interest?

When the FDA released the Lyme vaccine, they did so with guarded endorsement due to long term safety concerns about its potential to cause autoimmune disease. LYMERix now has class action suits filed against it for this same concern which the suits claim involve up to 30% of the general population. A Commissioner of Health in one New York county involved its citizens in the Lyme vaccine trials and actively promotes the vaccine. When confronted about his being paid for speaking on behalf of LYMERix and owning stock in SmithKline Beecham, he admitted this financial connection exists, YET denied it created a conflict of interest AND refused to disclose the amounts involved.

Research to reduce ticks in the environment which could virtually eliminate Lyme and other tick-borne diseases, is ignored and receives a pittance of funding. YET millions of dollars are being made by pharmaceutical companies, insurance companies, and medical researchers who line their own pockets. It's time to fund this neglected field of science and turn it into an effective tick control program to rid us of these causes, TICKS.

Ms. Auerbach is the coordinator of the Hudson Valley Committee for Lyme Disease Patient Advocacy.

A sign of memory loss

by Virginia Sherr, MD

The sign display artist and business owner had sought psychiatric help for increasing panic, exhaustion and an atypical lack of initiative. Usually a vivacious, energetic type, Steve (not his real name) had gotten so he would just sit and stare out the window in the afternoons, doing nothing productive, just ruminating on how he wasn't motivated any more. The more he thought about it, the more it occurred to him that he was abnormal as well as depressed. It wasn't that he felt so totally depressed as much as he just felt desperately overwhelmed by his lack of focus and his readiness to sit and stare at nothing. He tried to analyze it himself. He recalled some childhood trauma and wondered if that had finally caught up with him.

As his business began to falter and he could see himself and his business moving from the winner to the loser column, Steve decided to explore his psyche with me. In the first interview, it became clear that he had a number of physical symptoms for which his doctors had found no explanation. He had been reassured that his sweats, headaches, aches, pains, irritability, insomnia and what he described as mild memory loss were all part of the stress he was experiencing. Because he was a happy man with a wife whom he adored, two sons who were the apples of his eye and a business that was beginning to really take off, he believed that the only stress that could be causing all this must be internal. What did I think?

What I thought of immediately was what I had been dealing with in our aptly named Bucks County, Pennsylvania for several years: namely cryptic, unrecognized, persistent Lyme disease and/or other

deer tick-borne diseases that locally were showing up first as psychological problems. Unlike Lyme, Connecticut, where the infamous causative spirochete caused swollen, inflamed knees, in Pennsylvania the disease very often was first manifest by personality changes. The usual test, the ELISA, was negative but more sophisticated, advanced testing by a research quality laboratory, revealed strong evidence of Lyme disease and several other tick-borne diseases.

Steve was shocked. His wife was relieved that there was hope for the recovery of his former self. He was soon under treatment for his infections. But we began to realize that the memory loss was more than a small part of his problem. His withdrawal and sense of lack of ambition had been in part a reaction to the fact that Steve could not remember what he was doing from one minute to the next. The resultant effort to keep track of things was exhausting and he constantly felt overwhelmed. As he began to understand the reality of his memory loss, Steve was frightened. Everything he had worked for was about to go down the tubes. He tried hard to resurrect the notion that this was just a psychological problem that analyzing would cure.

My experience with Lyme patients allowed me to reassure him that this would improve over time as his antibiotic treatment continued. Then I warned him: "At first you have to protect yourself from the bruising that your brain's memory center has been taking. I call this protection the 'Post-it Maneuver' because, to survive successfully in this campaign, you will have to plaster your surroundings with notes and reminders. The memory loss can be temporary but the damage from things forgotten can be

permanently troublesome.” He complied.

Next session Steven came in laughing. “Well, I took your advice. The job I had yesterday called for a big custom-made sign that needed a sturdy base. Because I know I keep losing things, I decided to tape the brand new sign I had brought to the job onto the wall over the site where I was working. That way I couldn’t forget it. I finished the sign base, caught my breath and began to look around for the sign. It was nowhere to be found. A sense of panic swept over me. Oh, my God, I’d gone off and left it at home. I called my wife, alerted my craftspeople to the crisis, and sped home cursing my stupidity. No one had a clue to the sign’s whereabouts. I searched my other trucks—no sign! In deep despair and confusion, I trudged back to the worksite prepared to tell my client that I could not make his deadline, when what to my wondering eyes should appear? The sign! Big as life and right over where I had been working. Then I remembered where I had made a giant ‘Post-it’ of it.”

Despite his laughter, Steve felt desperate. “How will I know if what you say is true—that my memory will come back?”

“Steve, just wait for a moment of surprise. One day, you will be minding your own business when suddenly you will recall something totally irrelevant and generally unimportant. It will occur as an intrusive thought. An example would be a sudden awareness that you left the toothpaste tube cap off last night. At first, you will think, so what? But then you will do a double-take and say, ‘I REMEMBERED THAT!’” Steve left looking incredulous.

The artist had a terrific sense of humor so I was not surprised that when he came in several sessions later, he was chuckling as he said, “It happened; it happened just the way you said.” I asked his meaning. “You’ll never believe this. I was at work when an irrelevant memory

intruded, just like you told me it would. I suddenly recalled that I had been the one to invite my friend to dinner!” He looked at me knowingly.

“And..?”

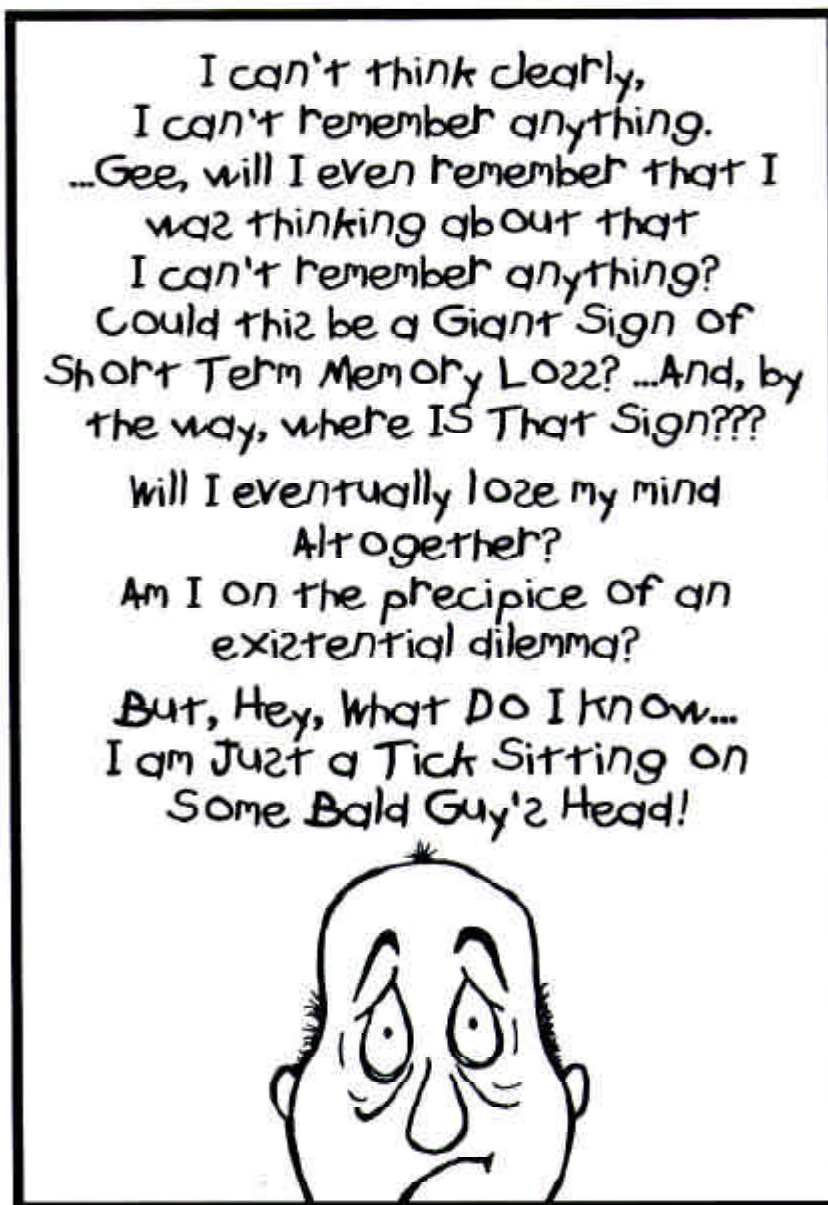
“Don’t you see, it made all the difference. So I called my friend and explained it to him.”

“I still don’t understand.”

“It happened months before I knew I had Lyme; my wife and I went out to dinner with our closest friends. At the end of the meal, he didn’t reach for the check or even offer to split the bill with me. I felt devalued and angry that he’d treat such old

friends that way. I’ve been angry with him ever since ’though I never said anything to him. As soon as I remembered I had been the one who had asked him to be MY guest, I rushed to the phone and called him and said, ‘It was MY bill!’ He was pretty surprised because he had no memory of the event at all. When I explained it, he thought it was all pretty cool.

“And so far as I am concerned, every time I drive by my big billboard, it makes me remember what it is like to forget.... I guess you could call it a sign—of memory loss!”



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Beginners' Pages

Permethrin tick-killers provide superior protection

Reprinted from www.tickinfo.com, "Your Best Source For Learning About And Protecting Yourself from Ticks."

The DOD Chemical Protection System

The Department of Defense (DoD) utilizes a system of two chemical components in conjunction with the field dress uniform. The EPA approved components of this system include the insecticide permethrin and the insect repellent deet (*N, N*-diethyl-*m*-tiluamide) in concentrations less than 33%.

Permethrin is virtually nontoxic to humans and no systemic effects have been reported. In EPA and FDA tests, it was uncommon to have any skin reddening, rash or other irritation. When used as a repellent, permethrin is applied to exterior clothing where it dries and bonds to the cloth fiber. This water-based formula is nonstaining, odorless and has exceptional resistance to degradation by sunlight (UV), heat and water.

Although permethrin is approved for skin application under certain circumstances such as head lice formulas, it is not applied to skin as a repellent. Permethrin does not bond to skin (stick) and is quickly deactivated by skin's esterase action into inactive compounds. Because of these attributes permethrin offers no repellent benefit on skin. It is only effective when used as a clothing treatment. *Deactivation of permethrin on skin occurs in approximately 20 minutes, When placed on clothing it will last 3 weeks and will even last through weekly launderings.*

With the long history of success permethrin has achieved, it is best not to second guess these extraordinary results. By following the directions provided on the product you can be

assured of results that achieve protection at or near 100%. Any variation of instructions that placed less permethrin on clothing will result in diminished performance.

Permethrin Mosquito Tests

The early history of permethrin development involved tests on mosquitoes conducted by the US Army and Air Force. Tests showed that when lightweight uniforms were treated until moist (approximately 3 ounces) the permethrin alone (0.5% solution) gave 97.7% protection from mosquitoes and 99.9% protection when used in combination with deet (33% solution). Two detergent washings did not diminish mosquito repellent and killing action of permethrin-treated uniforms.

An interesting side note: The effectiveness of permethrin can be shown in the following report highlight that was reported in a very matter of fact statement. During testing in the Everglades, "*Mosquitoes were also repelled because of the side-stream effect caused by numerous treated uniforms within the same general location. This required that the test site be moved to locate more mosquitoes!*"

Permethrin Tick Tests

Test on ticks conducted in Massachusetts concluded that 100% protection was provided against the Deer tick (*Ixodes scapularis*) which is the primary vector of Lyme disease in the Midwest and Northeast. The same outstanding results occurred when testing the Western Black Legged tick, Lone Star tick, American Dog tick and Brown Dog tick. Similar results have been found with other tick

species throughout the United States and Europe. Two detergent washings did not diminish repellent killing action of permethrin-treated uniforms. In tests, ticks that crossed only 10 inches of treated fabric fell from the uniform, later dying due to this limited exposure.

DEET (*N, N*-diethyl-*m*-tiluamide)

Deet is an approved repellent for skin application. Exposure to high concentrations of deet can pose some limited health hazards. At the time concentrations of 33% as provided in the 3M Ultrathon product were chosen by the military for its superior performance and high margin of safety. Up until the 3M product was chosen the military had been using a 100% deet. It was uncomfortable to wear and easily damaged certain materials.

Since the 3M Ultrathon introduction, some new developments have been made using deet in special micro encapsulated formulas that have tested quite well and last some 20 hours between applications. Deet-based products are available in a wide variety of formulas that can address the very specific needs of the individual traveler, outdoors person, family member and even young children. Specific blends with other repellents to repel biting flies are called composites, while others formulas have been added to sunscreen for convenient dual-purpose application.

Early research on deet showed that performance dropped off when concentrations of 35% or higher were tested. As an example, if a 30% deet concentration offers satisfactory repellent action for four hours, an assumption that a 60% deet would last eight hours is not correct. The 60% product may only last about 5 hours.

In the use of standard deet formulas, it is more effective to use lower concentrations of deet with more frequent application than to assume the higher concentrations to

be longer lasting. They are not. Most brand-name deet-based products already have a deet range from 15% to 33%. Once the threat of insect/tick bite is over, the repellent should be washed off. Deet by itself tested between 85% to 89% effective at repelling ticks (deet does not kill either ticks or mosquitoes) and 97% against mosquitoes.

The DoD system consists of *both*

permethrin treated clothing and deet applied to skin. The use of one without the other will undermine the system and increase the risk of insect or tick bite. Many non-deet products are available on the market and are not part of the DoD protection system. They show ineffective repellent performance and are not recommended for any situation where disease transmission is a threat.

Repeated application directly to skin is not advised nor is it effective for ticks since it is quickly deactivated by chemicals in the skin.

In a paper published in 1989 in *Experimental & Applied Acarology* (6:343-352), UC Berkeley entomologist Robert Lane conducted a field study using permethrin-treated overalls. Ticks exposed for less than 15 seconds apparently recovered within 24 hours, but "none of them could have bitten humans had they been allowed to remain on such clothing. Exposure times of greater than 45 seconds incapacitated ticks for at least 24 hours or killed them. All ticks exposed to freshly treated clothing dropped off within a few minutes of contact." Larval and nymphal ticks died or were moribund an hour after only 10 seconds of exposure.

Lane noted that according to a 1986 study (Mehr et al.), permethrin was the most effective repellent among 10 commercial and 11 experimental repellents tested on white mice against the soft tick *Ornithodoros parkeri* Cooley.

Permethrin is also the acaricide used to impregnate the cotton balls in an innovative product which targets tick-carrying mice. *Damminix* tubes filled with the permethrin-permeated cotton are placed around the area to be protected. Mice take the cotton balls to build their nests, where the permethrin kills the ticks parasitizing them. The manufacturer, EcoHealth, Inc. of Boston, recommends applications in the spring and midsummer. *Damminix* is placed only where mice may live, such as brush and wood-piles.

EcoHealth also has a promotional brochure entitled "Fight Lyme Disease" which emphasizes prevention methods, including the *Damminix* product. Citing research done at Fire Island Pines in New York, they state, "*Damminix* dramatically reduces the incidence of infected ticks."

EcoHealth may be contacted by calling 800-234-TICK.

Acaracides (tick-killers) that really work available from SCS Limited

Coulston PermaKill Permethrin Solution - 8oz, \$25

Duranon Odorless Tick/Mosquito Repellent - 6oz, \$5.50

Each 6 ounce aerosol container (also available in non-aerosol) is designed to treat two complete outfits. This includes adult sized long pants, shirt and socks. Follow instructions and don't skimp. The less you apply, the less active ingredient will remain bonded to the fabric and the less protection you'll have.

Contact information:

Telephone US 1 (800) 749-8425 International (845) 429-5394

Fax US 1 (877) 749-8425 International (845) 429-6175

website: <http://www.scs-mall.com>

SCS, Limited

Post Office Box 573

Stony Point, NY 10980

SCS offers bulk purchase discounts to support groups for fund-raising purposes. Call for information.

Permethrin is safe and effective

Permethrin is a synthetic pyrethroid, related chemically to insecticides derived from chrysanthemums. According to the Physicians' Desk Reference, permethrin, I(3-phenoxyphenol) methyl (+)cis, trans-3(2,2-dichloroethylenyl) dimethyl cyclopropane carboxylate, is a chemical derivative of pyrethroid isomers. Its molecular formula is $C_{21}H_{20}Cl_2O_3$. It is active against a broad range of pests including lice, ticks, fleas, mites, and other arthropods. It acts on the nerve cell membrane to disrupt the sodium channel current by which the polarization of the membrane is regulated. Delayed repolarization and paralysis of the pests are the consequences of

this disturbance.

In the 1980s, the manufacturers of Permanone experienced some difficulty obtaining approval from the Department of Environmental Conservation for distribution of their permethrin-containing product because the labelling called it a tick "repellent," while it actually kills ticks as well. There were also questions about carcinogenicity based on a mouse study where 5000 ppm was added to their food. However, permethrin was deemed safe enough to be used in a creme for the treatment of scabies, even in children over two months of age. (For this purpose, one application is generally curative.)

Patient Stories

It was not Alzheimer's—Lyme causes death

by Kathryn Harp

I dedicate this personal story to the bravest woman I have ever known, Shirley J. Forsman – Mom. She lived the hell of undiagnosed Lyme disease for over nine years. She knew about Lyme disease because she was a nurse for all of her working years. She saw the tick on her stomach, removed it properly, recognized the EM rash that appeared just days after the bite and went to the doctor immediately. Thankfully, she'd had 60 wonderful years before this time. She was an intelligent, vibrant, loving, giving, outgoing lady before she died from Lyme disease.

Before I share her story with you, she wanted you to know Pine County, Minnesota, as well as numerous other counties in Minnesota, and many other states within the United States and many countries around the world are infested with Lyme-diseased ticks. You are at risk and may already be harboring the infection. You are responsible to seek out your diagnosis, ask for the Lyme disease test, learn all that you can about the disease, teach your doctor all that you learn, get your test results in your hand, learn about what they mean, learn about the treatments available, tell the doctor which treatment you need and seek out another doctor if your requests are not met.

Mom's symptoms were many. She suffered in every way, every day until her last breath was drawn in the early morning, November 9, 1999. She was bitten by the tick Memorial Day weekend, 1990, in Pine County, Minnesota. She went to the first of many doctors on June 19, 1990. The EM Rash was at least seven inches in diameter on her stomach. She was dizzy, fatigued, had flank pain,

nausea, decreased energy, headaches, blood in her urine, fevers off and on, vaginal odor, and many other complaints, at this visit. Her medical chart lists these symptoms and the diagnosis was "HAS LIGHT RASH" which was treated as ringworm and "CYSTITIS" which was treated as a bladder infection. None of these symptoms ever resolved. Bladder infections and rashes of many kinds came and went throughout the course of the next nine plus years.

Mom suffered the arthritis, encephalitis, meningitis, subcutaneous colitis, cellulitis, conjunctivitis, floaters, ringing and clacking in her ears, visual hallucinations, auditory hallucinations, severe headaches, bell's palsy, numbness, tingling, hair loss, shooting pains, abdominal pain, belly pain, anorexia, weight loss, diarrhea, jerking, twitching, grand-mal seizures, memory loss, dementia, heart block, heart palpitations, sweating episodes, momentary blackouts, blurred vision, and incontinence. She lost the ability to walk, to talk, to read, to comprehend, to eat, to swallow, to participate in life and in the end, to take a breath. She gave up diseased organs from her body believing it would bring her some relief. She ingested the many prescriptions: anesthetics, painkillers, tranquilizers, prednisone, morphine, pancreatic enzymes, questran, dilantin, haldol, aspirins, tylenols, iodine dyes, iodine contrasts, go-litely, the enemas, the aggressive ulcer therapy meds, vitamin B-12, centrum vitamins, synthroid, sulfas, and lots of other short term antibiotics, after surgeries but, the only medicine that showed any signs of bringing her relief came after she was diagnosed properly in July, 1999. It was ROCEPHIN.

Not one doctor had ever tested for Lyme disease. I requested the test be given to her in June, 1999. I thought for sure during the course of nine years one of the doctors had tested for Lyme disease. They were all aware that this is what she thought she had to begin with. She'd traveled extensively throughout the world and the United States. The doctors stated they were testing for every kind of ova, disease, parasite and organism that could possibly have infected her. These doctors included Ophthalmologists, Audiologists, Hematologists, Urologists, Gastroenterologists, Family Practitioners, Internal Medicine, Urology Surgeons, Gall Bladder Surgeons, Gastroenterology Surgeons, Pancreatic, Kidney and Liver doctors, Anesthesiologists, Emergency Room doctors, Dentists, Neurologists, Psychologists, Psychiatrists, Bone and Joint Surgeons, Cardiologists, Dieticians, Public Health Nurses, Social Workers, Pharmacists and every kind of Technician you can think of.

Not even one of these professionals could identify Mom's symptoms with Lyme disease. Not even one of these professionals referred her to a Lyme literate doctor or even tested her for Lyme disease. Not even one of these professionals thought it could possibly be Lyme disease. After three years of continuously searching for answers they sent her home from the Mayo Clinic with an Alzheimer's and Crohn's disease diagnosis in July, 1993. Yet, Lyme disease had infiltrated every organ, muscle, joint, membrane and cell in her body. She told them all it was the only thing she thought she might have been infected with. Not one of these professionals ever tested the tissue, colon, blood, urine, gallbladder, stool, or anything else that they got out of her body during all of these surgeries for Lyme disease. Northern Family Medicine, Bemidji Merit Care, Bemidji Bone and Joint Surgeons, Bemidji Hearing Center, her Dentist, North Country Hospital, Fargo Clinic, the Hospital in Fargo, Mayo Clinic and the Hospital

in Rochester, all missed the diagnosis. This leads me to believe that they are under educated, misinformed, told not to diagnose, told not to treat disseminated disease, or they just don't want Lyme disease to be here.

LYMEDISEASE IS HERE. LYME DISEASE MIMICS MANY DISEASES. LYMEDISEASE DIAGNOSIS IS BEING MISSED. MINNESOTA IS A LYME ENDEMIC AREA. LYME DISEASE KILLED MY MOM AND SHE LIVED LONG ENOUGH TO PROVE THIS TO YOU. DOCTORS SHOULD BE LOOKING FOR IT!!!!

I credit Dr. Haggerty, IM at Bemidji Merit Care Clinic for having an open mind and the willingness to explore with me the possibility that Mom was right, she had Lyme disease. She died with an accurate diagnosis, SEIZURE DISORDER, BROUGHT ON BY LYME DISEASE. I credit Tom Grier for teaching me about Lyme disease. I thank him for the final three months I had with Mom while on Rocephin. I will treasure the light in her eyes, the laughter we shared and the words that came back for her while on the Rocephin. She knew she was safe, she knew she was home, she knew she was loved and she knew we never gave up on getting an accurate diagnosis. She knew she had Lyme disease and she was able to express her love and appreciation for all that we did before she died. I will always wonder what could have been if she didn't have to stop the IV Rocephin and start the orals. I will always wonder why there are parameters to medicine when it's working. I will never forget one day of Mom's suffering. **IT WAS NOT ALZHEIMER'S - LYME DISEASE CAUSES DEATH!!!!**

Shirley J. Forsman was uninsured in 1990 as she was unable to work as a nurse with the debilitating symptoms of this disease. Every doctor visit, prescription and surgery was paid for in cash out of her life savings and sale of her income property. The estimates of these initial costs to her well exceeded \$100,000.00 and she

had to eliminate her assets before Medical Assistance would help her. Health Insurance companies of course denied her access to their insurance because, she had a preexisting condition. She made two unsuccessful work attempts in the summers of 1990 and 1991 while suffering Lyme disease symptoms. She made these work attempts because, her condition was misdiagnosed and the medical bills brought her to near bankruptcy. She suffered everyday on these jobs and knew that she should not be making nursing decisions as her thinking was

A \$75 Lyme disease test could have saved us, the State, the health insurance companies, and the government well over \$500,000.00.

clouded. Thankfully, no one else suffered.

She applied to receive State Disability in the years 1990, and 1991 so, she could access Medicare. She was denied because, they determined that she could work with the all of the misdiagnoses and, "A nurse would be near a bathroom." We appealed these decisions and lost.

Once she had exhausted all of her assets, Medical Assistance became available to her at a spenddown of \$561.00 per month. Fortunately, we lived together so my job covered the living expenses and the pension she received on my dad's death covered her spenddown. Mom turned 62 in 1992 and was able to access early retirement under my dad's social security. Medicare picked her up and we immediately took advantage of open enrollment in Blue Cross/Blue Shield of MN. By this time, we were deeply in debt but, glad to finally have medical coverage for her. Mom started Adult Day Services during the

hours that I worked, in September, 1993 as the dementia had completely taken over her life. She was no longer appropriate for this program by May, 1994 and was referred to the local Nursing Home. Mom and I determined that a nursing home was not the appropriate placement for her. Beltrami County Nursing Services stepped in for us. Mom had been the Nursing Director there. June, 1994 Mom began In-Home Health Services, while I worked, until she died.

Trazadone and Haldol were introduced in 1994 to help control Mom's violent episodes. She made attempts to run away, get away and just walk away in search of some kind of relief from the hell that she was living. Grand-mal seizures started during this time and attempts to control them with Dilantin were introduced. Dilantin did not work on her Lyme disease grand-mal seizures because they were caused by a buildup of quinolinic acid in her brain. The medication nearly killed her so it was stopped, as were many other medications throughout the years. Seizures started out once every three months, to once a month, to twice a month and then regularly every nine days, like clockwork.

By now, she had crossed the threshold of dementia and she died the first time, when she lost herself. Dr. Craig Haggerty tested Mom for Lyme disease in June, 1999. Her ELISA was positive, out of Fargo Clinic. Western Blot, was nonconfirming, out of Mayo Clinic. The intent at this time was not to treat. I taught Dr. Haggerty everything I learned from Tom Grier as Mom was seronegative from cross-reacting/complexed antibodies. Her system was so inhibited by the disease she didn't display the immune response in five banded areas on the Western Blot but, by this time I knew the antibodies were there, the flagella protein was there and the spirochete band was there as I had studied Tom Grier's book on Lyme disease. I demanded antibiotics be introduced and backed it by letting Dr. Haggerty

know if he didn't treat, autopsy would produce the spirochetes. I was sure of this. I contacted Mom's attorney at this time to let him know I was acting in Mom's best interest, she could not act on her own behalf and the family wanted antibiotics introduced to determine if Mom would respond. She did.

Tom Grier agreed to consult with Dr. Haggerty. I asked Dr. Haggerty to contact Tom Grier and he did. Three days of intramuscular 1gr. Rocephin was injected into Mom and a catheter placed to collect urine for these days. LUAT antigen tests were then run by IGeneX lab on Mom's urine. Mom's test came back ten times higher than a Highly Positive cutoff. Antibiotics had to be introduced to elicit an immune response to the organism because Mom had been harboring the infection so long she didn't have an immune response to it any more, without the help of antibiotics.

I had to send Mom's testing, all of it, out of the state of Minnesota to get an accurate test. I know Blue Cross/Blue Shield did not like this but, that's another story. Rocephin was working with Mom. The parameters of medicine evidently determine when you have to start the orals. That's what Dr. Haggerty told me. Mom's attorney told me that attorneys and courts can't tell doctors what to do when they are operating within the

parameters of medicine. Mom didn't have a chance at getting well because of these parameters. Mom's attorney says we can't sue for misdiagnosis because, it's been over two-years since she got sick.

I don't know if the Medicare system cut off her Rocephin (premiums of \$50.00 a month), or if her Blue Cross/Blue Shield of MN cut it off (premiums of \$152.00 per month), or if Medical Assistance (with a spenddown of \$230.00 per month) cut it off, as she was covered by all three. What I do know, is that cutting off the Rocephin killed her!!!!

I know too, that not testing for Lyme disease in 1990-1999, cost us, the State, the health insurance companies, and the government well over \$500,000.00. A Lyme disease test is \$75.00 and she may have been cured with a couple of months of antibiotics back in 1990. Lyme testing is grossly misunderstood by doctors. Lyme disease is unquestionably misunderstood, underdiagnosed and misdiagnosed. We don't have an Alzheimer's population boom coming at us. We have a LYME DISEASE EPIDEMIC within the United States on our hands and the government should open their eyes to it.

Kathryn Harp lives in Bemidji, Minnesota. She may be contacted by email at thumper@paulbunyan.net.

that is present in about 60 percent of Lyme patients. Her symptoms included severe fatigue, flu-like achiness, mild depression and her school grades started to drop.

"We chalked it up to stress because she was in her senior year," said Rebecca's mother Teresa.

The girl called to schedule an appointment to begin IV therapy on a Monday morning and the next day, she was informed that her doctor was no longer practicing medicine. He was one of 16 Lyme disease specialists in New York who are having their licenses revoked for prescribing long-term antibiotics. Other Lyme specialists in New Jersey, Michigan and Connecticut have had their licenses revoked as well. Many Lyme patients living and coping with the disease in Adams County travel hundreds of miles each month to seek out these literate physicians.

"We're all traveling to New York because our doctors don't know enough about Lyme disease," Teresa Peake said.

Her daughter is one of four patients from Gettysburg who makes the 12-hour round trip, which usually requires an overnight stay. On the way back from their first doctor's visit, the Peakes were involved in a serious automobile accident. Meanwhile, Peake, a senior in high school, is deathly ill. She fears that if she is unable to hold down a full-time college schedule in the fall that she will be taken off her parents' health insurance.

Antibiotics debate

When not treated properly, which often may involve long-term antibiotics, the spirochete (bacterium) often returns with greater impact and more complications months later.

"I was just getting to the point of feeling well and now it looks very bleak," said 14-year-old Joni Smith of Gettysburg, who was diagnosed with Lyme disease in March 1995. Peake and Smith were seeing Dr. Perry Orens of Great Neck, N.Y., who

Frustration of finding treatment adds to pain for sufferers

by Debra Brownley - Times Staff Writer

This article appeared as part of the publicity campaign which preceded the Lyme Disease Awareness rally at Gettysburg, Pennsylvania, on April 8.

"I'm basically scared to death that there's not going to be anyone to help me," 19-year-old Rebecca Peake of Bonneauville said with tears in her eyes. Peake was seen 12 times by a physician before she was diagnosed with Lyme disease in May 1999. The disease, caused by corkscrew-shaped

bacteria (spirochetes), is transmitted by tiny ticks belonging to the *Ixodes* family. In the Northeast, the most common proven carrier is the deer tick.

Peake did not see the tick that bit her or had a telltale bull's-eye rash

From left, Lovette Mott, Dr. Joseph Burrascano, US Senator Arlen Specter (R-PA), and Vicki Karam Smith. Mott, a lawyer forced to close her practice because of Lyme, called for legislative reform to end harassment of physicians treating Lyme patients. She and Smith, whose 14-year-old daughter Joni has Lyme, organized the Rally. Burrascano is currently being investigated by the NY Health Dept. for his cutting edge treatment practices. Senator Specter is Chairman of Labor, Health and Human Services and Education and Related Agencies, a Subcommittee of the Appropriations Committee.

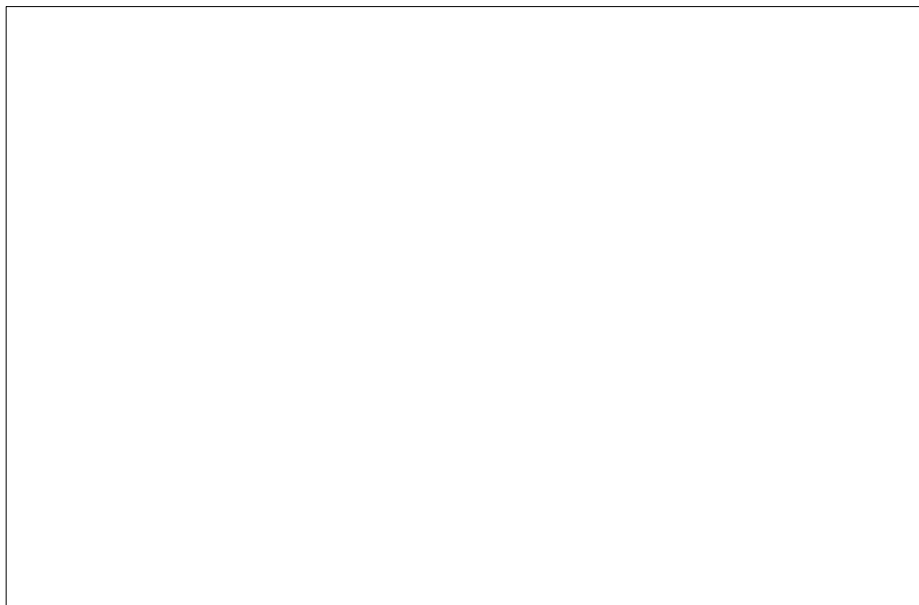


Photo courtesy of Vicki Karam Smith

specializes in pediatric Lyme. He was the first physician to have his license revoked by the New York State Department of Health, Office of Professional Medical Conduct on Nov. 25, 1999. Now, the two teens are left in limbo, not knowing where to turn for treatment.

“We know Rebecca needs the IV therapy. Now, where does that leave us?” her mother asked. “It’s a sick feeling because we don’t want her to get started, and then have to stop because some doctor gets his license pulled.”

Ken Trimmer, 64, of Biglerville, was also a patient of Orens. He was borderline positive for Lyme disease because of taking antibiotics for 10 days prior to the tests. Trimmer’s pain started in his hips, then moved from his lower back to his knees, migrated to his shoulders, elbows, wrists and finally to his knuckles.

“For three weeks, I couldn’t hold onto the steering wheel or a cup of coffee. I couldn’t button my clothes,” Trimmer said.

Trimmer was also bleeding internally and was anemic. He had such terrible pains in his joints that it suppressed his appetite, and he lost 30 pounds. His family doctor originally diagnosed his condition as a pinched nerve in his back.

Number 28

“I feel that if I hadn’t have gotten to Dr. Orens, I would have been bed ridden by now,” Trimmer said. “Now, if I need any more treatment, I have no one to go to.” Trimmer has since returned to his family physician, who re-diagnosed his condition as rheumatoid arthritis and continues to take the antibiotics for Lyme disease that were prescribed to him by Orens.

Insurance companies

Some Lyme disease patients go in and out of remission, which causes astronomical medical bills. A lot of insurance companies are not willing to recognize the treatment or pay for it because, in many cases, it’s a lengthy course of intravenous antibiotics.

“The bottom line - it’s all about money and the insurance companies challenging the specialists treatment recommendations,” said Joni’s mother Vicki Karam Smith. After seven weeks of IV treatment with Orens, many of Smith’s symptoms subsided. She didn’t have as many headaches or stomach aches, and she was able to attend school on a daily basis.

“My grades have drastically improved back to where they used to be ... and my vision’s back ... and I’m not dizzy anymore,” Smith said, adding that she used to fall down the steps.

After discontinuing IV treatments,

her headaches returned. (The spirochete cycles every 28 days and releases toxins, which cause Lyme victims to have recurrent headaches.) At that point, Orens referred her to the Columbia Presbyterian Medical Center in New York for a brain SPECT scan last November. The brain scan cost thousands of dollars and is still under appeal with the insurance company. Later that month, Orens’ license was revoked, forcing Smith to resort to prescription refills of oral antibiotics. Then she found another Lyme literate physician in Westminster, Maryland. So far, all of Smith’s tests are negative and she is now in remission.

Trimmer also said it’s questionable as to whether or not antibiotics prescribed by Orens and others, who have had their licenses revoked, will continue to be refillable. But for now, the insurance companies seem to be honoring the prescriptions.

Lyme experts targeted

Many doctors shy away from treating Lyme disease because they’re unwilling to contend with harassment and fear losing their licenses. The ones who have not, usually have a family member or a close friend that sparked their interest in pursuing long-term treatment. Thus was the case with Orens, whose own

daughter has been undergoing treatment for 14 years. She is currently seeing Dr. Joseph Burrascano Jr. of East Hampton, N.Y. At one time, he also had Lyme.

Burrascano is one of the nation's leading Lyme experts - and the latest to be targeted. Last July, investigators searched and temporarily removed files from his office.

Burrascano has also been treating Lovette Mott, 43, of Gettysburg since last February. However, she was first diagnosed with Lyme in August 1998. Mott was treated by several local physicians before being referred to Burrascano. Since the last two-part Lyme series published in the Gettysburg Times, which featured the Mott family, her condition has worsened. She spent five days in Harrisburg Hospital with what doctors thought was an infection in her back. For two months, Mott wore a back brace. Then physicians concluded that it was probably Lyme.

Her husband Ken, 60, and their 12-year-old daughter remain symptom-free. However, the Motts' 14-year-old son is still battling Lyme and has some short term memory problems.

Lovette Mott had an established law firm on Baltimore Street in Gettysburg, but has since had to give up her practice. Orens and Burrascano have held regional and national meetings on Lyme.

"And yet the very people who are trying to educate their profession are under investigation," Ken Mott said.

Harassment

By law, all complaints filed against a physician must be investigated. In New York, the precise charges are kept secret and the complainant is allowed to remain anonymous. But in many cases, it is the insurance company that has filed the complaint.

According to Michael Schoppmann, a New Jersey medical malpractice lawyer, insurance companies investigate any physician whose practice involves more than 15 percent Lyme patients.

At a Southeast Pennsylvania Lyme Disease Conference held in June 1999, Schoppmann told attendees that over a three-year period, investigators go through all the doctor's records, then present the information to the state medical board, which goes after the physician's license.

Orens said he was questioned by the Office of Medical Conduct seven years ago because of a complaint, but then there was a long period of time where he heard nothing. The 72-year-old physician's license was revoked last November, three years after he retired.

Orens claimed that investigators seized 16 of his patient files, but never called on any of them to take the stand during a hearing. One of the files seized was that of his own daughter.

"I did nothing to hurt my patients," he said.

However, Orens said that one of his patients was hospitalized, treated and released four hours later from an infection, which he claimed was not related to Lyme disease.

Dr. Raymond Dattweiler, who is affiliated with Stony Brook Hospital on Long Island, N.Y., stands his ground that three weeks of treatment cures Lyme.

"My success record has been outstanding. I've treated thousands of Lyme patients, and I have yet to see one cured in three weeks," Orens said in opposition.

Dattweiler has testified on behalf of insurance companies against several doctors who prescribe long-term antibiotics. He is also an advisor to the Centers for Disease Control, National Institute of Health, and the Food and Drug Administration. Further, Dattweiler holds a 25 percent interest in the SmithKline Beecham LYMERix vaccine, which was approved by FDA last year.

"I predict that within a year the vaccine will be taken off the approved list," Orens said, adding that he has

seen several patients who developed Lyme symptoms and chronic arthritis after receiving the vaccine.

"I have never once, ever, referred a patient to the Lyme vaccine," he said.

But even if charges are dropped, such a complaint can ruin a doctor's reputation. Orens spent 40 years in practice, the last three of which consisted of about 60 percent Lyme patients. He graduated in the top third of his medical class at UCLA. For 20 years, he was the assistant professor of medicine at Cornell University School of Medicine.

Now, with having to pay two different attorneys' fees of \$900 per hour, Orens fears he will lose everything that he and his wife have worked for the past 46 years.

"I have pledged myself to undo this wrong. I was railroaded in a kangaroo court," said Orens, adding that he plans to appeal the court's decision.

Laboratories popular for Lyme tests like IGeneX in Palo Alto, Calif., do not escape the scrutiny either. Last year, the lab was investigated twice by the California Department of Health Services and once by New York health officials.

State epidemic

The Centers for Disease Control and Prevention recorded 11,603 cases of Lyme disease nationwide in 1995 (the most recent statistics). Of those cases, Pennsylvania and seven other Northeastern states accounted for 92 percent. In the past decade, the number of Lyme cases reported in this state has increased to epidemic levels.

Since last year, the commonwealth has moved up a notch from ranking third to second in the nation for Lyme disease.

Ticked off - fed up

A new Gettysburg Lyme Disease Support Group was birthed by several Lyme victims, family members and their advocates having to cope with the many complex symptoms that the

disease can present. The group meets monthly at the Motts' home in Gettysburg. To learn more about this complicated disease or to share with other Lyme victims, call Lovette Mott at 334-6339.

Research and relief

Cholestyramine (CSM) is an FDA-approved medication used to lower elevated levels of cholesterol. It has been used safely in millions of people who have taken the medication for extended periods of time. Now, Dr. Ritchie Shoemaker of Pocomoake, Md., is prescribing CSM to Lyme patients. He just received a \$300,000 grant from Bristol-Myers Squibb, a pharmaceutical company, for a three-part study. The first part of the study has already been completed.

Under an FDA exemption, the drug is being used to treat chronic, neurotoxin-mediated illnesses such as Lyme disease.

"In Lyme disease, when an antibiotic hits the spirochete, the bacteria explodes and toxins are released in the brain and central nervous system," Lovette Mott explained. "His theory is that toxins are what is causing some of our symptoms."

Provided there is no re-exposure, the treatment will remove all toxins over time. Most patients are symptom-free in two weeks, but depending on the amount of toxins in a person's body, it may take longer.

About 22 Lyme victims and family members from Adams and Franklin counties are participating in part two of the study. Rebecca Peake and Lovette Mott are just two from this area who will be taking CSM as part of their treatment. Shoemaker has used CSM in the past to treat his own father, who was also diagnosed with Lyme disease.

Politics

The Motts hope that politicians at high levels will get involved and feel there is a need for a senatorial hearing on Lyme disease. They have written

to as many as seven senators in Pennsylvania, Maryland and New York. U.S. Sen. Rick Santorum and U.S. Rep. Joseph Pitts introduced the Lyme Disease Initiative of 1999. The bill is a five-year, \$125 million blueprint for attacking the disease on all fronts.

The program is designed to make the development of better detection tests for the disease a high priority; to foster better coordination between scattered programs within the federal government through a joint agency plan of action; and to protect workers and visitors at federally owned lands in endemic areas through a system of periodic Lyme disease risk assessments.

"Rest assured, as the 106th Congress continues, I will work to enact legislation that aims at helping the victims of Lyme disease," wrote Santorum in a letter addressed to the Motts. State Rep. Stephen Maitland, R-Cumberland Township, also wrote a letter on behalf of the Smiths and forwarded it to the state Department of Health.

"Lyme disease is a very serious problem for people that have it because it is hard to detect and hard to treat," Maitland said.

In addition, letters were sent to "20-20," "Dateline," "60 Minutes,"

and Gov. Tom Ridge asking him to contact New York Gov. George Pataki to reinstate licenses.

"We need some major movie star or public figure with Lyme disease to come forward or they're just going to continue to pick off our doctors and pretend that there's no problem," Vicki Karam Smith said.

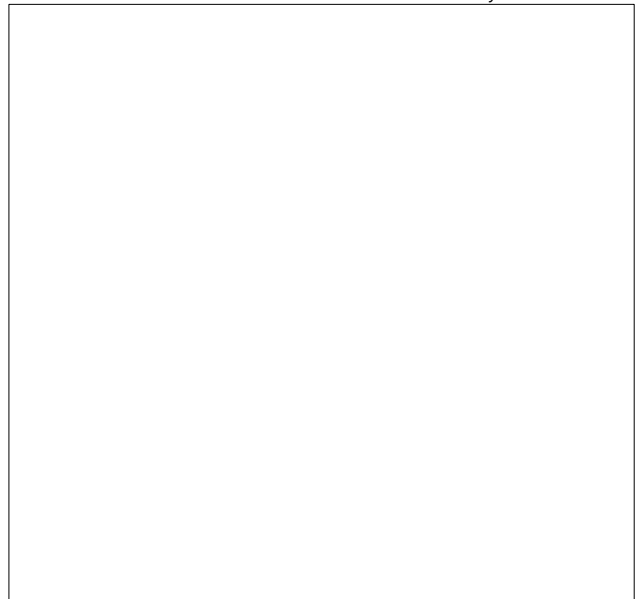
Circle of hope

More than 200 people are expected to attend a Lyme Disease Awareness Rally on Saturday, April 8 from 1-4 p.m. on Lincoln Square in front of the Gettysburg Hotel. Orens is expected to deliver a speech. The public is invited to attend. Following the rally, a physician panel discussion and informational meeting will take place at The Gettysburg Hospital Community Room from 4-5:30 p.m. Burrascano will be among those who will speak as well as Nick Harris, director of IGeneX Lab in California; and Dr. Harold Smith, emergency room physician for Saint Joseph and Geisenger hospitals. Santorum and Maitland will be attending. U.S. Rep. Bill Goodling (R-19) and Ridge have also been invited. The event is a prelude to a larger rally that will be held in Washington, D.C., on May 3.

From the March 3, 2000 Gettysburg Times. Reprinted by permission.

Photo courtesy of Vicki Karam Smith

L-R, US Senator Rick Santorum (R-PA) and Lyme patient Lovette Mott display the T-shirt designed by Gettysburg Lyme Disease Support Group members for the event.



Patient Support

Trust your experience and question authority

This is the text of a letter written by a patient (who prefers to remain anonymous) to Senator Arlen Specter.

Dear Senator Specter:

This is to urge you to face the threat presented by Lyme Disease bravely and squarely. I wish I had done so. Because of my misplaced faith and head-in-the-sand approach, I not only contracted Lyme Disease in the first place, but made poor decisions that led to my now having Chronic Lyme Disease, with my health maintained only through long-term antibiotics. Two years ago last summer, I attended a meditation retreat in an area highly endemic for Lyme. The retreat center where it was held is highly regarded and one of the best known in America. The meditation teacher was and is probably the most world-renowned embodiment of what is called “mindfulness”- paying attention to what is happening in the present moment. He and a group of followers had been coming to the site to give retreats for more than a decade.

There were signs clearly posted on the grounds of the retreat center warning of ticks carrying Lyme Disease. Inexplicably, some of the retreat sessions were held with participants seated on the grass and also beside a lake frequented by deer. Children and their parents literally rolled in the grass during breaks, enjoying the beautiful outdoor setting. I was amazed at this risky behavior, but not a word was said to discourage anyone from doing these things. I thought that surely the organizers of the retreat must know something that I did not that would preclude contracting Lyme Disease. Since I was not from an area that was known for Lyme, I chose to assume that the many people there who were from endemic areas knew the issues

and were responding intelligently. Although I was puzzled, I did not want to seem “negative” by bringing up any unpleasant questions since the object of our retreat was to savor the moment at hand. To feel better about the situation, I bought into the idea that some doctors thought that

“Denial and deference to authority led to my now having Chronic Lyme Disease.”

Lyme Disease was rare.

When I noticed a highly suspicious but not absolutely perfect bull’s eye rash on my wrist while still on the retreat, I was concerned that my new primary physician would label me “suggestible” if I brought it up with her. Cowed by what I knew of managed care, I didn’t want to risk her not taking me seriously in the future. My own willful determination not to allow anything to interfere with my much-prized, long-awaited “mindfulness” retreat also ironically played a role. I just didn’t want to think about having to find and get to a doctor. I decided to adopt a wait and see approach. That choice was one of the worst mistakes of my life. The rash was gone after a couple of days so I forgot about it until a week later when I suddenly had unmistakable symptoms of disseminated Lyme Disease.

Again, I delayed. It was another

three days before I went for treatment. Since I knew that some doctors considered Lyme a junk disease, I was unable to decide whom to approach. I was aware that early treatment was important, but I didn’t understand that “early” meant hours, not weeks.

Unfortunately, when, ten days after the rash, I finally did get treatment it was also not a sufficiently high dose. I received Doxycycline 100 mg twice a day instead of the three times a day that I had read many believed to be necessary. Once again, I deferred to the treating doctor’s judgment while awaiting an appointment with a Lyme-literate M.D.

Making inquiries, I found that far from being rare, one out of eight staff members at the retreat center typically contracted Lyme during a given season before they began spraying with insecticide. Several fellow retreatants independently reported to the leaders of the mindfulness group that they too had contracted Lyme Disease during the month of the retreat.

Denial and deference to authority led to my contracting Lyme in the first place and, combined with the delays in getting proper treatment, to my now having Chronic Lyme Disease. Serology and other tests have confirmed the diagnosis that was first made on the basis of my medical history. Blood tests also revealed that I still had active disease even after six weeks of IV therapy. A brief period off of the antibiotics after months of treatment led to a rapid recurrence of symptoms and shortly following the break, serious new ones emerged.

Presently, I am doing pretty well on the whole although I still have some worrisome symptoms. What the future holds is unknown with this disease. While being on long-term antibiotics is no picnic, I am exceedingly grateful that they have allowed me to reclaim my life and to be productive. I am but one of a large number of people with similar experiences who have been greatly helped by long-term antibiotics.

My earlier repeated denial and abdication of responsibility when faced with the threat of Lyme Disease regrettably mirrors the approach of society at large. I implore you to see to it that in future people receive forthright education as to the real risks they face, have a clear understanding of the treatment that may be required, have access to that treatment, and most importantly that our Lyme-literate doctors be allowed to

continue their good work in peace.

We cannot allow blind obedience to harmful protocols to be forced on patients or their doctors any longer. Enough damage has already been done. Let us then finally have an end on all fronts to dealing with Lyme Disease with "Eyes Wide Shut."

The author lives in Southern California.

intermittent severe joint difficulties in the absence of high RF, paresthesias, severe, possibly migraine, headaches prompting referral to neurologists, glaucoma, profound fatigue and several episodes of chest pain,. He has seen cardiologists, neurologists, other psychiatrists, and there has been no unifying understanding to account for the multisystem problems he has had. And I'm sure there were other medical problems I've forgotten about over the past fifteen years.

Over the past several years, since I have been working in an area endemic for Lyme disease, I have been maintaining a lower threshold for testing for this devastating and frequently overlooked illness, and I have successfully identified, and referred for what has proven effective treatment, a number of patients with Lyme disease. Among these are several whose ELISA and Western Blot laboratory testing showed fewer than the CDC research criteria specified five bands. I decided to begin testing Mr. XXXXXXXX, and found he had several positive bands on the Western Blot. I was suspicious and thought the long sought answer might be at hand. I referred him to Dr. XXXXXXXX, a known expert in Lyme disease, for further evaluation.

Dr. XXXXXXXX thought Lyme a possibility and began treatment with oral antibiotic agents. These medications had a positive effect on some of Mr. XXXXXXXX's symptoms, most notably the joint pain and peripheral neuropathies (paresthesias), but they have not penetrated the central nervous system sufficiently to address the neuropsychiatric manifestations, which continue unabated.

On March 8, 2000, a SPECT scan performed at Columbia Presbyterian Hospital and interpreted by XXXXXXXX XXXXXXXX, M.D. revealed "Bilateral moderate to marked global cortical hypoperfusion with heterogeneity and periventricular white matter disease consistent with encephalitis or vasculitis, such as Lyme disease."

Following this confirmation,

Mental health specialist goes to bat for patient's treatment

by Richard Brand, MD

The author, a psychiatrist, composed the following letter in support of a patient's appeal to his insurance company following denial of treatment because of "insufficient evidence to support the diagnosis of Lyme."

To Whom It May Concern:

At the request of Mr. XXXXX XXXXXXXX and his treating physician, Dr. XXXXX XXXXXXXX, I am writing in support of Mr. XXXXXXXX being given a trial of intravenous medicine for treatment of chronic disseminated Lyme disease with multiple system involvement and devastating neuropsychiatric manifestations. I am treating the latter.

By way of history, Mr. XXXXXXXX has been in treatment at this office since April 18, 1985. His original diagnosis was depression, but some intermittent psychotic episodes pointed toward mania, and the diagnosis was changed to reflect bipolar illness.

However, I was never comfortable with that diagnosis, for a variety of reasons. Although I have treated hundreds of patients with bipolar disorder, including rapid cycling, mixed states, bipolar disorder with comorbid anxiety and comorbid SSE (subsyndromal epilepsy), his presentation was unlike any other in the lack of relation to precipitating events, the intensity and ego-dystonic nature of

the outbursts, the disjointed nature of symptoms juxtaposed against opposing moods and life events, and the utterly unpredictable timing of mood swings, or rather mood flurries, interspersed with severe fatigue.

Even with the most severe refractory mood disorders, there is a recognizable pattern, a trend toward response to medication. Mr. XXXXXXXX symptoms were random and senseless, in a man with a lengthy history of high intelligence, superior mental organization, and a late-life onset of such a severe illness. It began to appear less functional and more neurological, or encephalopathic. In addition, the numerous medication trials (practically the entire pharmacopoeia) had failed to help, and, in some cases, produced atypical responses of acute mental confusion, difficulty with word finding, and neurocognitive debility.

Another complicating factor (or rather series of factors) during Mr. XXXXXXXX's lengthy tenure in my office was the frequency of unusual intercurrent events and illnesses or symptoms. He suffered hearing loss,

Dr. Xxxxxx initiated treatment with intravenous medication on March 27, 2000. The result has been a sharp increase in joint pain, peripheral neuropathy and neuropsychiatric symptoms. This response, a Herxheimer reaction, is pathognomonic for classic response to effective antibiotic treatment of Lyme and other tick borne pathology, further supporting the diagnosis and treatment recommendations.

As your in-house medical staff is undoubtedly aware, the CDC suggests that the diagnosis of Lyme disease is made on clinical grounds, and that negative serology does not rule out the diagnosis. Research criteria, your doctors will inform you, must be rigorously restrictive so that outcome studies are assured the confidence of an unequivocal diagnosis against which to perform rigorous clinical trials. This is not the same bar that one sets for clinical decision making.

There are numerous studies, including several performed in conjunction with testing related to the Lymerix vaccine, which demonstrate that up to a third of patients with PCR or biopsy positive Lyme disease show negative serological results. One possible factor is the administra-

tion of antibiotic medication for intercurrent illness.

In the case of Mr. Xxxxxxxx, many signs point to a diagnosis of Lyme disease, including the response to neuropsychiatric as well as antibiotic medicines, and the overall clinical picture. The decision to deny needed intravenous medication is ill conceived, and Mr. Xxxxxxxx will receive my support in all arenas, including legislative, media-based, administrative and legal remedies in pursuit of his right to treatment for his illness.

In conclusion, I support Dr. Xxxxxx's decision to begin a trial of intravenous Rocephin and urge your company to immediately provide reimbursement and other support in Mr. Xxxxxxxx's behalf. As you know, Lyme disease is uniquely responsive to stress, including financial pressures related to the payment for treatment, and delay of this important component may adversely affect Mr. Xxxxxxxx's recovery.

Dr. Brand is a psychiatrist in private practice in New City, NY.

Postscript: The letter had the desired effect - temporarily. The patient was continued on Rocephin for a total of five months before a denial was issued.

Please subscribe to the Lyme Times. Take advantage of our special offers and bulk rates to increase awareness of Lyme disease in your community!

requests for representation at the appeals process. Of course, the pursuit of each and every case requires a great deal of out of pocket expenses, and up front costs.

As many of you are already aware, most individuals who are on disability related to the debilitating effects of Lyme disease do not have the financial resources it takes to pursue their claims. But The Dominion-Life Foundation has never turned a client away even though it is becoming more and more difficult to accept all the claims we are confronted with on a daily basis.

With your help we can meet each and every individual's request for help and representation. Without that help many Lyme patients face losing their homes, and an inability to provide for the daily necessities of life.

The Lyme Trust

We have established a Lyme Trust Account, a permanent "reserve" whose goal is \$65,000. This trust would provide perpetual income to cover "out of pocket" expenses that patients/clients do not have and would insure their ability to apply and fight for benefits for which they are entitled. For the time being we have been able to cover those costs ourselves, but with the flood of new cases, it is becoming more and more difficult. We will be able draw from this trust account to provide payment of costs associated with representation of each client. At the resolution of each and every claim we can then replenish this account.

Therefore, we are asking for contributions to this "Lyme Trust

Foundation takes up challenge

by **HG Antonio Di Giovanni**

The Dominion-Life Foundation is one of the few, if not the only organization which has successfully represented Lyme patients before the Social Security Administration, the Workers' Compensation Appeals Board, and health insurance companies. We are proud to boast that we have never lost a case in over twenty-five years, unlike any other organization in existence.

The Dominion-Life Foundation is not in the business of profiting from its efforts on behalf of its clients: we

seek only to recover the expenses we have incurred in the pursuit of our client's claims. Most firms charge 25% of each client's award; The Dominion-Life Foundation has never sought in excess of 10%. Likewise, none of the staff "employed" by The Dominion-Life Foundation is compensated for his/her work; this is what makes us a truly unique nonprofit organization. We perform our tasks out of love for all mankind.

As news of our success spread we have been inundated with

Account” of whatever you can afford: \$5.00, \$10.00 or even \$25.00. Whatever you can afford will help. All assistance should be sent to Post Office Box 5084, Walnut Creek, California, 94596; or directly to the Foundation office address at 2242 Gladwin Drive, Walnut Creek, California, 94596. We also have the ability to accept credit card donations. To contribute by credit card, simply send a letter or email to our office with your name, address, and telephone number, your credit card number and then indicating Visa or Mastercard, the expiration date, the amount you wish to contribute, and your signature if by letter. We will forward a receipt to you for your record and future tax purposes.

By June 1, 2000, the Lyme Trust had raised \$4000.00. This is only a fraction of the money needed to accomplish the work we are faced with. Please give generously.

His Grace Di Giovanni is Director and President of The Dominion-Life Foundation. He may be reached by phone at 925-930-7846 / FAX 925-930-8451 or email TDLF@aol.com. The Foundation website is at www.dominionlifefoundation.com.

Thanks to you

The Dominion Life Foundation would like to thank the following individuals for their generous donations to the Lyme Trust Account:

Barbara Barsocchini, Malibu, CA
Mrs. Maniar
Lucia Hui, Berkeley, CA
Nick Harris, IGeneX Laboratories, Palo Alto, CA
Kris Krishnan, Los Angeles, CA

Health Check Forms must be integral part of strategy

by **HG Antonio Di Giovanni**

One of the most important avenues of documenting an individual’s claim, and the strongest and most powerful force in our prevailing in a client’s claim, is the completion of daily Health Check Forms. With each and every new client we obtain a list of their primary complaints related to their battle with Lyme, or for that matter, any debilitating disease. Then we create a form that we mail to the clients to complete each and every day. At the end of the month, they mail us the original copies, while mailing another set to their treating physician.

Almost 100% of the time, defense lawyers are not prepared for such in depth documentation, and when presented with sometime 200+ forms, they are prone to finally give in realizing that the patient and their counsel (TDLF) have been extremely circumspect in documenting the degree and extent of the patient’s confrontation. It also eliminates much argument over what the patient’s complaints are, and to what degree they suffer from these complaints. If, from the first time of exposure and diagnosis, a patient were to begin completing these forms, it would help their treating physician immensely, and especially, if we represent them, making it that much easier to expedite and resolve their claims.

Order your Lyme bumper sticker now!

Over 3000 newly designed bumperstickers with the logo “Lyme Disease: A National Health Crisis” have already been sold, thanks to the enterprising spirit of Debbie Allen Harris of Bowling Green, Kentucky, who created the 3.75 by 11.5 inch bumpersticker after soliciting suggestions from participants on the online newsgroup sci.med.diseases.lyme.

The bumperstickers are available for \$ 2.00 each (includes postage) for quantities of 1 - 5, \$ 1.50 (includes postage) for quantities of more than 5.

If your group or organization needs several or many, Harris is willing to work to meet your special needs. She is willing to take large orders, and to discuss advertising in your newsletter or other medium.

To order send a check or money order made payable to

LYME AWARENESS, INC

Mail to:

Lyme Awareness, Inc.
PO Box 20107
Bowling Green, KY 42102-6107

Be sure to include your full mailing address and your email address (if available, otherwise include your phone number) for further contact. Harris plans to ship all orders within 24 hours of receiving requests. If this batch goes quickly, Harris intends to order more.

“It REALLY sends a clear message,” says Harris. She encourages people to advertise the project at support group meetings, in news letters, etc.

Harris is also putting together a website at www.lymeinformation.com through which online ordering will be available. She may be contacted by email at britesmiles@hotmail.com.

See Bumpersticker on back cover.

Seven strategies for making the most of your doctor visit

By Sheree Parris Nudd

You waited a long time for the appointment with the specialist who was reportedly knowledgeable about this mystery disease. It was also a long wait in the waiting room when the day finally arrived. But when it was your turn, you were pleased to note that the doctor seemed thorough and open. He ordered medications and tests that correlated with everything you had read.

You asked the physician for instructions on which days to take specimen samples for the lab tests. He said the lab would give the instructions. But when you called the lab about the test and asked for instructions, you were told, "No, you have to get that from your doctor."

Now what to do? You call the doctor (within an hour of leaving his office). He is busy, pressed for time, and somewhat abrupt in his answer, and you are still left on your own in your search for accepted procedures.

Now you're not so sure how much you like him. But he's the only Lyme Literate M.D. within miles, and he accepts your insurance. You've been through seven doctors before this one and you waited two-and-a-half agonizing months to get the appointment. You're not about to bail out now.

Helping yourself or a family member through the maze of healthcare when it comes to a chronic or undiagnosed illness is a lot different than being a healthy person who simply visits the doctor for the occasional muscle strain, physical, or routine test.

To be sure, you should change doctors if it's clear that you're not making progress under your present one, especially if that physician leaves your symptoms unaddressed and is not current on recent Lyme

research. But it has become increasingly clear to me that each of us must be a "full partner" with the physician in obtaining and understanding appropriate medical care. In this article, we'll explore some ideas for best utilizing those precious 15 or 20 minutes that make up the face-to-face doctor visit. Perhaps you will find some of these suggestions to be helpful.

1. Keep a symptom journal

After reading the suggestions of others with chronic illnesses, I began to record my husband's symptoms. I rate his days with a numerical value, tracking any cyclical flare-ups, and to trying to see if, over time, he is getting better. The "symptom journal" I use is a week-at-a-glance pocket calendar.

The "rating system" suggested by someone on the sci.med.diseases.lyme newsgroup uses a scale of 1 through 5. A one means "pain-free, as good as you have ever felt." A rating of five means "feeling so bad that you have to take to your bed." It was interesting to review the journal and see the pain

and fatigue fall into a three-week cycle.

Just before doctor visits, I review the journal and type out a rough outline of week-by-week symptoms for the physician, and give it to him at the beginning of the visit.

2. Don't stew in the waiting room

Until something changes in the present healthcare system, there's a good chance you'll experience some long waits in the doctor's office. Don't stress out. Instead, plan ahead. Allow plenty of time, and bring a book or magazine, or one of those travel pillows that fit around your neck for a sitting-up-nap. Or bring some blank greeting cards and write notes or letters to friends or loved ones. When else do you have a long, uninterrupted period of time to handwrite a letter... a practice that is practically a lost art?!

3. Write your questions out ahead of time. Hand your doctor a copy at the beginning of the visit.

I do this every time we go to the doctor. I accompany my husband on his medical appointments and take notes. (If you are very sick, or if you are not the type to be proactive, insist that a partner or trusted friend go with you). At the beginning of the visit, the doctor gets a copy of the list of questions as well as the chronology of symptoms.

Neurologist	Cardiologist	Rheumatologist	Psychiatrist	Infectious Disease
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Tick-borne Disease Panel

The first benefit is that we don't forget to ask an important question. But the other benefit, I believe, is that the doctor "sees" the scope of the task right up front. He knows pretty well how much needs to be covered and can then pace himself and fit all the questions into his tight schedule, without wondering "how many more" questions we may have.

Sometimes we will include questions like, "What do you think of XYZ medication?" or "Is it important to test liver function while on this medicine?"

4. Try to pinpoint your biggest concern and ask what your options are.

Having trouble sleeping? Feeling like the current medicine is doing nothing for you? Worried about being able to do your job due to decreased energy? Does the medicine tear your stomach up?

Report your concern and ask "What are the choices in terms of how best to address this problem?" If the doctor suggests a particular avenue of treatment, ask about side effects, and ask what the doctor's second choice is if this strategy doesn't work.

5. Asking questions in between visits – try to discover your doctor's

preferred style of communication.

I sometimes fax the doctor updates and questions in between visits (this is more common when starting or reacting to a new medication). He writes the answers and faxes back... and seems to prefer this to phone calls. I sometimes still call for clarification of an item, but it takes less of his time than this way than if I have not first communicated the issue by way of the fax machine.

Our doctor has an office staff, but not an office nurse. For other doctors who have a nurse or physician's assistant, it is often very effective (and much quicker) to explain the problem and ask your question of him/her. He or she will touch base with the doctor and call you back. I get much quicker results this way than if I insist on speaking to the physician.

6. Tracking medications

Oh yes, the symptom journal pages that we hand the physician each visit include documentation of medication doses, start or stop dates, and reactions, if any. For this, the doctor has expressed appreciation, particularly for the documentation of medication start and stop dates.

Doctors have to do a lot of documentation. The written notes

save the physician time and are much more accurate than if a patient merely says, "Well, I think I stopped taking it on a Tuesday in April...? Yes, it was little Bobby's birthday and I just couldn't face another pill."

7. Keeping your own set of records

With a chronic or undiagnosed illness, some sets of symptoms only become apparent *retrospectively*, that is to say, looking back at the history of the pains, feelings, and problems that one experiences. I periodically reread the entire medical record. Each time I do, I find that I have a greater understanding of the illness, due to additional reading that I've done from medical journals and from other peoples' experiences.

Conclusion

The most important point is to find a way of communicating and tracking progress that works for you and for your doctor. A planned approach can decrease stress for both of you and increase the value you receive from your healthcare dollar.

Sheree Parris Nudd is a healthcare administrator and writer living in Maryland. Copyright 2000 Sheree Parris Nudd

Auto Mechanic | Brother-in-Law | Kids' Teacher | Fitness Guy | Attorney

A Better Tick-borne Disease Panel

Rate & comment on your doctor, or find a doctor

From a participant on the sci.med.diseases.lyme newsgroup

WebMD has a very nice site here where you can search for doctors in your area, and also make your opinions known on the doctors you have had in the past.

http://my.webmd.com/find_a_phys/doctor

"Tisha" says, "It's about time people got some consumer information on their health care providers."

Lyme Bill, cont. from p. 1

further progress on Lyme Disease by setting forth health goals for health officials, then providing the guidance and funding needed to accomplish them. Smith's bill also calls for the development of a reliable diagnostic test for Lyme disease that will accurately indicate who has Lyme, who does not, and who is cured.

Smith said that he has heard many horror stories from constituents about missed diagnoses, worsening symptoms, physician investigations and insurance company woes. A reliable test for Lyme disease can help alleviate these problems.

"We need to declare war on Lyme disease, said Smith, "and that is why this legislation is so crucial. I am absolutely convinced that if we invest a sufficient amount of resources and dedication to fighting Lyme disease, we can win," added Smith.

This legislation, said Smith, also requires a reassessment of the Centers for Disease Control and Prevention's surveillance criteria by setting forth a goal of reducing the incidence of Lyme disease in the top 10 endemic states by 33%. It also creates a public-private citizens' advisory task force to ensure accountability over the project and expands efforts to educate physicians and the public about the threat of Lyme disease.

Smith is also aggressively monitoring the current funding that is already being spent on Lyme disease. Smith coauthored, along with Senators Santorum and Dodd and Representative Joe Pitts, a letter to the nonpartisan Government Accounting Office to investigate how current funds are being spent.

"As we generate and solicit the support needed to enact HR 2790 into law, I am also pursuing a dual track approach to improve accountability over what funding is already being spent on Lyme disease," said Smith.

Patients claim guidelines have caused much suffering

Protest vigil, from page 1

Steere, who has been credited with identifying Lyme disease a quarter century ago, has insisted that most cases of Lyme disease can be successfully treated with only 30 days of antibiotics, and if symptoms persist, they are probably caused by "something else." His guidelines are popular with cost-conscious insurance companies. Patient advocates say that widespread dissemination of Steere's guidelines has created an atmosphere in which Lyme disease patients have had difficulty getting accurate diagnoses and adequate treatment, particularly in advanced or "late" stages.

Carrying posters and chanting, protesters congregated on the corner

of the Hotel Pierre directly beneath the banquet room, behind police barricades. A wheelchair with colorful fresh flowers was set up outside the barriers on the corner of 5th Avenue with the sign, "IN REQUIEM, Rest In Peace," in memory of Lyme disease fatalities, which caused all the traffic and pedestrians to slow down and gawk, according to one participant.

One of the posters had a large cow head in the middle and proclaimed: "Steere Me No Bull — Lyme Disease is not cured in 30 days" Three large posters displaying the names of Lyme patients who were not able to attend The Vigil carried the following message:

"Dear Dr. Steere: We object to

Patient perspective... in their words

In the recent N.Y. Times article "Questioning Long-Term Lyme Cases," Dr. Steere is quoted as saying he was "a victim of organized harassment." We know a lot about organized harassment down here in Texas; it's been utilized to stop clinicians from recognizing and treating Lyme disease for too many years.

From doctors who remain parochial in their views ("There is no Lyme here") to insurance companies that have seized on the cost-containment features of Dr. Steere's treatment protocols, we have been victimized. There is no test that conclusively demonstrates that *Borrelia burgdorferi* has been eradicated, yet we are pronounced "cured" by the calendar. Amazingly, after this "cure by calendar," spirochetes are found in skin, spinal fluid, synovial fluid, blood, ligamentous tissue, muscle tissue and iris tissue.

R. James Martin and Karen J. Rose, Eules, Texas

We are all intimately acquainted with the anguish of this disease, compounded immeasurably by Dr. Steere's determined grip on the research funds and on the dissemination of scientific information concerning it. If the world was as he'd apparently like it to be, he could continue to attempt to control and clamp down, to use intimidation tactics on our doctors until they all are forced to give up. He could stay on his throne and receive accolades from the ignorant and from those in collusion with him indefinitely. But, I think two decades is quite enough. One of the posters today summed it up: "Now what Dr. Steere? Should we all just disappear?" I am probably misquoting that wildly. Whatever it was, it was good.

Prestige, influence, and power can be the undoing of some people. They cannot let go of it for anything. The childhoods of two of my kids have been sacrificed to this man's ego. It helps a little to stand on the corner of Fifth Ave. and 61st St. and shout, "Tell the truth!" and "Steere must go!!!" It doesn't remove our tragedies, but if it caused him the slightest moment of discomfort, then it was a very good thing.

Carla Southwick, New Jersey

This young woman with her mother holding a poster is a Lyme patient.

your monopoly on Lyme Disease Research and Treatment. Your insistence on "Overdiagnosis/Overtreatment" philosophies has left severe health conditions for us all.

We object to harassment of our doctors who treat us and to the award of honor to you on this night.

Signed, 784 Lyme Disease Patients/Victims from across the world"

One of the protesters had designed a headpiece from a recycled motorcycle helmet, covering it with crimped silver paper and feathers, with a piece that curved over the front of the face like a big beak. A sign said, "Allen Steere Lyme Disease Prevention Device"

"I loved it, just loved it," said The

Vigil organizer Jeannine Der Bedrosian of New Jersey. "It stuck out above the crowd like a totem pole!"

The protesters periodically erupted with several chants, "Shame on Steere, Shame on Steere" and two crowd favorites, "Steere Clear of Steere, Steere Clear of Steere" and "Whaddo we want?" "A Cure!" "When do we want it?" "Now!" They also sang an abbreviated version of "We Shall Overcome (Lyme Disease)." Press coverage by several different reporters and cameramen recorded the entire event. It was later broadcast nationwide on ABC World News and will augment a special program being worked on.

According to Der Bedrosian, the

noise was definitely heard inside the hotel. She observed a hotel security person castigating the police, who defended the patients' right to protest. Inside, the Hotel Pierre was crawling with security men in headsets.

Patients complain that physicians, researchers and patients have suffered serious adversity as a result of Steere's oft-cited philosophy. Physicians are experiencing loss of licenses, censure, or restriction of medical practice if Steere's guidelines are not followed. Many make voluntary limitations on how many Lyme patients they will accept due to fear of sanctions. Patients assert that the pool of doctors willing to treat Lyme disease has shrunk to a critical level and many are unable to find or sustain adequate treatment. Insurers routinely discontinue or limit insurance coverage for Lyme disease, citing Steere's guidelines.

Patients continue to suffer a multitude of disabling symptoms such as brain damage, memory or cognitive difficulty, blindness, crippling arthritis and even death, patient advocates say. Many have suffered debilitating chronic effects for years despite official insistence that short-term antibiotics cure Lyme disease. In a new turn of events several of these patients have filed complaints for investigation of Steere by the Massachusetts Board of Registration in Medicine (*see Lyme Times #28*). Following an earlier protest against Steere at the Bethesda campus of the National Institutes of Health, Steere stated that "perhaps there is an overreliance by others on my views."

This article was taken in part from a Voices Of Lyme press release and from eye-witness reports by J. Der Bedrosian. Shortly after The Vigil, Der Bedrosian was denied 5 out of 6 months insurance payments to the two home care companies that administered her IV treatment, despite both companies having previously verified that she would be covered.

MOW marchers met with legislators

from page 1

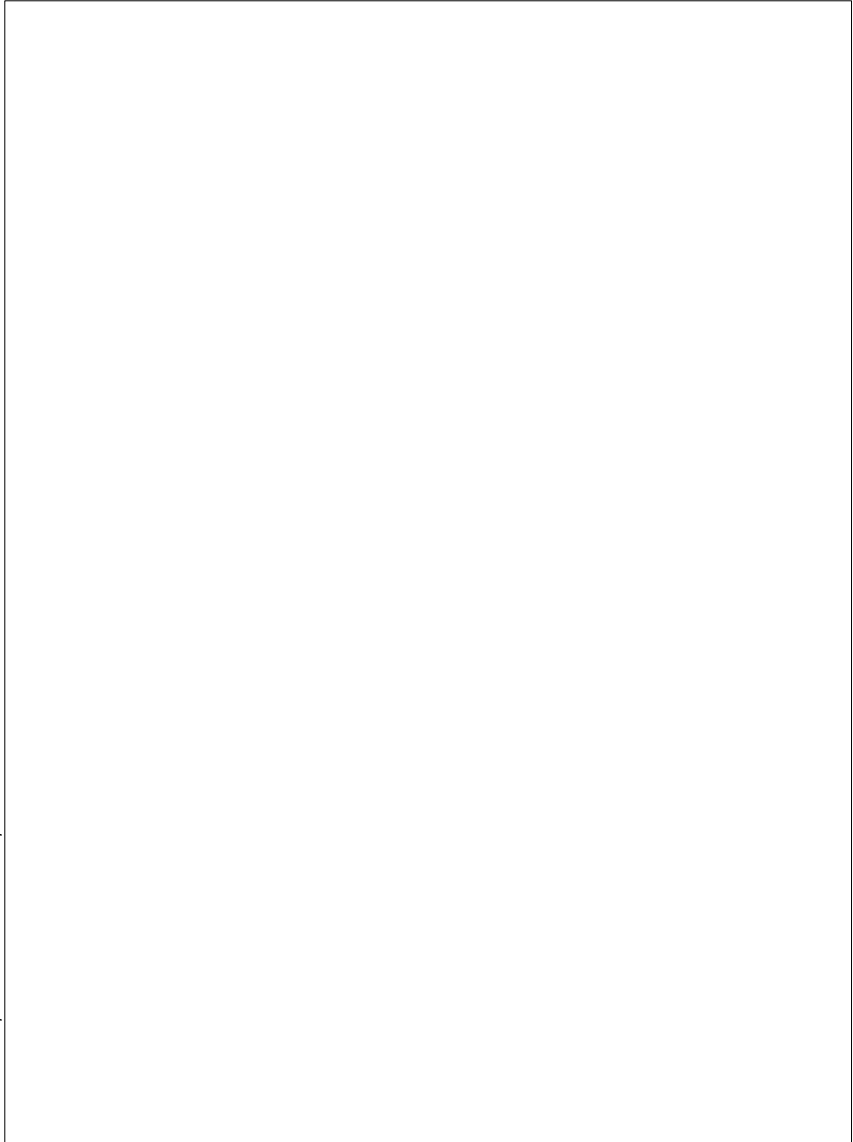
ralled large groups of patients to attend this rally. Many others drove or arrived by public transportation.

In the morning, attendees at the rally connected long green ribbons containing the names of Lyme disease victims in attendance as well as those present in spirit. These ribbons extended around and around the particular portion of the mall the rally occupied. Hundreds of ribbons

bearing names of patients were displayed in an impressive array for the public to consider.

Mrs. Marvina Lodge of Florida, known affectionately to all as "Lovey," coordinated the preparation and display of the ribbons and the colorful Lyme disease quilt squares, which had also been displayed in Gettysburg (*see story on page 14*). Her address to the crowd met enthusiastic response.

This young mother contracted Lyme during pregnancy. Her daughter was congenitally infected and was born with a cardiac defect.



Stephanie Gail/Lavender Park photo

Rally attendees marched around the Senate swamp and the ribbon display several times, although the bright sunlight and heat affected many. Patient Lovette Mott, organizer of the Gettysburg Rally, also gave a rousing speech and led the crowd in singing "Grievin' On a Lyme Train," accompanying the singing on a guitar. MisTick, also in attendance, worked the crowd and met many admirers, while posing shamelessly for the cameras.

New Jersey Lyme Disease Association president Pat Smith addressed the Rally, reading a long list of many Lyme disease organizations which had signed on to support passage of the Lyme Disease Initiative Bills. Senators Rick Santorum, Chris Dodd and Representative Chris Smith were present and expressed their support for these bills.

"Lyme Disease is a serious health concern throughout the Northeastern United States," said Congressman Chris Smith (NJ-4) during the press conference portion. "The Lyme Disease Initiative contains a package of desperately needed reforms, combined with additional resources totaling \$125 million, to help combat this emerging public health threat," added Smith.

Smith stated that this legislation represented a means of forging further progress on Lyme Disease by setting forth health goals for health officials, and providing the guidance and funding needed to accomplish them.

In addition to aggressively monitoring the current funding that is already being spent on Lyme disease, Rep. Smith coauthored and announced, along with Senators Santorum and Dodd and Representative Joe Pitts, a letter to the nonpartisan Government Accounting Office (GAO) calling for an investigation of how current funds are being spent.

The letter calls for the GAO to conduct a review of the Dept. of Health and Human Services' (HHS)

Lyme Disease programs. Smith expressed concern over receiving credible reports of misuse of funds, conflicts of interests and harassment and retaliation in the conduct of the federal government's Lyme disease programs.

Karen Forschner echoed the Lyme Disease Foundation's support of the GAO investigation.

New Jersey patient Jeannine Der Bedrosian had reserved appointments in advance with busy NJ legislators, promising that a delegation of New Jersey representatives (Lyme disease patients and sympathizers) would appear for the senators and congresspersons. With prepared packets for each, including documentation of long term and chronic Lyme disease, articles on the treatment controversy, and the LymeRix vaccine lawsuit, she planned to visit the three House of Representatives' office buildings and the two Senators' office buildings at opposite ends of the mall.

As she met the arriving patients on the buses, she gave them their appointment information, legislator building and office location. "I handed the packets out and directed

people and they fell into the swing of it," Der Bedrosian said, adding that out of a possible 13 representatives and two senators, the New Jersey delegates divided up into groups and visited ten representatives' and two senators' offices. The remaining three representatives had already signed on the bill.

The delegates engaged Sen. Torricelli's health aide for about 45 minutes, discussing various points such as who is appointed to the Task Force established by the Lyme Disease Initiative Bill, "to reflect Real-World Patients and Doctors and Group Leaders and not lab researchers who espouse theory," Der Bedrosian said. Rep. Pallone's staff aide kept a group of eight delegates for over 1/2 hour with questions.

"We had quite a contrast from doctor's wife to LymeRix victim to child-victim to longterm and chronic victims, and family members," Der Bedrosian added.

More MOW photos may be viewed on Lavender's Lyme Rally Sights at <http://homepages.go.com/~sglp/albums/album2>.

newspaper, you find an article or obituary about someone who has died of a Tick-Borne Illness, please contact us so they may be included.

Most, but not all of the people on the site have a Tick-Borne Illness on their death certificate as Cause of Death.

There are, in the Lyme pages, suicides as well. Columbia University psychiatrist and professor Dr. Brian Fallon has stated his belief that Lyme disease patients are much more prone to depression and generalized anxiety than other patients with similar chronic diseases such as lupus. He believes there is a physiological basis for this. A disease can affect the will to live in the same way it affects joints, tendons, hearts and eyes. Lyme disease is known to infect the brain.

David Lee Thomas, 18, of Tinton Falls, New Jersey, died on May 18, 2000, after a long battle with Lyme disease. David was a member of the varsity swim team, the Baptist Church of Red Bank and Monmouth High School.

Christina "Christy" Marie Lambeth, 19, of Winston-Salem, North Carolina, died February 10, 2000, after losing the battle to Lyme disease. She was born July 8, 1980, in Forsythe County. Surviving are her mother, father and sister.

Lynette McKinney, 64, died on March 3, 2000, at St. Francis Hospital, Poughkeepsie. Mrs. McKinney was born in Washington, DC, and was an artist, wife, mother, and grandmother. She leaves her husband of 40 years, John McKinney; two daughters, and two grandsons. Mrs. McKinney was very active in the community.

Angela Amato, 53, after many years of illness, died from complications of Lyme disease on January 26, 2000. She leaves a daughter, Elaine, who misses her very much.

Beverly Stanton, 53, died February 17, 2000.

Owen Klepper, a Cornell Univer-

In Memoriam

Tick-Borne Illness Memorial Pages

by Sarah Weiss

"Ill-favored ticks ...the foulest and nastiest creatures that be." Pliny the Elder (23-79 A.D.)

The Lyme disease obituary website may be accessed at <http://www.angelfire.com/punk/lymedisease/memorial.html>

These pages are dedicated to those who have died of Tick-Borne Illness: Lyme, Tularemia, Babesiosis, Ehrlichiosis, Relapsing Fever, Colorado Tick Fever, Tick-Borne Encephalitis and Rocky Mountain Spotted Fever.

If you have a loved one who has died of a tick-borne illness and you
Number 28

would like to see them on this page or the website, you are more than welcome. Please email AramSarah@cs.com or contact the Lyme Times editor. Provide as much information as possible and any page preferences. The website also links to Memorial Pages made by people's families or friends. If reading a

sity alumnus, lost the battle to cancer and Lyme disease. Owen was a marketing communications specialist.

Rena McNulty of Pittsburgh, Pennsylvania, died on Monday, April 3, 2000. She is survived by her husband; three daughters; and four grandchildren.

William 'Bill' Nichols had suffered from Lyme disease for twelve years before taking his own life on April 12, 2000. Bill was desperately ill from the complications of the disease, which was in his spinal column and his brain. For the past two years, he had to struggle to get out of bed, often became disoriented, and was unable to drive a car. He was also losing his eyesight and his ability to walk. Unable to continue with his research, Bill found that he no longer had the energy to concentrate, and was terrified of losing his faculties. He suffered from terrible headaches, debilitating tremors, skin lesions, and cough and eyesight problems, which kept recurring despite the massive doses of antibiotics being administered to him. But he struggled

bravely, and was kind and gentle to the end, always trying to help others in any way he could. It is with deep pain and sorrow that I write these words for a very special friend who will live in our hearts forever. Roger and Marilyn Girsomero Arroyo Grande, California — [*From Spotlight On Lyme, Vol. 5, No. 4 July/August 2000 Issue*]

Paul Fjare, a life member of the American Camping Association, died of complications of Lyme disease. He worked in camp consulting and camp design for nearly thirty years and was a former member of the National Standards Board. [*Camping Magazine, Jan 2000 v73 i1 p6*]

John W. McGrath, 75 Accountant; avid sportsman; former Chatham resident, died Jan. 22, 2000 in Florida. He was the husband of Barbara F. McGrath for 52 years. Born in Boston, Mr. McGrath was raised in Sharon, Mass., and served as a corporal in the Marine Corps during World War II. Surviving besides his wife are a son, four daughters, and 10 grandchildren.

hearings, the OPMC knows that the legislature and the public are watching to guarantee fair trials.

“My own goal is that by the time Dr. B. comes to trial no one will believe that Lyme disease is an easily treated illness and everyone will be aware of the kind of politics that has led to persecution of Dr. B and other LLMDs,” she states.

Patient advocacy groups are still encouraging patients to write letters to US Senator Arlen Specter, telling him about difficulties they have faced in getting diagnosed, treated and reimbursed for Lyme disease.

“If Senator Specter gets enough of our personal stories, he might call for a Senate hearing addressing physician harassment among other critical issues,” Lubarsky said.

Address letters to:

Sen. Arlen Specter
711 Senate Hart Building
Washington, DC 20510
Attn: Erin Quay

OREMAIL:

erin_quay@specter.senate.gov

Lubarsky advised patients to keep copies of all correspondence, and send copies of their letters to Rep. Chris Smith, 2370 Rayburn House Office Bldg., Washington, DC 20515.

Burrascano denies that he is nervous about the impending proceedings, but admits that the case has taken up all his free time and time with his family in recent months. He has also been forced to curtail his research. He is aware that the outcome of his case will have far-reaching implications.

“I am bothered by how this has had such a negative emotional impact on chronic Lyme patients worldwide, and the doctors who have had the strength of character to stand behind them,” Burrascano said.

Legal costs may top \$100,000.00. A legal defense fund has been set up. To contribute, make checks payable to “Burrascano Legal Defense Fund”

Action Alert

Burrascano OPMC hearing scheduled for October 26

Taking advantage of the legislative recess, the Office of Professional Medical Conduct (OPMC) branch of the NY Health Department has notified Dr. Joseph Burrascano that his formal administrative hearing has been scheduled for October 26, 2000, with the ostensible goal to discipline him if they can demonstrate that he treated patients inappropriately. Patient advocates credited an intensive letter-writing campaign undertaken by patients to members of the NY legislature with slowing down the OPMC, which delayed several months before scheduling the hearing.

Page 28

The format of the hearing/trial is to meet once a week until the process is complete. It is expected to continue for two to three months, and within six weeks of its completion, to render a verdict.

The setting is like a mini-trial, with a state prosecutor, a panel of three to serve as the jury, plus Burrascano, his attorney, and his and the State's expert witnesses.

Patient advocate Ellen Lubarsky thinks that patients need to focus on the most effective ways of ensuring that when Dr. Burrascano and other Lyme experts come up for their

Mail to: BLDFC/O Monica Miller P.O.
Box 410 Kinderhook, NY 12106.
People may also contribute online at
www.goods4.com. The thought of the
expense makes Burrascano angry.

this money could be spent for the
patients,” he said. “I guess, though, if
we can win this case, the victory will
be for all of us, and maybe this will
turn out to be money well spent.”

“Imagine what could be done if

Sample letter

by Ellen Lubarsky

Below is a sample letter that can be sent to the NYS legislators. You can either write you own or copy this one, but please do write. The list of people to send this to is in the far column.

Dear

I am writing to alert you to an urgent situation in New York State which affects the health of thousands of Lyme disease patients in New York and throughout the country, and to enlist your support and intervention in the situation. Dr. Joseph Burrascano, one of the most highly regarded physicians in the treatment of Lyme disease, has recently been brought up on official charges of medical misconduct by the New York State Office of Professional Medical Conduct (OPMC).

The OPMC has claimed that the current investigations of Dr. Burrascano and several other Lyme specialists who follow similar protocols are not at all related to their treatment methods for Lyme disease. Yet at the same time, OPMC has publicly revealed their bias against Dr. Burrascano and his colleagues' longer term approach to the treatment of chronic Lyme disease. In a letter written to Lyme disease patients dated 12/21/99, Ansel Marks, Executive Secretary of the OPMC, stated, "Rarely, if ever, have ... published guidelines indicated that anything more than two-three weeks of antibiotics are required to cure Lyme disease." This statement contradicts a significant pool of peer-reviewed scientific literature demonstrating the persistence of Lyme disease infection in spite of treatment with three weeks or more of antibiotics.

Earlier this year, we forwarded to the legislature some of the above mentioned scientific information. Our concern at that time was that a high percentage of Lyme specialists throughout the country had been reported, almost simultaneously, to their state licensing boards, suggesting a pattern of harassment and bias by those who believe that Lyme disease is always easily cured.

At that time we felt that the OPMC's documented bias should preclude it from sitting as judge and jury over those physicians with legitimate scientific differences of opinion. We had asked for legislative intervention to look into this issue. Unfortunately, the legislature recessed before the issue of formal hearings was addressed, and the OPMC launched formal charges against Dr. Burrascano during a time when no intervention was possible.

In short, there is a major controversy within the medical community about the treatment for Lyme disease, and the OPMC has displayed a bias in favor of one side of that controversy. I urge that the legislature launch an investigation of the OPMC to determine whether it is acting impartially in its investigations of Lyme disease physicians. I urge that there be a moratorium on the administrative hearings of these physicians until such time as the impartiality of the process can be assured. I further urge you to create a forum in which the voices of Lyme disease patients can be heard.

Like many other Lyme disease patients, I feel that the action of the OPMC against Dr. Burrascano and other physicians who have been willing to treat chronic Lyme disease constitutes a great threat to my health, if not to my life. Please do not turn your back on the continued harassment of those doctors who have helped seriously ill people during a major medical epidemic. Please do not turn your back on me and thousands of other chronic Lyme disease patients.

Thank you,
(Sign name AND address).

Send your letter to the following legislators (see next column):

Hon. Kemp Hannon Chairman
Senate Health Committee
Room 609 LOB
Albany, NY 12247
HANNON@SENATE.STATE.NY.US

Hon. Richard Gottfried Chairman
Assembly Health Committee
Room 822 LOB
Albany, NY 12248
GOTTFRR@ASSEMBLY.STATE.NY.US

Hon. Patricia Acampora
Room 725 LOB
Albany, NY 12248
ACAMPOP@ASSEMBLY.STATE.NY.US

Hon. Maureen O'Connell
Room 326 LOB
Albany, NY 12248
OCONNEM@ASSEMBLY.STATE.NY.US

Hon. Joseph Bruno
Senate Majority Leader
Room 909 LOB
Albany, NY 12247
BRUNO@SENATE.STATE.NY.US

Hon. Joel Miller
Room 531 LOB
Albany, NY 12248
MILLERJ@ASSEMBLY.STATE.NY.US

Hon. Vincent Leibell
Room 802 LOB
Albany, NY 12247
LEIBELL@SENATE.STATE.NY.US

Hon. Michael A.L. Balboni
Room 803 LOB
Albany, NY 12247
BALBONI@SENATE.STATE.NY.US

Hon. Stephen Saland
Room 946 LOB
Albany, NY 12247
SALAND@SENATE.STATE.NY.US

Hon. Fred W. Thiele, Jr.
Room 530 LOB
Albany, NY 12248
THIELEF@ASSEMBLY.STATE.NY.US

Hon. Michael Forbes
3680 Route 112
Coram, NY 11727

Governor George Pataki
State Capital Albany, NY 12224
ATTENTION: Mary Gifford
GOV.PATAKI@CHAMBER.STATE.NY.US
(IF you email Gov. Pataki, write Attn:
Mary Gifford on the subject line).

Research

Experimental treatment uses cholesterol drug to bind hypothetical neurotoxins

by Donna Herrell

Richie Shoemaker, MD, of Maryland, has completed a preliminary study of the use of cholestyramine (Questran, a benign powder used to lower cholesterol) on 100 patients with long-term, antibiotic-treated Lyme disease. Based on the dramatic positive results of the study, Dr. Shoemaker is ready to submit his work to a major journal for publication. He will also be ready to perform an FDA-IND (more rigorously monitored by FDA than an independent research study) study shortly.

Dr. Shoemaker believes that neurotoxins play a major role in the symptoms of, if not the cause of symptoms of, chronic Lyme patients, and he has been able to successfully utilize cholestyramine to bind and remove the toxins from the body. He became involved with this treatment

when he discovered the cause and treatment of Pfiesteria, a dinoflagellate disease which also involves neurotoxins, that was killing fish along the east coast.

Attending physician approval is necessary to participate in the study, an informed consent must be signed, and certain criteria must be met. If you are interested in receiving the informed consent packet, Write (no faxes) to Dr. Shoemaker, 1604 Market Street, PO Box 25, Pokomoake City, MD 21851. You must include a self-addressed PREPAID PRIORITY MAILENVELOPE.

Donna Herrell is editor of the new website About Lyme Disease Guide, <http://lymedisease.about.com>. She may be contacted by email at lymedisease.guide@about.com

e. live in CT, NY, NJ, or Eastern Pennsylvania

f. currently have a positive IgG Western blot or PCR

Patients who think they might be eligible based on a-e above and who wish to have free blood testing should contact the study coordinator, Dr. Kathy Corbera, at 212-543-6508 and she will arrange free testing at their doctor's office or at Columbia.

The Normal Controls will get neuropsych testing and brain imaging but no spinal tap and no treatment. The normal controls will receive up to \$750 for completion of the study participation. The normal controls should have no history of a learning or memory problem, no current medical problems, and no prominent psychiatric problems.

To qualify for the study, patients need to have current tests that indicate 5 CDC IgG bands on WB at both Stony Brook and BBI or a current positive PCR from Mayo. The study will pay for the current testing if patients feel they might qualify. Historically, they should also have either a reactive IgM or IgG Western blot or a well-documented EM rash. Finally, people who don't have a well-documented EM rash also need to have evidence somewhere in the charts of any of the following: swollen joints, radicular pains, lymphocytic meningitis or encephalomyelitis, cranial nerve palsy, cardiac conduction delay. Fallon does not emphasize the latter criteria because he doesn't want patients to exclude themselves based on the belief that they don't have such documentation.

"Often, the evidence is there if you look back at the records," Fallon said.

Patients who wish to place brochures in their doctor's office about the study should contact the researchers either by email <CULyme@aol.com> or by phone at 212-543-6510. The study website address is: www.columbia-lyme.org.

Patients needed for persistent Lyme disease treatment study

Dr. Brian Fallon is actively seeking Lyme patients and healthy normal controls for his NIH funded persistent Lyme disease study.

The Lyme disease patients will receive state-of-the-art brain imaging and comprehensive blood, CSF, and neuropsychological testing. They will also be given 10 weeks of IV treatment with either Ceftriaxone (rocephin) or placebo; placebo-randomized patients will get 6 weeks of IV rocephin for free at the end of the 24 weeks.

The Lyme patients need to be:

- a. between age 18-60
- b. have previously received at least 8 weeks total of IV antibiotic therapy
- c. have previously tested positive on Western blot (IgM or IgG) or have a well documented EM rash
- d. have current memory or attention or word finding problems

TOFU!
Ticked Off and Fed Up!!!
Motto on T-shirts worn at Gettysburg

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
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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.

Take advantage of our special bulk rates for your rally or conference. Write LDRC, PO Box 707, Weaverville, CA 96093. Allow 2-3 weeks for delivery; more for large orders (over 100). Offer good while supplies last.



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The following charges and policies govern requests for bulk orders of the Lyme Times:

10	\$10.00
25	\$20.00
50	\$35.00
100	\$50.00
250	\$100.00
500	\$150.00

Additional shipping costs may apply. Prices may vary according to quantity and shipping method.

Shipments of bulk quantities of the Lyme Times are subject to approval by the Lyme Times Circulation Committee. The following will be considered

- 1) Special one time events: Health

Fairs, Public Forums, Conferences, Symposiums, etc. Written requests are required and should include: A) The event B) Sponsoring organization C) Date D) Anticipated number of attendees E) Quantity of Lyme Times desired

Requests should be submitted, if possible, prior to the printing of the issue to ensure adequate supplies.

2) Shipments to Physicians, at their request.

3) All other bulk shipments may be limited to specific geographic "target" areas as determined by the Committee.

Please let us know if you don't receive your Lyme Times. 3rd class bulk rate mail is not as reliable as first

class. If you are missing your copy, let us know and we will mail you a new one.

Library Education Program

We encourage readers to check their local libraries for Lyme disease information. If there is none, ask your librarian if s/he would be willing to start a file of Lyme articles and newsletters, to which you could add from time to time. The "back issue" packet makes a perfect starter kit for libraries, and serves as the backbone of a Lyme Information File.

**Special Offer

For this issue only: we will send a single copy to anyone for \$5.00. This includes a brown manila envelope, first class postage, and handling.

Calendar

Grass Valley Lyme Disease Seminar

Tuesday, October 24, 2000
5:00 pm to 9:00 pm
Sierra Nevada Memorial Hospital
Grass Valley, California

For information contact Peggy Leonard at flwrpeg@foothill.net

Emerging Infections of the Central States (EICS)

Friday, October 27, 2000
1:00 to 6:00 p.m.
Spencer Board Room
Saturday, October 28, 2000
8:00 a.m. - 5:00 p.m.,
Spencer Auditorium
Saint Luke's Hospital
Kansas City, Missouri

Check the EICS website: <http://www.crosswinds.net/~eics/index.htm>

For more information contact Karen Iadanza, email: karen.iadanza@med.va.gov or phone (573)-814-6000, extension 3712

Mark your calendar!
Lyme Disease in California and the wildlife profession - a workshop
Friday, February 23, 2001
Sacramento, California
Details in the next issue of the Lyme Times

LDA Conference on Lyme and Other Tick-borne Diseases

Saturday, November 4, 2000
7:30 a.m. to 6:30 p.m.
Reception 6:45-8:45 p.m.
Doral Forrestal
Princeton, New Jersey

The Lyme Disease Association, Inc., formerly the Lyme Disease Association of New Jersey, Inc. presents this conference which will focus on children and adolescents.

9 CME category 1 credits will be offered to physicians and health care providers by the Jersey Shore Medical Center (JSMC) Division of Meridian Hospitals Corporation (MHC).

The fee is \$125 for physicians and \$80 for non-physicians and medical students. For hotel information, call the Doral Forrestal at 1-800-222-1131 or visit www.forrestal.com.

Arno Karlen, author of recently published **Biography of a Germ**, will be featured as the opening speaker. Other speakers include clinicians and researchers who are some of the most knowledgeable in the world on Lyme disease.

For more information: e-mail lymeliter@aol.com, or call (732) 938-4834.

Send announcements for the Calendar to the Editor

LDRC West Coast Lyme Disease Conference

Saturday, November 11, '00
9 a.m. to 1:30 p.m.
California Pacific Medical Center Auditorium
San Francisco, California

New York Psychiatric Institute researcher Brian Fallon, MD, will be the keynote speaker on neuropsychiatric Lyme disease.

The conference will also focus on Lyme disease and other tickborne diseases in the western United States. Topics to be covered include the ecology of Lyme disease, testing for Lyme and other TBDs. New entomologic findings on ticks in California will be presented. A public forum is being planned.

For more information email info@lymedisease.org or phone 707-468-8460.

Patients may attend the public forum from 3 to 4:30pm. \$5 donation

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