



the Lyme Times

NUMBER 26

Education, Support, Advocacy, Research

JULY-OCTOBER 1999

Outreach director promises Lyme TV show

Several doctors treating Lyme disease patients are currently being investigated because of complaints filed with Offices of Professional Medical Conduct in several states [see story below]. Upset about what he perceives as an unjust attack on these physicians, Stephen J. Nostrom, director of Lyme Borrelia-Out-Reach in Mattituck, New York, plans to strike back.

Nostrom hosts and produces a monthly program on cable TV. He plans to do a series of shows featuring key players who will be given an opportunity to comment on what is widely viewed in the patient community as being a concerted campaign to put their most knowledgeable doctors out of business.

Nostrom plans to do a two or three part series, each segment one

See TV show on page 22

Inside:

Jean Hubbard gives an in-depth report on Lyme encephalopathy in children. Page 35

NJ congressman introduces new Lyme Bill in House

On August 5, Congressman Christopher H. Smith (R-4) introduced the Lyme Disease Initiative of in the US House of Representatives. Last year, Congressman Smith introduced the Lyme Disease Initiative 1998. Unfortunately, its introduction in May 1998 came at the end of the 105th Congress, so there was little opportunity for any action on that bill. However, the introduction provided a springboard for discussion of the provisions and scope of the bill.

Congressman Smith introduced the new bill to the current 106th Congress after soliciting considerable input from government agencies and

from nationwide Lyme groups through Pat Smith and the Lyme Disease Association of New Jersey, Inc. It is similar in scope to last year's bill, asking for \$125 million over 5 years for Lyme disease and related tick-borne illnesses. Last year's bill asked for \$120 million. It includes new components for the Department of Interior (Parks) and Agriculture, along with the original provisions concerning the Centers for Disease Control, National Institutes of Health, and Department of Defense. The new bill, like the old, creates a task force that includes members from the public (govern-

See Lyme Bill on page 20

"Lyme-literate" doctors being targeted in "ethics" probes

"If patients don't do something about it, they will not have any doctors willing to treat them."

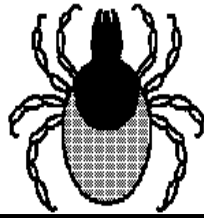
New Jersey pediatric neurologist Dorothy Pietrucha gave this warning in 1993. At the time, Pietrucha, who was responsible for hundreds of very sick children, had come under fire after a study by the Centers for Disease Control showed that a few of her patients had their gall bladders removed after she treated them for

Lyme disease with IV ceftriaxone. Since then, numerous other physicians considered "Lyme literate"-- or LLMDs--by patients have been brought up on various charges.

One of the latest is Dr. Joseph Burrascano of East Hampton, New York, one of the nation's leading Lyme physicians, who has been reported to the New York State

See Ethics probes on page 23

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Lyme Times

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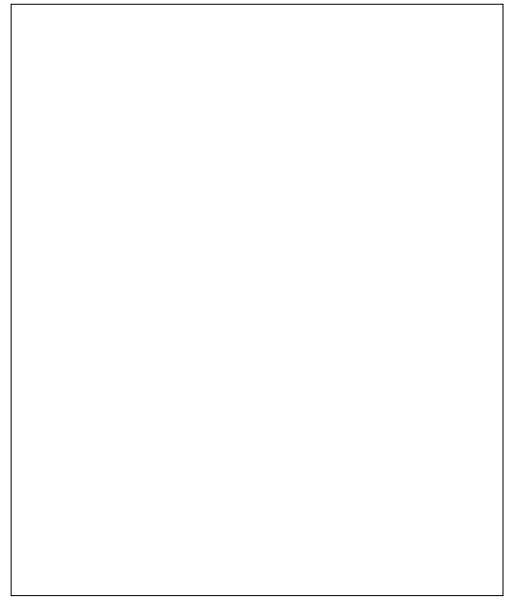
Letter from the Editor

Dear Readers,

Shortly after my oldest son's wedding in June, I took off for the international Lyme disease conference in Munich. While I am always happy to see many Lyme friends from the U.S., my main interest was to establish a relationship with the Germans of the newly founded self-help support group network, and to see how we can work together. Germany is perhaps ten years behind us in terms of patient awareness and organization. Our two reports on the conference are from members of the network. [see page 29]

A matter of increasing urgency for patients and doctors alike is the harassment of "Lyme-literate" physicians, or LLMDs. Several articles in this *Lyme Times* address this issue; look for followup in future issues as our proactive campaign takes shape.

The Michigan Lyme Disease Association is making outstanding outreach efforts, described on page 18. It is an inspiring example of what just a few people can do when they put their minds to it. Linda Lobes, who fields the calls which come in on the 800 number, describes herself as a multi-tasker with a very helpful husband. Indeed – how else could she handle over 2000 calls in a few months? Congratulations, MLDA!



Hanna Priedemuth, left, and Phyllis Mervine with birthday bouquet presented to her by German support group during international conference in Munich.

We are grateful to the conference organizers, in particular Bettina Wilske, for providing us with press passes, and second, I'd like to thank the support group members who gave me flowers and shared their time with me, especially Dieter and Anne Gossel who provided companionship, interesting discussions, and several wonderful dinners, Peter Rohleder, who wrote one of the conference reports, and Helmut Zappe, MD, who (with his wife) has translated the Burrascano guidelines for a German website. I look forward to our continuing collaboration.

Features

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Erratum: The article "An Interview with Dr. Kenneth Liegner" which ran in the last Lyme Times was excerpted from the website for AmericasDoctor.com <www.americasdoctor.com>

The Lyme Disease Resource Center was founded in 1990 as a non-profit 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 tick-borne 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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Number 26**Editorial****It's time to act**

An unholy alliance of insurance companies, conservative physicians, and health agencies is attempting to control the standard of care for Lyme disease by persecuting our most valued physicians and laboratories. Their crime? Their diagnostic and treatment practices deviate from a norm that has been predetermined by a minority of physicians and researchers who have set themselves up as experts and dictate their reality to the rest of the world. They are not motivated by scientific concerns or by the desire to promote health, although science and health are their purview. They have been corrupted by money and power. Their latest brutal tactic subverts a legal process designed to protect citizens from unscrupulous, immoral, or dangerous medical practices, twisting it to suit their own purposes.

These persecutions directly damage us and our children. They result in denial or curtailment of treatments our physicians deem necessary. They intimidate and deter physicians from accepting Lyme patients. They discourage reporting of cases. All of these factors make life harder for people who are already sick.

The insurance companies, of course, are looking to control costs. Their computer systems red-flag claims they consider excessive. Teams of company lawyers draw up elaborate briefs and forward them to local enforcement agencies. It's a no-brainer for an attorney general who takes the physician to court. His work is done for him. Insurance-inspired suits are more common in highly endemic states where claims for long-term or expensive treatments are more likely to make a significant impact on the insurance company's bottom line – profit.

Physicians also report other

physicians. No doubt there are occasions when one physician legitimately turns in another for ethics violations, but these are doctors who exploit the system to attack colleagues. We are not allowed to know about the vested interests of the complainant, since the process allows anonymity. Competition for patients, financial concerns, prestige, or philosophical disagreements are likely motives.

The third, and least forgivable collaborator in the persecutions – health agencies. The CDC is the supposed guardian of the public health, but their restrictive case definition, originally “for surveillance only,” metamorphosed into a clinical guideline – without the benefit of discussion or scientific rationale. It was published last spring as part of a CDC educational grant by the American College of Physicians, an organization dominated by rheumatologists.

State medical boards seem to be in collusion. Many of their members “have an attitude,” and are not interested in the targeted physician's track record with patients. Never mind if his patients are doing well and come to his defense. If he has deviated from the norm, as the board defines it, he's guilty.

One attack on a physician has become business as usual in the Lyme community. Two or three attacks are noticeable, four or five newsworthy. We have at least six cases this summer alone. Even if fully exonerated, the physician has been punished – defense is costly and reputations are damaged. And in the process, patient privacy is violated.

What hurts one innocent physician, hurts all physicians. Should this unholy trinity be allowed to dictate medical practice? We think not. It is time to act.

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

Setting Lyme patient quota is immoral and unjust

I am a family practice physician who has been lecturing to physicians about Lyme disease. I am myself disabled with Lyme and unable to practice medicine. Today I received a phone call from one of the doctors whom I have educated and have been referring patients to their office. He stated that his office would no longer be accepting new Lyme patients, that they had decided to "cap" their Lyme patient volume at a certain number in order to avoid being singled out by insurance companies for having too many Lyme patients in their practice.

If this were a case of AIDS and a patient were refused care based on his/her diagnosis, this would be called discrimination and the ACLU would seize the cause. How can physicians be penalized for treating patients with Lyme disease when not treating them clearly violates the patients right to receive appropriate medical care? Where do the Physicians for Social Responsibility and the ACLU stand on these issues?

There is a major moral wrong being committed here. Where are the guardians of justice when we need them?

Teresa MacKnight, D.O.
Andover, Maine

Tick checks on children one of parents' most important tasks

Everyone should know that it's of the utmost importance to safeguard children from Lyme beyond merely spraying them with DEET products. I live in Connecticut, and every evening I have the tedious task

of performing "tick checks" on my 8-year old twins. The number of "crawling" ticks I remove is ridiculous. I've been very fortunate to have never found a biting one. Armed with a printer's loupe, since a magnifying lens just doesn't cut it, each child's body takes between 20-30 minutes.

Parents in tick-prone areas would be remiss for not checking every night. If you've never seen one of these tiny arachnids you wouldn't believe how small they are. Pictures do not do justice to their incredibly small size, sometimes smaller than a fleck of dirt. That's why I need a printer's loupe. It helps if the child takes a shower before the checking starts as ANY dirt can be a potential tick. Also, aside from the child overdosing on DEET-containing products, in my experience I've discovered that these nasty bugs sometimes could care less if there's DEET on the body.

There are too many doctors out there who either know little about Lyme disease or misdiagnose it as some other autoimmune problem. My feeling is that you should seek out an informed doctor regardless of the distance you need to travel (within reason).

I suggest a nice big piece of masking tape wrapped sticky-side up on your hand (on which to stick suspect specks), a really bright set of lights on in the room and arm yourself with a printer's loupe. No matter how long it takes each night to do a "tick check" on your kids it is one of the most important tasks we, as parents, can do for defenseless children.

Georgine Schaefer
Gales Ferry, Connecticut

Political activism must replace patient apathy

I am sorry to report that the harassment of physicians who aggressively treat Lyme is succeeding in its goal. Several local doctors here in Maryland who previously treated and were knowledgeable about the disease turned me away when I approached them with a suspected case of Lyme. Another prescribed a low dose of oral antibiotic for an extended period, despite neurologic involvement and over two years since the tick bite. This was not ignorance. It was fear. I have to go out of state, a 600-mile round-trip. Even there, in New York, the Lyme specialists are under attack. Some New Jersey physicians have already been driven out of business. Very soon, between insurance company refusals to pay and lack of physicians, we will have no options at all. The door is slamming shut.

In the state of Maryland there has been very little political activism among the Lyme community. The support group with the largest mailing list has disbanded. There were many sick people who were not getting well. And just when support groups are most needed to counteract the opposing forces.

In the Lyme book by the American College of Physicians it states: "Nationwide efforts are well underway to limit practice variation...." So there it is, from the horse's mouth. This is a national effort to enforce conformity, an entirely inappropriate activity in an emerging disease that still has no accurate diagnostic test and no proven treatment. They are succeeding not only in limiting practice variations but also in creating a climate of fear where patients are denied any treatment at all.

I think activism is the only way this can be changed and I would encourage efforts to organize a plan of action to be used by people in the various states. Maybe we need to take

a page from the book of other groups who have successfully challenged the establishment. It is clear that the majority of physicians has opted for safety and is willing to abandon Lyme patients because of the controversy. They are in a better position to fight: they are not sick, they have the information and the connections, and the financial standing. But evidently we can't count on them. If there isn't some organized and well-planned activism, we are all in trouble.

Man the barricades!

L.L.Finn
Frederick, Maryland

See L. Finn's article on page 27.

Lyme patients should take their fight to the street

Lyme patients need to hire a PR firm or a New York advertising agency to make our message heard loud and clear. Most people who have never had Lyme could care less. Even my relatives keep telling me, "You look fine?" They have never had LYME -- this includes the majority of doctors. My point is we should get more organized and radical and learn a lesson from the our friends who have had to fight to get adequate treatment for AIDS.

Let's start a nationwide campaign to provoke the other side to respond. When they do we will say, "We have science to back us up. What do you have? Just your opinion?"

In addition, we should start suing more people. Take the offensive. If a journal or doctor states that there is no such thing as a chronic Lyme infection, then s/he should be sued for using his/her credibility to undermine prolonged treatment for those of us who need it. Such lawsuits may be dismissed as frivolous. But people might start asking "Why are those Lyme patients suing all these people?"

People love a good fight. If we

will stop being so polite then people who have never had Lyme and don't care about it might just pay attention, because they will realize that we don't just have a disease that makes our joints hurt and then it goes away with thirty days of treatment. They will realize that people aren't getting better and they are being snubbed by the very people who have taken an oath to help heal.

We need more than letters to editors. Let's take this fight to the street.

Rob Grant
Memphis, Tennessee

Lyme vaccine given with Hep A vaccine caused Lyme symptoms

I had a single Lymerix vaccine on April 13—fortunately I didn't follow it up with booster shots. I've had multiple problems since that time. I live in New Jersey; my community averages 85 deer per square mile. I had been treated for Lyme with doxycycline twice before with 10-day prescriptions—in 1991 and 1995. Moreover, I have an autoimmune condition --Hashimoto's disease-- am yeast sensitive, and was given the Lymerix vaccine concurrently with a hepatitis A vaccine. SmithKlein

Lyme journal makes debut on Medscape

The Journal of Spirochetal and Tick-borne Diseases has been placed on Medscape. Full-text articles may be accessed by going to Medscape at www.medscape.com, selecting "site map" and then selecting "journals."

The JSTBD is published by the Lyme Disease Foundation.

Beecham never tested the Lyme vaccine given concurrently with any other vaccine; and they eliminated people with autoimmune problems and sensitivities to yeast from their trials. In my opinion they didn't test a large enough population of people who probably had been infected with Lyme disease previously.

Needless to say, my physician did not "do his homework" when I, thinking I'd prevent problems by getting vaccinated, stupidly requested these vaccines. Now I've got genuine problems, including heart, blood pressure, neural, ocular, and arthritic manifestations that don't cease. I'd be most interested in reading about other people's experiences. Maybe we can enlighten each other and the public at large about how to deal with this "disaster."

I never had any appreciation of what Lyme disease was or did until after I got this vaccine.

Carole Mekjian
Belle Mead, New Jersey

German reader helps supply Lyme Times to support groups

I wish you every success with the *Lyme Times*. Since Lyme is an international affair we need an "*International Lyme Times*" and I'm sure we'll see it one day. However, we all must do our best to make this advancement unnecessary; a cure has to be found in the not too distant future, so we can shift our activity to other rewarding subjects and meet every year in the best health to celebrate Lyme Memorial Day.

Until that day, don't forget: "He who fights may lose, but he who doesn't fight has already lost."

Dieter Gossel
Hamburg, Germany

Thanks to a generous donation by Herr Gossel, Lyme Times are being sent to the German Selbsthilfegruppe (Self-help Group) network.

The dirty truth behind Lyme disease research

by Stefanie Ramp

The Lyme Times usually concentrates more on science and less on politics, but the events of the past year have brought increasing realization to Lyme patient advocates that some sort of political action may be necessary to ensure continued access to medical care for patients with chronic Lyme disease. The following article provides a well documented description of the controversies and focusses on the conflicts of interest and problems with insurance companies.

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Patient persistence paid off

by Betsy Feldman

The following letters appeared in July on the online Lyme disease newsgroup at sci.med.diseases.lyme.

Patient: I am so tired of being diagnosed with one thing after another. Fibromyalgia, Lyme, and now as of yesterday Chronic Fatigue Syndrome. Which one is it? They stopped my Lyme treatment right in the middle of it, after the western blot came back negative, and decided I now have CFS. I think they are trying to label me as 'CRAZY.' Well I just might be after they get through with me.

Response: I can certainly sympathize with your concern. I have been where you are. The sicker I became, the more I worried that I would die of whatever this horrible illness was, and no-one would ever know why. It was both extremely frightening and infuriating. I held on to my conviction that my symptoms were due to a physical illness, and not psychologically based. And I forced myself to continue looking for answers until I found out what I had. This meant visiting a dozen doctors in the course of over eight months, wasting precious time and money, until I was lucky enough to hit the bakers dozen!

Unlike you, I was not diagnosed with one thing after another. I plain wasn't diagnosed with anything. (well, except for an ignorant neurologist who was pretty convinced I suffered from panic attacks. Or an equally insensitive twit who sarcastically quipped that I must have a new twentieth century disease!)

A negative western blot does not definitively rule out Lyme. Were you given the WB IGM or IGG? And are you going to an MD who is knowledgeable about Lyme? If you are not, I would suggest finding one immediately.

While some people do in fact have anxiety based symptoms, and of course other illnesses besides Lyme, it is also true that those who have a

treatable physical illness are dismissed and patronized because they happen to have vague, non-objective findings. Or, the documentaton IS there, and the physician fails to ask the right questions.

It is a tragedy when people are too tired, and too sick to fight this,

and accept these ignorant medical opinions. In my case, the good news is that refusal to give up and persistence really paid off in the long run. After over three years of treatment I am about 85-90% better, love my job, and have a busy and enjoyable life. So, don't give up, be persistent, and REFUSE to accept that they will never find out what is wrong with you.

The author contracted Lyme disease in 1994 and is a member of Michigan Lyme Disease Association. She lives in Troy, Michigan.

Tick costume made a "hit" at Cape Cod Hallowe'en party

by Rae Record

I went to a costume party last year as a female deer tick complete with a belly full of spirochetes and with blood stained borrelias hanging out of the mouth parts.

To make the costume, I had a base of black tights and a black turtleneck. I made the bottom bloomers out of a thin black gauze which you could see through. To give me the "full as a tick look," I stuffed them with mostly with clear plastic laundry bags which sparkled through the gauze. I found this very long spiral pasta that looks just like Bb, put them in a clear baggie and tucked it in my waist. Then I put one of those green glow sticks behind it and it made the "chetes" glow through. I made the three mouth parts out of felt (looking at the picture of the tick in the LDF brochure) and sewed them on a hood. Then I pasted some strands of the pasta tainted with fake blood hanging off the hat. I stuffed four panty hose legs with batting and then stuck some pasta on them. Then I rolled the whole thing in the gauze and sewed a seam so that the pasta could be seen in the legs. I tied each in four places to look like the joints on the ticks legs. Then I sewed one

set on the legs of the bloomers and one set on the waist. I used clear fishing line to tie these equal distance apart so that they hung from my wrists. Everytime I moved my arms the legs all moved. For the top I used a dark red gauze which I just folded over, cut a hole in the center for my head to go through and rounded the bottom and let it hang - sort of like a bib. I taped a label "Dixie, the Deer Tick" on my front. To top off the effect, I carried a bucket half full of "chetes" which I dropped a little red food coloring in without stirring it, I wore very dark, heavy makeup with dark gray eyes and very dark lipstick and I had some fake blood dripping off my own mouth.

I played the part of Dixie the whole evening and told everyone in my VERY southern accent that when I hitched a ride on that pelican, I thought he was headed for California where I intended to ge me some of that lizard blood. But somehow that pelican got confused and I ended up at this very weird party in Brewster on Cape Cod. It was a lot of fun...of course, everyone there already knew that I'm crazy!

Patient stories

Lyme causes severe GI symptoms in previously treated patient

by Brian Carroll

A couple of months ago I posed the question, "Can Lyme disease mimick a heart attack?" The reason I asked this question was because I developed compatible symptoms, namely, a severe feeling of indigestion in my chest along with a grabbing pain in my lower throat. When I finally made it to my local ER they thought enough of it to admit me and I ended up staying there for an entire week.

All cardio testing, including a stress test with contrast, resulted normal. The nurses even gave me nitroglycerin pills during some of the more severe episodes to see if they would provide any relief but they did not - they only added headaches to the mix. At the time of my discharge my family doctor told me this could all be gastrointestinal. I was thinking, yeah sure doc; while still fairly certain that what I had experienced was heart-related and wondering how it could be that all of the tests were normal. I went home scratching my head.

A few days later I started becoming quite nauseous, mostly in the mornings, so naturally my first thought was oh no, I'm pregnant. Almost immediately, I remembered that I was a man and this concern quickly passed but the nausea remained. Also, I began experiencing lower abdominal pain so I made an appointment with a GI doctor. He ordered both an endoscopy (down the throat, esophagous and into the stomach) and a colonoscopy (well, you know what this is).

The endoscopy revealed an area the doctor described as

"erythemateous" on the stomach lining as well as inflammation of the duodenum. Biopsies of these areas were negative for *H. pylori* and negative for spirochetes upon electron microscopy. No other tests were performed on these samples.

Subsequent to this procedure, I learned of a study done by Martin Fried, MD, Director of Pediatric Gastroenterology, Jersey Shore Medical Center, in which endoscopies were performed on children with Lyme disease who were experiencing GI symptoms. Guess what? The endoscopy results from his study showed inflammation of these kids' duodenum and stomach wall linings, too. Electron microscopy of tissue samples revealed spirochetes which were suspected as being *Borrelia burgdorferi* in 50% of these cases. Coincidence? I think not.

Next, the colonoscopy results. Here's where we hit the jackpot.

Distinguished Physician Award nominations sought

The Lyme Disease Resource Center is seeking nominations for 1999 Distinguished Physician Award, which recognizes a physician for clinical excellence, leadership, compassion, and dedication to the treatment of Lyme disease. Send nominating letters to the Editor. The Award will be announced in the next Lyme Times.

Tissue samples sent for PCR testing to BBI Clinical Labs in Connecticut were "positive for the OSP A gene indicating the presence of *B. burgdorferi*, the etiological agent of Lyme disease." And tissue samples from this same procedure that were sent to NIH for testing turned up "rare structures" which the performing pathologist said are spirochetes "very suspicious" for *Borrelia burgdorferi*. Also noted on the NIH report is the finding of a "previous non-specific colitis." When I informed the NIH pathologist that separate colon tissue samples sent to BBI Labs came back PCR positive, he said that it all ties in very neatly and really makes a strong case for active Lyme disease infection.

Brief History: I had a documented EM rash with fever and chills in 1994 (delayed diagnosis for 9 months), subsequent heart problems (not the stuff mentioned above), many neurologic problems including Bell's palsy, 9 positive ELISAs, 3 positive IFAs, 3 positive Western blots, 3 highly positive LUAT tests, abnormal neuropsych tests and one very messed up brain SPECT scan...and oh yeah, I live in Connecticut. Most would agree (excepting certain doctors at Yale, of course) that I have Lyme disease.

I've had two courses of IV antibiotics and more than two straight years of orals and after all that we now come up with Bb in my colon. This tells me a couple of things. These bugs are difficult to eradicate - and they don't seem to care in which neighborhood they reside.

In anticipation of any possible sentiment that my case demonstrates the ineffectiveness of long term antibiotics, I say au contraire mon frere - at least I can function while under their influence.

Brian Carroll lives in Wilton, Connecticut. He is becoming a regular contributor to the Lyme Times.

Plethora of symptoms finally adds up to Lyme

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Patient Support

New York residents can report problems with HMOs

by Ellen Lubarsky

There is now an important website where New York State residents can register their specific complaints against managed care companies. The National Association of Social Workers, (NASW), New York City Branch, has been collecting reports of abuses by managed care companies from both patients and health care providers in New York State. They are compiling these statistics so that they can identify the barriers to decent medical care and then support legislation that would best protect patients. They recently put out a preliminary report of the data they have collected thus far. This report generated interest from the New York State Attorney General's Office which can prosecute companies not in compliance with the NYS Managed Care Law, which is actually one of the better laws in the country.

If you are a New York State resident and have had a problem with

your managed care company, you can fill out and submit a form on-line by going to: <http://www.naswnyc.org>. Press the button for the Managed Care Critical Incident Report on the BOTTOM of the page (a little hard to see, but it's there). Fill out the form and send it.

For people who are not online, the phone number is 212 668-0050 and the address is: NASW, NYC Chapter, 50 Broadway, 10th floor, New York, N.Y. 10004. Your identity will be kept confidential.

NASW is collecting complaints about all medical conditions, not just Lyme. However, their project gives the Lyme community an opportunity to collect data about Managed Care Abuses specific to Lyme patients. The Lyme Disease Coalition of New York and Connecticut, Inc. has volunteered to keep track of this data so that it can be made available to the Lyme community.

So that we can get a copy of your Managed Care Critical Incident Report from NASW, please write on your form, in the space where you are asked to explain your problem, "I give permission for a copy of my form to be given to the Lyme Disease Coalition of New York and Connecticut". As with NASW, the LDCNY/CT, Inc. promises to keep your identity confidential.

New support groups form in New York

New York State has two newly formed Lyme disease support groups.

The Manhattan Lyme Disease Support Group will be meeting on the 4th Monday of every month at Cabrini Hospital, 227 East 19th Street, ROOM 335, New York, N.Y. A small core group has been meeting since March.

For further information or to let organizers know you plan to attend, people can call: 1) Val at 212-995-9500 ext.275 (W) or 212-252-9872 (H) or 2) Ellen at 212-799-2554

Long Island also has a new group. The contact for the group is Bob Levine, phone 516-434-7697 (office), 516-473-4389 (home), or email omicron@erols.com. The group will meet the first Wednesday of every month at 7:30 pm at St. Charles Hospital in Port Jefferson, NY.

"I'm hoping to use this group to distribute information on Lyme - the real story—as well as to offer support to others afflicted with this nightmare," says Levine. "I am ultimately interested in organizing a group with specific political goals to address the many problems with Lyme disease. This group is the first step."

Send support group notices to the Editor

Looking at Lyme brain fog

by Jonathan R. Strong

I don't doubt that someone will post links to articles on the subject, but I can give you the dubious benefit of my experience. It's difficult to pinpoint as it manifests subtly:

— My short term memory is very bad. I will head off into another room or office, or go up- or downstairs only to arrive and have absolutely no idea why I started out in the first place. I will have a discussion with someone in my office, agree to do something immediately, and become instantly distracted by something else so that I totally lose track of what I promised to do.

— My focus on organizational tasks is dreadful. I can have an enormous amount of work on my desk, and find myself shifting papers around 8 or 9 hours later, having accomplished nothing. I can go into work with a great attitude, watch an entire day slip by, and have no idea what I did for the day.

— Certain details disappear in the middle of conversations. It has become quite difficult for me to recall names and dates on the spot. I am well-known amongst my colleagues and clients for being able to tell them more about their own businesses than they themselves know—however I have lately found that I will sometimes freeze mid-sentence and have no idea what point I was trying to make. This often manifests as my going off on tangents and losing my point along the way.

— Keeping and relating large groups of detailed info in my head at one time has become increasingly difficult. Until the past few months, I would thrive on this, and would happily discuss complex technology architectures without having to refer to notes.

— I have a general feeling of discomfort when hit with a lot of information at once. I tend to

withdraw from conversations with more than one or two people, which is completely unlike the "old me". Almost feel like I want to duck my head and avoid the confusion

.—Last year I went through a disturbing period when I had significant trouble saying words that began with the sound "I" (e.g., "eyeball", IBM, etc.). I tended to repeat the "I" sound two or three

times before I got the word out. I never had this problem before, and it mysteriously disappeared after about five months.

— Sometimes I *do* feel light-headed, but more often what I've described above dominates. [* in italics:]

Jonathan Strong has had Lyme for 11 years. He *has an undergraduate degree in cognitive psychology, a masters degree in psychoanalysis and an MBA in finance and management.*

New fund-raising group to use multilevel marketing approach

Lyme patient Todd Summer has announced the formation of the Lyme Education and Research Network (LEARN), an organization for raising money for Lyme disease research. LEARN received California non-profit status in December, 1997 and IRS non-profit status in March, 1998. According to Summer, the organization will adopt an Amway type sales approach to raising money. Amway uses a multilevel marketing approach with commissions on sales paid out to different levels within the organization.

"The IRS indicated that the structure may be reviewed over time," said Summer. "But the IRS has also stated that this structure will

be viewed in the same regard as one individual or firm doing fundraising. In this network structure a commission is paid just as if one individual were doing the fundraising, only it is split, in most instances, seven ways," he explained.

The board of directors of LEARN consists of five people, four of whom have Lyme disease. Summer himself is an independent sales representative who was previously vice president of the retail division of New Jersey Books, Inc., a small college bookstore chain that grossed several million dollars.

Other members are Summer's father, Gordon Summer, a marketing executive who has won awards for his successful promotion/advertising campaigns; C. Dwayne Goode, P.D., who owned three pharmacies and is now retired; Cindy Goode, P.D., pharmacist; and Rita Stanley, Ph.D., educator and patient advocate.

Summer hopes that LEARN will take off and raise money for Lyme disease. He may be contacted by email at MadTodd@aol.com or by telephoning (760) 729-0101.

Lymerick

by Carolyn Cramoy

There once was a Dr. Placebo
Who had such a very big ego,
When his patients got well,
He thought HE was swell.
When they didn't he knew THEY
were "weirdo"

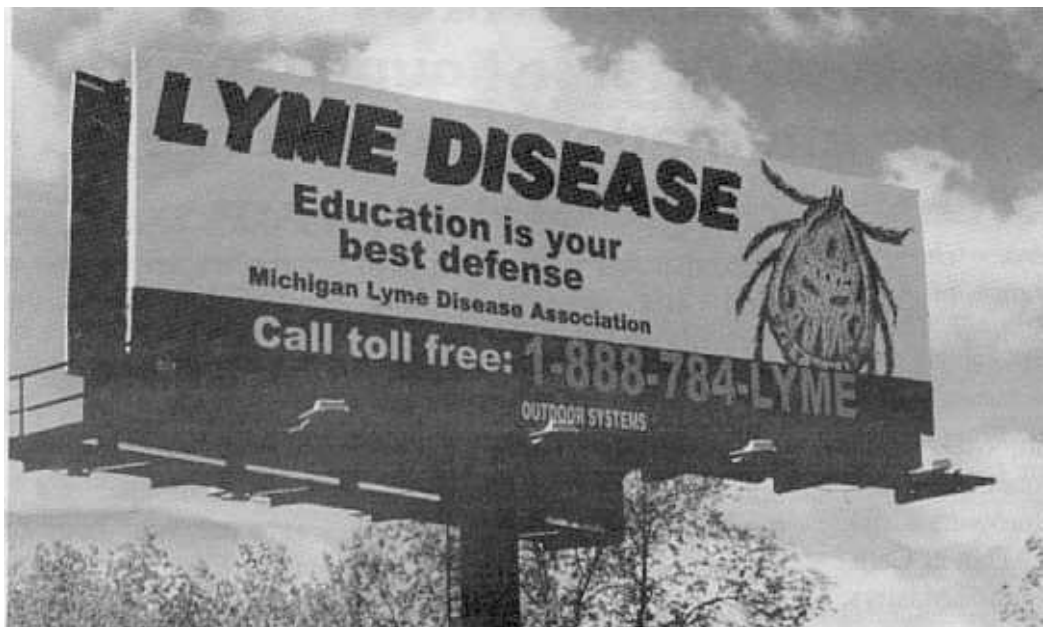
Regional News

Persistence pays off for Michigan group

MLDA member Bev Grunheid writes: "We are very proud of what this group of sick Lymies is doing in this state. Poor Linda was sitting in the pouring rain so the photo is really bad, but maybe now with our thrust we will educate and help more Michigan residents."

Reprinted from The Detroit News

Almost 2000 people have called the Michigan Lyme Disease Association since a billboard was posted near Flint in May, 1999.





Ten years ago, Linda Lobes suffered a tick bite that was first diagnosed as a spider bite. It took years of chronic illnesses for doctors to finally diagnose Lyme disease.

Reprinted from The Detroit News

Reprinted from The Detroit News

Lyme bill, cont. from page 1

ment) as well as private sector (including Lyme advocacy groups).

The goals of the bill in priority order are as follows: detection test, improved surveillance and reporting system, Lyme disease prevention and development of indicators in the ten highest endemic states, prevention of tick-borne diseases other than Lyme, and improved public and physician education.

“I believe this bill will provide the recognition needed for chronic Lyme disease and some much needed funding for research and education. The bill is not perfect,” says Mrs. Smith, “however, it provides good compromise language to satisfy government agencies and to protect the interests of Lyme disease victims.”

Mrs. Smith is working with Congressman Smith (no relation) to obtain a Senate sponsor and cosponsors for the House bill. She encourages patients to contact their representatives and senators to ask them to support or sponsor the Lyme Disease Initiative 1999.

The LDANJ has sent information packets on the bill to many Lyme groups across the country. Included is a letter to Congressman Smith supporting the bill and a sign-on sheet to indicate that a Lyme groups wants to sign-on to the letter. If your group did not receive a packet and wants information or wants to sign onto the letter, please e-mail Lymeliter@aol.com or write LDANJ PO Box 1438, Jackson, NJ 08527.

Patient input needed to support updated report form

The Massachusetts Lyme Disease Coalition is asking for patient input to push their pet project toward its goal.

Last year the group spent months consulting with experts in an effort to design a new Lyme disease case report form for the Massachusetts Public Health Department. The new form broadened the definition of Lyme disease so that doctors could check it off even if it didn't meet the conservative CDC surveillance criteria. It also included an optional space for test results of the other increasingly common tickborne diseases, ehrlichiosis and babesiosis. But at the last minute, the MDPH decided to ignore a consensus of experts that suggested the more progressive reporting form.. [See *Lyme Times* 23 & 24].

So now the Coalition is urging all Lyme patients and their families and

friends in Massachusetts write to Massachusetts Governor Cellucci as soon as possible. According to Coalition member Carla Colson, many letters are needed to push the State into utilizing the revised form.

“We need to have a many letters as possible to make this work,” states Colson. “Only a couple of lines to the governor will suffice.”

The revised reporting form will include: a.) the reporting of ALL Lyme disease cases, including not only those which meet the CDC (surveillance) criteria, but also those which are clinically diagnosed by physicians; b.) the inclusion of all forms of the erythema migrans rash (“bull’s-eye” or non-classical) >5 cm, with clear examples of the non-classical rash which is more prevalent; c.) the inclusion of laboratory results (from any lab a doctor chooses) for Lyme disease as well as ehrlichiosis & babesiosis.

New web page helps patients express opinions to legislators

A new web page service called Lyme Political Action Connecticut was launched in May, geared at focussing the electorate on pro-patient Lyme disease legislation pending in the Connecticut legislature. In its first day of operation, it helped residents send dozens of email messages.

The site was created by Darien resident Bruce Fletcher whose wife suffers from Lyme.

“My goal in creating this page was to create a place that provides simple step-by-step instructions for people who want to express an opinion to our legislators about the need for pro-patient Lyme disease laws. With 30 seconds work this web site helps people to send a personalized note to the 20 top decision makers in Hartford.”

The Connecticut Lyme Bill went through several incarnations before being passed. Patient advocates who spent days in Hartford working with committee members to obtain more patient-friendly language were positive.

“While it's not perfect, it provides a good foundation that can be built on,” said Fletcher, while Karen Forscher of the Lyme Disease Foundation said that the advocacy group would continue working to improve the next version of the bill.

The new website is Lyme Political Action: Make your voice heard! <http://www.netcom.com/~fletch14/LymePAC.html>

Excerpted in part from LymeNet Volume 7/Number 05, May 1999. The LymeNet website is at www.lymenet.org.

Sample letter to send to Governor

His Excellency Argeo Paul Cellucci
State House Room 360
Boston, MA 02133

Dear Governor Cellucci:

I am writing this letter to urge you to hold an Executive Oversight Hearing, in an open forum, where the significant issues of Lyme disease can be discussed. It is imperative that an effective Lyme Disease Reporting Program be instituted in Massachusetts. I insist that the Massachusetts Department of Public Health take Lyme disease seriously, and that the MDPH and the Governor be accountable to the public and the Lyme Community.

Sincerely yours,

*Email, FAX, or mail Governor Cellucci as soon as possible.
Email: goffice@state.ma.us FAX: (617) 727-8136. Send a copy of your letter via mail to the Massachusetts Lyme Disease Coalition, P.O. Box 1916 Mashpee, MA 02649, fax: 508-563-7780, or email: molalor@capecod.net.*

Lyme leader urges patients to make a stand

Many in the Lyme community are familiar with Steve Nostrum, who has helped thousands of Lyme patients since 1987 through his own foundation, Lyme Borrelia Out-Reach, offering referrals, tapes and counseling.

by Steve Nostrum

Dr. Burrascano has been under attack for years, as well as other physicians and health practitioners. If it is not common knowledge, it should be that Dr. Burrascano prefaced his testimony [critical of NIH Lyme programs] in the Senate [in 1993] by saying, "I put my license upon the line in testifying." This is a matter of public record.

Any doctor or health professional can be brought up on any charge from anyone. The individual will not know what the charges are, nor the person or persons making the charge or charges. In this scenerio, one cannot battle if one will! Under the existing law, those enforcing the investigation will indeed come into the doctor's office, take any and all patient documentation, hoping to find irregularities.

It must be also understood that we as citizens and patients have the same ability to visit upon those seeking to destroy the ones caring for us the same attack. And we must muster up within the Lyme Community an attack! An attack upon such attackers so as to make their heads spin!

These same "attackers" are on record as being well paid consultants with a war chest of finances based upon their affiliation with well-known universities and ties to foundations. This is and has been a well-planned and well-financed campaign. The "attackers" have appeared in federal and state courts as paid consultants to testify against Lyme patients. Via the insurance companies they are affiliated with, they have attempted to prevent additional treatment for Lyme

patients. In some cases they have alliances with laboratories and to the Lyme vaccine. These alliances must be investigated to discover the real motives for their attack.

As I write, litigation in the form of lawsuits are being prepared and mailed— lawsuits in the hundred million dollar range for slander and

TV producer promises to feature all patients' letters on upcoming show.

defamation of character.

It is my hope that those reading this will have the courage, as well as the character and pride to tell their personal, objective, true encounters with some of these (and I will be kind here) egotistical, money-hungry wanna-bee's, hell-bent upon destroying those who have helped us all. Take pen in hand and write to the lawyers of those being attacked unjustly.

Speak up NOW about your personal experiences in these evil men's/women's offices. Share them NOW with the powers that are in support of those being attacked! NOW! Now is the time to put this Evil to rest! To stop once and for all, the lies, the hurt affecting, infecting all too many of us as well as our loved ones. Now is the time to tell the truth and nothing less, so as put asunder the Evil that besets all too many of us. Evil, in that it makes our

skin crawl, makes us wonder if we are people with a voice, if any one cares, if any one can make a difference?

I say we can. I say we are able to put the absolute fear of God into the evil that seems not to stop or give up, and I say that we have a "stone" as mighty as David's, with a sling more powerful! Because we know, because we are many, we are legion. We are not alone!

And should this battle go further, we can tell ourselves, "I gave a darn, I made a difference! I did something! I feel good!" We can individually as well as collectively say, "I made a difference! I stood up! I was counted!" It is up to all of us to speak out NOW!

Is it too late? No, Not at all! Will your personal, individual choice make a difference? YES. Every letter I receive will be tacked to the studio walls on an up-coming televised show dealing with this matter. The world will see what is happening here in the freedom land, The United States of America and all will be proud that their letter or card was not in vain. I will promise to get out their story to an audience of millions, on several TV shows!

*Stephen J. Nostrum, RN,
Infusion Therapies,
Founder/Director Lyme Borrelia
Outreach Foundation, Inc.
PO Box 496
Mattituck, NY 11952*

TV show, cont. from p. 1

hour long, probably beginning in December or January.

"I would especially like to hear from those being attacked," states Nostrum, "and if they would like to be a guest upon the actual show, that would be terrific."

Jerry Simons, PA, from Dr. Burrascano's office will feature on a program throughout October. On the last Tuesday of October, Dr. Burrascano will be a guest.

Ethics probes target Lyme physicians

continued from page 1

Department of Health, office of Professional Medical Conduct (OPMC). Investigators visited his practice on July 2 and temporarily removed patient files to search for evidence of “unprofessional conduct.”

By law, all complaints must be investigated, but in New York the precise charges are kept secret and the complainant is allowed to remain anonymous. Attorney Michael Schoppmann, a New Jersey medical malpractice lawyer, commented that the most risky behavior leading to disciplinary action of doctors in his state was treating Lyme patients, and that insurance companies are responsible for the complaints. [see report on page 34]. New Jersey psychiatrist Robert Bransfield thinks in some cases the regulatory agency has become the pawn of the insurance companies. And once investigators go in, they can always find something.

Dr. Perry Orens has a large Lyme practice in Great Neck, New York, just up the road from Burrascano, whom he admires. He has been investigated numerous times on what he considers spurious charges.

“I have an impeccable [medical] reputation over forty years. I have never paid one penny in malpractice. Yet I have had to spend over \$100,000 defending myself against these charges,” he raged. “All they come up with is something like, ‘We don’t like the way you organize your charts.’”

Investigations become a form of harassment

“Even if the charges are unfounded,” says Burrascano, “such a complaint can be ruinous to the practice, reputation, finances, and ultimately to the family security of

the physician so accused. On July 2, 1999 I had an interview with a physician representative of OPMC and I was able to fully defend my medical practice. However, he and my attorney both said that there have been instances where political influences from Albany [NY state capitol] have reversed the recommendation of the interviewing committee and have forced disciplinary proceedings to proceed anyway.”

“I was reluctant to give this testimony, as I feared that there would be reprisals against me and the many physicians whom I represent.”

Joseph J. Burrascano, MD

Laboratories popular for their Lyme disease tests do not escape, either. This summer alone, IGeneX Laboratory in Palo Alto, California, has been investigated three times, once by the New York Health Department and twice by the California Department of Health Services (CDOHS). New York brought in a PhD molecular biologist “who really knew what he was doing,” according to director Nick Harris. IGeneX passed the first two investigations with “flying colors,” but the third round (with CDOHS) is going very slowly. The investigator devotes only one-half day per week to the case, and in the meantime, three tests have been put on hold.

Many doctors, unwilling to contend with such harassment and

intimidation, have closed their doors to Lyme patients. Dr. Pietrucha is no longer accepting Lyme patients, although she denies that her decision was the result of harassment. Other doctors are more open about their reasons for steering away from Lyme [Ed. note: see *Letters*, p. 4]. The persecutions clearly have a chilling effect.

Being dropped by insurance companies hurts doctors and patients

Besides being the target of investigations, LLMDs are also running into other problems. Dr. Richard Horowitz of Poughkeepsie, New York, who presented his cutting-edge experience with the use of flagyl in treating chronic Lyme disease at the Lyme Disease Foundation conference in 1998, has just been dropped by Blue Cross/Blue Shield, leaving about 500 of his patients without means to continue treatment. The same thing has happened to pediatrician Charles Ray Jones, MD, of Hamden, Connecticut, who treats hundreds of children with serious late Lyme disease.

“This is like a McCarthy witch hunt,” fumes Jill Auerbach, coordinator of the Hudson Valley Committee for Lyme Disease Patient Advocacy. “We are really going to have to activate a counter attack and need to have people from all over the nation work together, for this has the potential to spread.”

Following guidelines which clearly run counter to the officially recommended CDC testing and treatment criteria, Burrascano returns a large proportion of his patients to health. But the OPMC investigators don’t seem to be interested in that kind of success. Joan O’Brien Singer, a licensed social worker from Westchester, NY, and disabled from Lyme disease, doesn’t understand why.

“If treatment and a cure were really the bottom line,” she says, “they should be kissing the feet of doctors who are willing to treat us

When you write to your Senator or Congressperson—

You may want to consider whether any of these points reflect your views. But remember that brief letters are more likely to be read than long ones. Make only one or two points; let other letter writers cover other points.

1. Conflict of interest: complainants may be paid by insurance companies to review (and deny) Lyme disease treatment claims. Complainants may be competing with target physicians in some way (research funding? patients? something else?) Complainants may have financial stakes in laboratories, research programs, tests, clinical practices, etc. which are threatened by the beliefs, practices and success of physicians who are targeted. Complainants may be insurance companies trying to cut costs.

2. Standard of care: there is no consensus in the medical community regarding treatment for chronic Lyme disease. Many researchers are investigating many aspects of treatment issues. The 2- or 3-week treatment protocols are arbitrary and have been shown to be unsuccessful in many cases. Dr. Steere's most recently published protocol suggests up to 6 weeks of treatment, but—beyond its recognition of the failure of shorter protocols—this too is arbitrary.

3. Lyme disease is often difficult to diagnose and difficult to treat. This is highlighted and attested to by the existence of thousands of Lyme Disease Support Groups across the nation. If cure were simple there would be no support groups.

4. Persistence of infection: many articles published in the peer-reviewed medical literature provide strong evidence for persistence and chronicity of Lyme disease. The Lyme organism has been identified by PCR, culture, electron microscopy, antigen capture, etc. in the tissues of patients and animals who have previously received multiple courses of currently recommended antibiotics.

5. Unreliability of tests: no test even approaches adequate sensitivity for detection of Lyme disease. No test approaches 100% reliability. There is considerable debate over the current CDC-recommended two-tier testing criteria, which were originally intended for surveillance purposes only, but now are being promoted in lieu of clinical diagnosis. No test can definitively rule out Lyme disease. There is no test that shows whether or not the infection has been eliminated.

6. Co-infections: New tick-borne infections are being discovered all the time; the role they play in interacting with Lyme disease is only beginning to be explored.

7. Scientific issues should be decided in the scientific forum, not in the proceedings of medical boards investigating alleged "misconduct."

8. The intention of the reporting law was to protect patients from unprofessional conduct by physicians. This process is currently being used to threaten, intimidate, and restrict physicians treating Lyme disease patients.

9. Anonymity of complainant: complainants are allowed to remain anonymous. This gives the complainant protection against reprisals, but

List continued on next page

and save tax-payer's dollars and other insurance longterm disability costs. But the witch hunts continue and those of us without the right insurance will be left out there hanging to dry, getting sicker, getting less able to do things."

Pietrucha said that doctors who are willing to take on a difficult disease should be given some support, and should not have to operate with this cloud hanging over them. She wonders what would happen to patients with AIDS if the same political climate prevailed in the treatment of that disease. Willy Burgdorfer, who discovered the Lyme spirochete, thinks that the bottom line is the physician's responsibility is to help the patient feel better, whether or not s/he can affect a cure. Since there is no consensus of opinion on either diagnosis or treatment, especially of chronic Lyme, doctors using liberal guidelines should be given the benefit of the doubt, especially if their patients are doing well.

Campaign is widespread

Burrascano is not the only target of the ongoing controversy about the diagnosis and treatment of Lyme disease, but he is one of the best known. Since 1985 he has successfully treated thousands of Lyme patients. His "Diagnosis and Treatment Guidelines" have been widely distributed since the mid-80s, and in 1997 his protocol was published in the respected medical reference, Conn's Current Therapy. He was the recipient of the 1998 Distinguished Physician Award given by the Lyme Disease Resource Center of California. Some observers believe that his high profile and outspoken opinions have made him an attractive target.

Burrascano's troubles started in 1993, when he attended a hearing before Senator Kennedy's Committee on Labor and Human Resources. The original meeting was not made public, for the original group of researchers who planned the presentation intended to report that the

work on Lyme disease funded by the CDC and NIH was going well. They specifically did not want Lyme patients or the front line, Lyme-aware physicians to be there and dispute that progress being made. However, word did get out, and there was a large response by the Lyme patients and their support groups - Senator Kennedy reportedly received over two thousand phone calls and faxes over a two-day period. The message was that treating physicians and chronic Lyme patients should be included, to provide a more realistic and balanced view. Consequently, the meeting was opened up, and, according to some attendees, this so angered the NIH representatives involved that, after the hearing, they were overheard publicly stating that Burrascano personally should be sued and the Lyme Disease Foundation, a non-profit patient/physician advocacy group on whose board Burrascano serves, should be attacked.

“In my written testimony, I

clearly outlined many serious improprieties by NIH and CDC grantees and employees,” stated Burrascano. “I was reluctant to give this testimony, as I feared that there would be reprisals against me and the many physicians whom I represent. Indeed, within two weeks reprisals began.”

Burrascano has documents obtained under the Freedom of Information Act to support his claim. At the same time, the Lyme Disease Foundation of Hartford, Connecticut, became the target of a wide ranging, illegal smear campaign by key members of the NIH, including the former Lyme Disease Program Officer, Edward McSweegan, who was subsequently removed from his position and reprimanded in 1995.

Burrascano has been investigated preiodically since that time, and many front-line Lyme treating physicians from many states have also been attacked. State medical boards have restricted the licenses of

several doctors – they are no longer allowed to treat Lyme patients. Others are currently facing charges. All these targeted physicians recognize Lyme disease and treat patients for more than the conservative three to four weeks. They may offer repeated therapy when patients relapse, and some are also experimenting with off-label uses of drugs when conventional medicines do not work, a practice recognized and allowed by the FDA.

Significantly, the allegations against these physicians were not based on complaints from their patients. To the contrary, most patients have jumped to the defense of their treating doctors. In the case of Joseph Natole of Saginaw, Michigan, when the State Medical Board overruled the judge who found no evidence of wrongdoing, restricted Natole’s license and fined him for “overtreating and overdiagnosing Lyme disease,” large numbers of Natole’s patients showed up in court to support him. Many contributed money for his defense.

It seems clear that competition for patients influenced Natole’s case. He was reported by another doctor who lost a patient to him; the patient allegedly said if he wouldn’t treat her for Lyme, she would go to Natole.

What can patients do about the problem?

Doris Aaronson, PhD, professor of psychology at New York University, thinks that the problem needs national exposure.

“We need to get on some big-time national TV show: like 60 Minutes. The TV producer could be offered a panel including doctors, researchers, heads of national Lyme support groups, and chronic Lyme patients who have been on long-term antibiotics. We should also write letters to the editors of national newspapers.”

There might be another tack patients can take. According to Debbie Parrett of the Ohio Lyme Disease Association, negligent

List, continued

it also prevents accountability. Without full disclosure, one can never explore the motives of the accuser.

10. Undefined charges: by law, the charges brought against a physician are not specified. In New York, the law authorizes the OPMC to use the original complaint to gain access to the physician’s charts, but the final charges may not be the same as the original complaint. They can use anything they find, even if totally unrelated to the original complaint.

11. Regardless of Innocence or Guilt, investigations can be ruinous to the practice, reputation, finances, and ultimately to the family security of the physician accused. Thus totally unfounded charges can be used to attack a physician very effectively.

12. Widespread campaign of intimidation: numerous Lyme doctors have been targeted, resulting in their licenses being restricted (typically restricted from treating Lyme patients). Significantly, allegations are seldom based on complaints from a patient. To the contrary, patients have jumped to the defense of their treating doctors and contributed to defense funds.

13. Long range effects: other doctors are reluctant to accept Lyme patients because of controversy, the acrimonious atmosphere, and fear of this kind of attack. This leads to further difficulties for all Lyme patients. Doctors with Lyme patients often choose not to report cases because they believe it invites trouble that might put their practices at risk.

conduct is the second most frequent reason for disciplinary action by state medical boards, according to statistics published by the group "Public Citizen" on its website. In her opinion, "negligent conduct" clearly applies to physicians who reject a Lyme disease diagnosis based solely on a serologic test.

"Hopefully those patients who have had this happen will be strongly encouraged to file a complaint with their state medical boards," states Parrett. "I feel we should be making an effort to have overly conservative physicians investigated."

Joe Josh Burke of Glassboro, New Jersey, agrees. He has had Lyme disease for at least eight years and offers information on a website called the Lyme Disease Audio Network (www.lymediseaseaudio.com). He thinks patients who were denied Lyme treatment should get into the act.

"We should buy ads in local newspapers in order to find the

patients. Next we should get funding to have them tested. If we can prove that the doctors failed to diagnose obvious cases of Lyme disease, complaints to the medical boards can be filed and with the purpose of revoking their respective medical licenses."

Insensitive remarks by noted Lyme authorities have further inflamed patient passions. American Lyme Disease Foundation executive director David Weld was quoted in **USA Today** as saying that people like to have Lyme disease because they can talk about it at cocktail parties. Yale's Dr. Eugene Shapiro makes it clear that he thinks worry about Lyme disease is worse than Lyme itself. And Dr. Allen Steere, chief of rheumatology and director of the Lyme Disease program at New England Medical Center in Boston, is continually stating that most people who think they have Lyme disease, don't. These ideas do not amuse people contending with a

chronic illness, who have to go from doctor to doctor to obtain care, and fight their insurance companies for the treatment their doctors deem appropriate.

New Jersey resident Donna Huddleston's daughter doesn't talk about her Lyme disease at cocktail parties-- she is only 14. Recently, her IV treatment was abruptly terminated after ten weeks, although she was still symptomatic. Her mother calls it "bureaucratic genocide." The child's temperature shot up to 101 degrees and she started having daily, multiple temporal lobe seizures, severe headache, and visual disturbances. A SPECT scan showed bilateral temporal lobe deficits.

"Now not only can she not go back to school, she is too ill to attend school even homebound," Huddleston said. "Medications are controlling most of the symptoms, but she still has a fever of 101 much of the day."

And the girl says, "I'd rather have AIDS. At least then, we could get treatment."

At the end of his presentation on the Lyme Disease Foundation's Chicago Video Conference in 1998, New York Psychiatric Institute's Dr. Brian Fallon put it into a nutshell.

"The clinical experience of Lyme disease is one of a fluctuating symptom pattern, uncertainty as to diagnosis and treatment, worsening symptoms when they're getting treated, bizarre symptoms, economic stressors. And then they're the focal point of a medical controversy. What an awful disease to have—that can cause tremendous psychological distress as well as organic psychiatric distress."

One thing seems clear: if patients do not act soon, in large numbers, Pietrucha's warning may come true: Burrascano—and his colleagues—may no longer be able to treat Lyme patients. And eventually there may be no Lyme-literate physicians left.

Following is a list of legislators

Instructions for completing complaint form in New York

From the website of the New York State Department of Health Office of Professional Medical Conduct (<http://www.health.state.ny.us/nysdoh/opmc/instruct.htm>). Some states provide forms, others do not. A letter including the basic elements below may suffice in your state. See article on next page for addresses in other endemic states.

To file a complaint about the treatment you received from a physician (M.D., or D.O.) or physician assistant licensed to practice medicine by the State of New York, please complete this form and return it to the Office of Professional Medical Conduct, NYS Department of Health, 433 River Street, Suite 303, Troy, New York 12180-2299. Phone: (518) 402-0836 or 1-800-663-6114.

Trained staff will review the information you give. We will investigate all matters of possible professional misconduct. If your complaint requires the attention of another office, it will be sent to the agency authorized to address your concerns. We will keep you informed of the status of your complaint.

To help us review your complaint, please:

- Type or print clearly in ink.
- Describe your complaint as completely as you can.
- Include the names of any witnesses.
- Include the names of others with whom you filed a complaint.
- Attach additional pages, if needed.
- Attach copies of papers which may support your complaint, such as bills or correspondence. Do not send originals.
- Please sign and date the form.

Send questions or comments to: opmc@health.state.ny.us

who may be contacted by patients who wish to express their views about the persecution of LLMDs. Letters may be sent to Any Senator, United States Senate, Washington, DC 20510.

Sen. Edward M. Kennedy (MA)
Health, Education, Labor And Pensions Committee
Telephone: (202) 224-4543
or in Mass. (617) 565-3170
Email: senator@kennedy.senate.gov

Sen. Daniel Patrick Moynihan (NY)
Tel.: (202) 224-4451
Fax: (202) 228-0406
or in NY (212) 661-5150

Sen. Charles E. Schumer (NY)
Tel: (202) 224-6542.
or in NY (212) 486-4430
Email: senator@schumer.senate.gov

Governor George E. Pataki
State Capitol
Albany, NY 12224
Email: gov.pataki@chamber.state.ny.us

(800) 735-2258 TTD for Disabled
e-mail: BPQA@EROLS.COM

Massachusetts Board of Registration in Medicine
10 West Street 3rd Floor
Boston, MA 02111
(617) 727-3086

Michigan Dept. of Commerce
Office of Health Services
Health Investigation Division
PO Box 30018
Lansing, MI 48909

Minnesota Board of Medical Practice
2829 University Ave, SE, Suite 400,
Minneapolis, MN 55414-3246
Tel: 612) 617-2130
Fax: (612) 617-2166
MN Relay Service for Hearing Impaired: (800) 627-3529
Toll-free: (800) 657-3709

Missouri State Board of Registration for the Healing Arts
PO Box 4
3605 Missouri Blvd
Jefferson City, MO 65102
Tel: (573) 751-0098

New Jersey State Board of Medical Examiners
140 E. Front St, 2nd floor
Trenton NJ 08608
Tel: (609) 826-7100

State Medical Board of **Ohio**
Public Inquiries Division
77 South High Street, 17th Floor
Columbus, OH, 43266-0315
Tel: (614) 466-3934
Toll-free (800) 554-7717

New York Office of Professional Medical Conduct
State of NY Dept of Health
433 River Street Suite 303
Troy, NY 12180-2299
Tel: (518) 402-0855

Pennsylvania State Bd of Medicine
PO Box 2649
116 Pine Street
Harrisburg, PA 17101-2649
Tel: (717) 787-2381

Rhode Island Board of Medical Licensure and Discipline
Department of Health
3 Capitol Hill, Room 205

Patients can file complaints at these offices

by Linda Finn

Below are the addresses of offices where physician complaints can be filed for the states with the highest numbers of reported Lyme cases. People in other states not listed can get this address from their state health department, or check the front of your local phone book.

If more Lyme patients filed complaints it would help to redress the balance so that the states know there are undertreatment and underdiagnosis problems. All they hear about now is overtreatment and overdiagnosis. It may not lead to disciplining a doctor but it will definitely wake up the state health departments if they get a lot of complaints. It will also make the opposition realize that they are not the only ones who can use this system.

The states have different procedures. Some have a complaint form. No lawyer is required to file a complaint against a doctor for wrong diagnosis, refusal of treatment, undertreatment or any other problem with a doctor that has caused harm to a patient. Filing a complaint does not preclude legal action at a later time by the patient.

The state board may try to turn it into an investigation of whether the complainant actually has Lyme

disease or not. They may request records from other doctors in spite of the fact that it really is not relevant to the complaints. Patients should not be intimidated into giving access to non-relevant records. Insist that the state board investigate the complaint using the records of the doctors complained about.

Keep copies of all correspondence and you may want to send copies to your state legislators as well.

Medical Board of **California**
Central Complaint Unit
1426 Howe Avenue, Suite 54
Sacramento, CA 95825-3236
Tel: (916) 263-2424
Toll-free: (800) 633-2322)

Connecticut Dept. of Health
PO Box 340308
Hartford, CT 06134-0308
Tel: (860) 509-7586

Georgia Composite State Board of Medical Examiners
166 Pryor St. SW
Atlanta, GA 30303-3465
Tel: (404) 656-3913

Bd of Physician Quality Assurance
4201 Patterson Avenue
Baltimore, **Maryland** 21215-0095
Tel: (410)764-4777
Toll-free: (800) 492-6836
Fax: (410)358-2252

Providence, RI 02908
Tel. (401) 222-3855
Fax. (401) 222-2158

Texas State Board of Medical
Examiners
Investigations Department MC-263
P.O. Box 2018
Austin, TX 78768-2018
Complaint Hotline (800) 201-9353
email:
investigations@tsbme.state.tx.us

Vermont Board of Medical Practice
109 State Street

Montpelier, Vermont 05609-1106
Tel: (802) 828-2673
FAX: (802) 828-5450

Virginia Board of Medicine
6606 W Broad Street 4th floor
Richmond, VA 23230-1717
Tel: (804) 662-9960

Wisconsin Medical Examiners
Board
PO Box 8935
1400 E Washington Ave
Madison, WI 53708-8935
Tel: (608) 266-2811

studies in the vaccine – they didn't act right anyway. Vector borne diseases to a warm vertebrate host are benign relationships and not very complicated.

Don't read European medical literature – it wastes too much time in basic sciences. Never do a direct test when investigating an infectious disease- these are the foundation of microbiology. Disregard other physicians who are basically thoughtless and need a leader. Disregard history – it points out human error. Try steroids to see if patients with bacterial infections get worse or better.

Antibiotics don't induce bacteria into other forms since bacteria are so simple. If one can't see a spirochetal form with silver stain, it isn't there. Stay in Boston so one doesn't need the vaccine. Now that the disease is so well understood, step forward and accept your medal.

Humor

The history of Lyme disease according to ...

by Harold Smith, MD

It is a New Arthritis, Viral, in Children, in a Few Joints, in a Small Town(s), responds to steroids and aspirin, doesn't respond any better to antibiotics, well actually it does involve some adults, get to a few more joints, uh does go to some other organs like heart and brain, but these are minor since the heart gets better in a short time anyway, so don't even use antibiotics for the heart, and, yes, the cognitive loss does occur in those few with neurological Lyme but it is minor (only lasts 18 months – try having a sore throat for 18 months and calling it minor – but this is just a brain) and gets better anyway without antibiotics.

Oh there are a few other organs involved like bladder, eyes, bowels, esophagus, uterus, placenta, sinuses, lymph nodes, respiratory system, spleens, livers, brain stem, peripheral nerves, spinal cord, kidneys, muscles, endocrine organs, bone marrow, white blood cells, cranial nerves, blood vessels, umbilical cords, fetuses, etc., etc., but it is really a rheumatological disease and best to be a coauthor on illnesses far beyond the realm of rheumatology.

It didn't exist before discovery in 1977, is very different in North America than Europe, is easily cured, and easily diagnosed by laboratory testing with serology. There must be five bands and there is no seronegative Lyme.

It is best to name a disease after a town so everyone knows what is being talked about. The ELISA test determines who has the disease and who doesn't – if done in the right lab. A conference is held in 1994 and science is best decided by signature. There are no coinfections. *Borrelia* doesn't exist in different forms. Who ever heard of a germ living intracellular?

No one gets better from a chronic persistent infection with chronic persistent antibiotics. Fibromyalgia is a specific disease. Depression isn't ever an infectious encephalopathy of long slow debilitation. When doing a study to determine the number of bands needed to detect borreliosis pick a hundred normal controls from chronic fatigue, multiple sclerosis, rheumatoid arthritis, systemic lupus and fibromyalgia. Forget the monkey

Step up for your heavenly reward

Two doctors and an HMO manager died and lined up at the pearly gates for admission to heaven. St. Peter asked them to identify themselves. One doctor stepped forward and said: "I was a pediatric spine surgeon and helped kids overcome their deformities." St. Peter said, "You can enter."

The second doctor said "I was a psychiatrist. I helped people rehabilitate themselves." St. Peter also invited him in.

The third applicant stepped forward and said, "I was an HMO manager. I helped people get cost-effective health care."

St. Peter said, "You can come in too." But as the HMO manager walked by, St. Peter added, "You can stay three days. After that, you can go to Hell."

source unknown

Conference Reports

Few bright spots for patients at international meeting

by Peter Rohleder

Munich was the town where this year's VIII International Conference on Lyme Borreliosis and other Emerging Tick-Borne Diseases took place. Without doubt, the site was suitably selected. Munich, the capital of Bavaria, and in particular the English Garden, near to where the Hilton Conference Hotel is located, is an endemic area for Lyme borreliosis. It is unlikely that anyone going to the conference had enough time to get infected there because the program was fully packed with lectures from morning to evening.

The introductory paper was reserved for the man without whose discovery more than fifteen years ago, the participants probably would not have come together at this time in Munich. If you want to let your fantasy play, you can speculate about what would have happened without Willy Burgdorfer's discovery. Later on, physicians all around the world would have found obscure causes for symptoms, for which we know today that their cause is Lyme disease.

One need not to be fond of tiepins and similar decorations to admit that seldom has someone other than Willy Burgdorfer carried a more suitable decoration with his golden, wound spirochete tiepin which one could admire if one had the chance when standing near him.

Admittedly, it is not easy to decide which presentations were the most interesting ones. There were more than 400 presentations of approximately 200 as actual lectures and 200 as poster presentations.

The group with the biggest vested interest in the results of the conference is probably the group of those who are chronically ill with Lyme-

disease. In my discussion with people belonging to this group, at least with those familiar with the publications of the last year, some disappointment was obvious. There was some hope appearing at the horizon. It was in November 1998 when Phillips et al. published a paper concerning the direct proof of *Borrelia burgdorferi* in the blood of chronic Lyme disease patients -- possibly a new gold standard, and a proof for something which has been denied by experts for a long time.

Unfortunately, at the conference it was difficult to find anyone who even mentioned this paper in passing. But was this really surprising? Acknowledgement of this test would have meant that large sections of the conference dealing with improved and/or standardized antibody detection methods or interpretation criteria would have been rendered dispensable.

Obviously, a certain amount of resistance and skepticism to Phillips' method would have been quite understandable, as long as no other laboratory has verified his method. But at least his paper would have been worth mentioning. It would be particularly interesting to know whether any other laboratories are in the process of verifying his method. Also the discoveries of Brorson and Brorson concerning the "Cultivation of *Borrelia burgdorferi* spheroplast L-Form variants and their transformation to normally, mobile spirochetes" would have earned more notice.

Interestingly enough it was Willy Burgdorfer with his long experience in the study of spirochetes who noted in his lecture, with almost the same

words he spoke at the New York conference in April:

"The most recent findings do confirm the development of membrane-derived cysts, blebs, spherules, vesicles and the potential transformation to motile, helical spirochetes, not as part of a complex development cycle but rather as a 'survival' mechanism of spirochetes to overcome or escape unfavorable conditions.... Other in vitro and in vivo factors shown to induce development of cysts include unsatisfactory culturing conditions, presence of antibodies and the effect of antibiotics."

On the other hand one would have expected that Phillips or another representative of this paper would have been on the offensive to defend their findings, although there was little time available to discuss the various lectures. Dagmar Hulinska, a co-author of the Phillips paper, was present. Who, if not these researchers with their scientific backgrounds, should have stood up and challenged the stereotyped utterings which we had the chance to hear again:

"Antibiotic therapy of more than three weeks in the case of neuroborreliosis doesn't seem to be necessary."

We can't expect that the few representatives of Lyme-disease support groups (mostly from Germany and unable to speak English fluently) would have been able to take over this function.

But it is probably wrong not to see the improvements which have been made in the last years. Serology has become better, the methods have been refined and big steps have been made in the direction of standardization. But the gold standard to confirm whether someone has been cured is still missing. Regrettably, it became clear, despite several interesting works concerning PCR, that this method is still too inaccurate to play this role. This does not mean that the PCR doesn't make

sense as an additional investigation tool for diagnosis in difficult cases.

In this context it should always be mentioned that even the proponents of a very restrictive interpretation of serological findings had to confess that the diagnosis Lyme disease is still a clinical one and should not only be based on the results of the serological tests. But this is often in contradiction to what we see in practice. No wonder-- physicians of today are trained to regard laboratory tests as the Alpha and Omega of diagnosis, similar to a machine in which you throw something in and the desired result comes out. The detailed knowledge concerning the background of the tests is often missing.

Many of the papers did not really present any new results - it was more the presentation of the results of the two last years. And many of them have been published in different medical journals before.

As is often seen nowadays at scientific conferences even in other areas, it was completely unclear whether the results of some discoveries should be further pursued, and if so, whether further research going into a specific direction could lead to solutions of problems in the near future. To name only one of them, for example, Donta's discovery that a toxin produced by *Borrelia burgdorferi* could be responsible for some of the symptoms of Lyme disease.

Interestingly, a newer discovery by Brorson and Brorson (until now only done in vitro) is that cystic forms of the borrelia are destroyed by the active substance metronidazol. This, in connection with the discussion about the role of cystic forms, throws light on the possible effectiveness of metronidazol for treatment, as has been discussed recently.

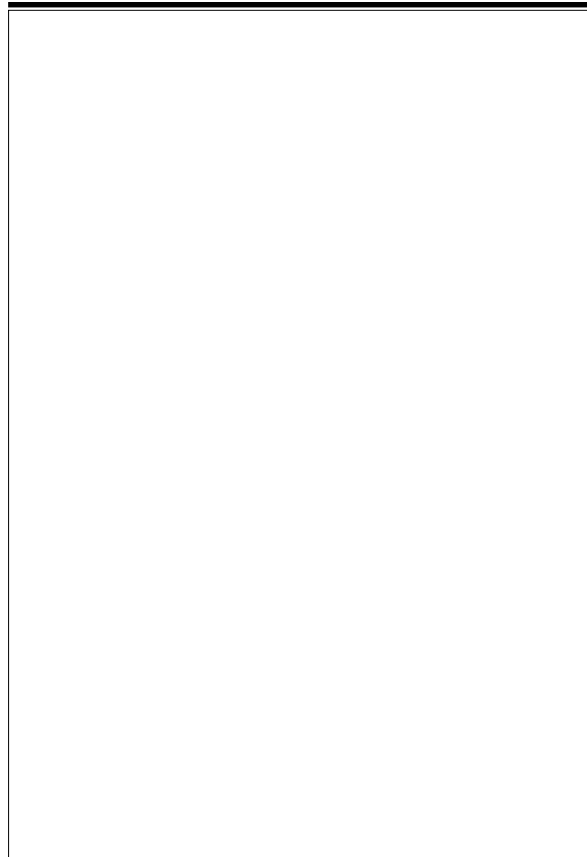
Something which was unquestionably gotten straight by the congress now, was the fact that with some cases of Lyme-disease, a co-

infection with Ehrlichia and/or Babesia could play a role. If, however, the knowledge of this fact comes into the heads of the physicians as slowly as has Lyme disease itself in the last 15 to 20 years, this discovery probably will not benefit the patients any time in the foreseeable future. Besides, it would be necessary to have good laboratories able to perform reliable tests for Ehrlichia and Babesia.

Another discovery, which, I must confess, I heard about only after the conference had finished, was the paper of Bela Bozsik, a physician

from Budapest, Hungary. He claims to have found a new test for verifying seronegative Lyme disease. The practical solution works by modifying the classic dark-field microscopic method with a new reagent. Bozsik wrote that he has been running these examinations for thirteen years. But going into detail could be the content of another article.

Peter Rohleder lives in Sankt Augustin, Germany. The Lyme Times appreciates his report, which he wrote in English.



Dr. Gossel explains a point to (l.-r.) Hanna Priedemuth, of Berlin, while Mr. & Mrs. Leipholz, of Kassel, look on during a dinner on June 22 at the Munich Park Hilton for activists from several Selbsthilfegruppen (Self-Help Groups) in Germany. Other people present but not pictured: Gunther Binnewies, Heidenheim-Brenz; Mr. Weidner, Dresden; and Peter Rohleder, Cologne.

Another view of the meeting

by Dr.-Ing. Dieter Gossel

As a rule, self-help groups always come into being if the professional problem-solvers offer no or only unsatisfactory solutions to the perplexed. At the close of the international Lyme disease meeting

in Munich on June 24, Allen Steere from Boston, USA, admitted that even with "effective" therapy, 10% of all cases of Lyme disease did not achieve a satisfactory outcome, and that the causes for this are unknown to him.

This means that for the 20,000 to 80,000 new cases in Germany annually, 2,000 to 8,000 become chronic. It is an alarming situation; in Munich we heard almost nothing about how to remedy it.

The standard medical practices can't satisfactorily solve the problem. Each year 2-8,000 new chronic cases – this means that alternatives to the usual antibiotic regimens are of great interest. Although proposals do exist – for instance hyperbaric oxygen therapy – which are studied and supported with some success at academic institutions, there was nothing heard about it in Munich.

One hopeful note comes from Norwegian researchers Brorson and Brorson. I had the opportunity to talk in some detail with Oystein Brorson. In their poster and in accompanying papers* the Brorsons show that metronidazole *in vitro* can produce two valuable effects: one, it prevents *Borrelia burgdorferi* from transforming its normal spirochetal form into its L-form, thus blocking their path of escape from a hostile environment, e.g. antibiotics or antibodies; two, it destroys the L-forms, disturbing their mechanism of DNA replication, while it has no effect on the normal spirochetal form.

Thus the Brorsons propose to treat Lyme disease by a combination of antibiotics: normal antibiotics against the normal spirochetes, metronidazole against the L-forms. This reminds one of the combination therapy now standard with the treatment of *Helicobacter pylori*, another spirochete causing gastric ulcers.

Because of his disease, Oystein Brorson is confined to a wheelchair. On that account he has a strong personal interest not only in the

purely scientific solutions but also in practical solutions. I recommend a thorough study of the Brorson papers. They might become very important one day for the self-help groups and their clients.

As often happens at big international meetings, one who has carefully followed the relevant literature (and understood it!) can find barely anything new. The main attraction lies in the chance of having one-on-one conversations on the fringes of the lecture hall. I used the opportunity to speak with Dagmar Hulinska, coauthor of the Phillips' paper. She has successfully cultured L-forms, but the medium she uses is slightly different from the published recipe. [*Ed. note: Hulinska emphasized that the pH of the medium was critical. This condition was not noted in the published article.*] Some of the obstacles to the development of the method have not only to do with scientific problems but also with communications failures between scientists.

The Phillips paper, from *Infection* 1998, caused much discussion in the USA and was mentioned by U. Neubert in the article intended for continuing medical education in "Borreliosis Therapy 1998." It was supposed to have been presented as a poster, but in the appointed spot was only a blank white surface; no one stood to explain and discuss the information. One is tempted to speculate on what might have been going on behind the scenes. Phillips was advertised as a speaker at a regional meeting in Michigan in the USA in September; maybe we will hear something about that. [*Ed. Note: The Lyme Times will try to report on this meeting in the next issue.*]

Under the somewhat misleading title "Seronegative Lyme Borreliosis" poster #283 would have been easy to overlook among the crowded offerings. In this poster Hungarian physician Bela P. Bozsik claimed to be able to implement a microscopic direct visualization of *Borrelia burgdorferi* in seronegative patients with the help of a powerful reagent called "Dual Dur." This method should compete directly with the cultivation method of Phillips et al, and, if it works, is presumably cheaper and faster.

For the price (expensive), the Munich meeting was scientifically a bad deal. Double sessions were frequent with both lectures and posters. I expected some survey lectures, summarizing all fields of present research, on an international scale, indicating the directions and prospects of future investigations, and what this might mean for those suffering from chronic Lyme disease. It was a vain hope. The keynote lecture by Willy Burgdorfer, officially presenting the existence of borrelial L-forms as "old hat," was overall substantially the same text as he gave at the April symposium in New York. If I didn't overlook something these ideas were found on only two posters and were not at all mentioned in the entire remaining program.

On the technical side, the slide presentations of many authors were pathetic, unreadable, or in many cases, overloaded with text. Timing violations occurred – especially with the American lecturers – and overruns were taken out of the time allowance of the next speaker, but the chairmen did not stop them. Happily, many contributions from the Pettenkofer Institute were clear and well prepared. The Institute considers itself in transition at the moment; the new chief is said not to be as interested in *Borrelia burgdorferi*, which has led to so many of the interesting contributions inspired by his predecessor, Frau Preac-Mursic. Unfortunately, I did not see Frau

* Brorson and Brorson. An in vitro study of the susceptibility of mobile and cystic forms of *Borrelia burgdorferi* to metronidazole. *Acta Pathol Microbiol Immunol Scand* 107:566-76. 1999; and

Brorson and Brorson. A rapid method for generating cystic forms of *Borrelia burgdorferi* and their reversal to mobile spirochetes. *Acta Pathol Microbiol Immunol Scand* 106:1131-1141. 1998.

Preac-Mursic at the meeting, nor hear a single word of appreciation from her numerous early collaborators and coauthors who did attend the meeting. Because of the excessive number of talks, I could have missed something.

I want to mention the satellite symposium sponsored by the firms Baxter (vaccine), Hoffman-LaRoche (antibiotics), Dade Behring (lab diagnostics), Grunenthal (microbiology and general therapeutics). Here I remember another of the excellent presentations by Frau Pohl-Koppe (Munich) on pathogenesis and therapy of Lyme borreliosis in children and the presentation of Frau Professor H. Hofme (Munich) on skin manifestations of this disease. They gave clear information on how to treat children and various skin manifestations, important because so many practicing physicians are still unsure of how to diagnose and treat. I was less impressed by the contribution of V. Fingerle from the Pettenkofer Institute in the symposium sponsored by Grunenthal. For a time he addressed the German doctors in his Schwabish dialect, which the many foreign listeners couldn't distinguish anyway, but in spite of this, they the same effect through a miserable simultaneous translation. It might have been a peculiar joke.

The final lectures about Lyme arthritis and the management of Lyme borreliosis were delivered by Prof. G. R. Burmeister and his assistant medical director, A. Krause, both of Charite Hospital in Berlin. In both presentations, which are included among other contributions in the Thieme book "Lyme Borreliosis," which was given out at the meeting, the authors assure us that the world is still orderly. Misdiagnosed actual chronic relapses, if they occur at all, represent an absolutely negligible quantity. I remember Palmstrom – "What is not accepted, does not exist!" Peter Herzer (Munich), who chaired the session, stuck to a similar theme.

A thought came to me, that the somewhat limited scope of the meeting could perhaps be attributed to the influence of the sponsors. Actually only lab diagnostics, vaccine and therapies were described. Behind these stand companies and products. Perhaps this explains the complete absence of alternative approaches. Is this what we call scientific freedom?

On Wednesday afternoon, the symposium directed at practicing physicians organized on the so-called

I cannot remember any speech in which the suffering of the patients was mentioned, or the avoidable chronicity caused by scandalous medical lack of awareness.

"Doctors' Sunday" [*Ed. Note: Doctors' offices in Germany are closed on Wednesday afternoons*], we saw the same familiar faces as at the rest of the meeting. The firm Grunenthal had seen to it that, through its representatives, all practicing doctors in the Munich area were invited (for free admission) to a nice cold buffet. One of our well-known LLMDs from Zurich (Switzerland) who has earned great respect with both lay people and professionals for continuing education about Lyme borreliosis, was said to have expressed deep regret that so few of his colleagues had taken this opportunity for further education on Lyme borreliosis offered by world experts in the field. If the people for whom the symposium was planned do not attend, the overriding problem with this disease will continue—wrong and/or too-late-correct diagnosis.

Around the end of December 1998 I met here in Hamburg a woman whose doctor, a specialist in skin diseases, wanted to treat an EM with cortisone. The woman was lucky; one of her friends was a hunter who had attentively studied the leaflet on Lyme disease put out by his hunting association. He made the correct diagnosis and saw to it that his friend was put under the care of a LLMD. This doctor wanted to enlighten his illiterate colleague and make clear the possible consequences for his patient. At last report his offer was pointedly refused.

From the point of view of self-help groups and their devotees, especially those with chronic disease, the results of the Munich meeting were disappointing. According to information from the Basel (Switzerland) AKM Congress Service, which organized the meeting, there were 686 participants, of whom 200 were from Germany and 140 from USA. The rest came from all of the countries of the world. Lyme borreliosis is a worldwide sickness and – this came out of the lectures only indirectly – a worldwide unsolved problem with the nature of a timebomb.

According to statements by different lecturers, the incidence varies from 0.3-0.6/100,000 in Ireland and Great Britain up to 500/100,000 in highly endemic areas of Europe and the United States. In certain central European countries, such as Slovenia, Austria, and southern Germany, one can count on an incidence of 100/100,000. The causes are only partly known.

It remains incomprehensible why we in Germany, except for a couple of the newly formed states (Brandenburg, Sachsen-Anhalt), have no obligation to report Lyme borreliosis, in contrast to many of our neighbors. Professor Stanek from Vienna correctly pointed out that a single surveillance criterion with a highly restricted case definition will remain as long as there is no certain

and generally utilized method of proof – a so-called gold standard. And the value of reporting is limited anyway if we don't all adhere to the same standard.

I cannot remember any speech in which the suffering of the patients was mentioned, or the avoidable chronicity caused by scandalous medical lack of awareness. No one expressed that the enormous financial expenditure for research, to which the participants of the meeting owe their livelihood, depends above all on the suffering of chronic Lyme patients. No one spoke of compensation for those who are suspected as malingerers and land after all in a psychiatric ward. H. Horst spoke about it in his book – as long as there is a lack of definite objective diagnostic criteria, people should use the principle: "The accused should have the benefit of the doubt," with the patient as the accused.

I sought out meeting participants from the Hamburg area, hoping to find LLMDs whom Lyme patients

could trust without the danger of great mistakes in diagnosis and treatment. My search was fruitless. I could have missed someone. The Lyme self-help group in Hamburg would be happy to have news to the contrary. If someone reading this report is or knows a practicing physician in Hamburg, please get in touch with us.

With that I will end my report and hope that my moral duty as unpaid correspondent of *Borreliose Magazin* has been satisfied. The next international borreliosis meeting will be in three years, in September 2002, in New York City.

*Dieter Gossel, a retired engineer, was a scientific advisor with Philips Research Labs in Hamburg. He has had Lyme disease since 1989. A German version of this report will appear in **Borreliose Magazin**. For information contact Jurgen Peters, Lyme-Borreliose Bund eV, Grosse Str. 205, 21075 Hamburg. Tel 040-790-57-88.*

audience. In addition he brought to light that tests are not always the key to diagnosis and how important a "clinical diagnosis" is. He talked about how difficult Lyme disease organism is to culture by comparing it with the similar syphilis organism which has never been cultured.

Lionetti explained that with *erhlichiosis*, a possible co-infection, some antibiotics commonly used for Lyme disease can't reach it because this particular infection lives inside the cells. However, the second line of antibiotics such as erythromycin and doxycycline are effective. The other co-infection is *babesiosis* and because it's more of a malaria-type infection, different types of treatment are recommended. While we've had less concern for the "dog tick" which rarely transfers Lyme disease to humans, we heard that it can transmit *ehrlichiosis*.

Dr. Lionetti mentioned the common problems with joints in Lyme disease often described as arthritic. Since central nervous system problems are so much a part of Lyme disease, perhaps many of these painful joints are actually caused by the nerves themselves.

Many questions were asked by the 60 to 70 attendees including questions concerning the apparent reluctance of public health authorities to recognize and publicize the fact that Lyme disease and Lyme disease infected ticks are present in Southern California communities. This reluctance affects the treatment available for patients - doctors do not suspect or test for diseases that purportedly do not exist in the area.

The spirited discussion during and following the formal seminar, scheduled for 7pm to 9pm, finally did not break up until almost 11pm.

Art Doherty contributed to this report. His web page, "Lots of Links on Lyme Disease", can be accessed at <http://www.geocities.com/HotSprings/Oasis/6455/lyme-links.html>.

LDF March to Victory lectures come to southern California

by Rene Landis

The Lyme Disease Resource Center in Southern California promoted a July 30 March to Victory whistle stop by Karen Vanderhoof-Forschner, Director of the Lyme Disease Foundation. Thanks to the efforts of LDRC Board Member Barbara Barsocchini, who made the arrangements, the West Los Angeles Vector Control District in Culver City hosted this event and director Robert Saviskas shared studies of tick surveillance in areas in Southern California. Yes, there are infected ticks in the Santa Monica Mountains as well as at the ocean level of Palos Verde Peninsula.

Forschner explained the March to Victory as a path to get closer to patients and professionals. The LDF is known for annual scientific conferences that bring together large audiences. But for those who can't attend those conferences, the March has brought Forschner and lecturing teammate Dr. Anthony Lionetti, to them instead.

Dr. Tony Lionetti was able to impart knowledge on all facets of tick-borne diseases. His experience and understanding attitude towards all, make him an ideal educator to patients and professionals alike. He addressed concerns expressed by the

Pennsylvania meeting draws over 400 people

by Patty Smith

The Southeast Pennsylvania Lyme Disease Conference held on June 12 was a big success. Over 400 attended. Pennsylvania Representative Joseph Pitts, who sponsored the conference, said he's never had such a turnout for any other event he's held. He and New Jersey Rep. Chris Smith's aide spoke first, followed by Jerri-Lynn Wier who organized the event. Jerri-Lynn, attorney and Lyme patient, talked about her illness and the difficulties she encountered getting diagnosis and treatment.

Dr. Gregory Bach, Family Practice Physician, presented a video on some of his sickest patients and their improvement with antibiotics. It was overwhelming evidence that antibiotics do work and he got a resounding applause. Fourteen-year old Matt, one of the Lyme patients featured, walked onto the stage and smiled to the delight of the audience. You had to see the video to appreciate the outcome of his treatment.

Dr. Emelia Eiras, Internal Medicine Physician, spoke on pediatric Lyme. Several case studies were presented on children who were treated, recovered, and went on to graduate from high school. Dr. John Drulle, Internal Medicine Physician, gave an excellent history of Lyme disease in our country. Dr. Teresa MacKnight, Family Practice Physician and current Lyme patient, talked about her devastating illness. She travelled all the way from Maine and gave the best slide show/lecture I've seen on Lyme. Dr. John Maher, Director of the Chester County Health Dept., discussed ticks and the posting of Chester Parks with tick warnings. Dr. Harold Smith, Emergency Physician and current Lyme patient, talked about the vaccine and the importance of consulting a physician knowledgeable about Lyme

disease before getting the vaccine. Also presented was Tulane's monkey study. (See Art Doherty's website for more details on this study).

Dr. Nick Harris, Director of IGeneX Lab, examined the problems in testing. Many labs do not test for bands #31 and #34 in the Western Blot, the most specific bands for Lyme and used for the development of the vaccine. Also, most labs do not report specific bands, but simply

The insurance companies investigate any physician whose practice involves more than 15% Lyme patients.

count the number of bands, and report back either "negative" or "positive," thus, the doctor or patient never knows if any of the specific bands are present. The Lyme Urine Antigen Test (LUAT), an excellent direct test for Lyme, and other tests were explained in language the general audience could well understand.

Dr. Robert Bransfield, psychiatrist, talked about the neurological and psychiatric aspects of Lyme. He discussed impulse control, aggression, and violence in our society with a infectious cause. For more information on this subject, go to his Mental Health and Illness website. He has the most comprehensive list of Lyme symptoms that I've seen anywhere.

Attorney Michael Schoppmann, who has represented a dozen Lyme doctors, said every one of the

complaints brought against his clients were from insurance companies. They investigate any physician whose practice involves more than 15% Lyme patients. Over a three-year period they go through the records of all of the physician's patients, then go to the state medical board who goes after the physician's license. The physician is allowed to keep his/her license on condition that they will no longer treat Lyme patients. He said it's up to us, the Lyme patients, to protect our physicians. We need to influence our state medical boards (influencing who gets appointed).

Pat Smith (no relation), President of the Lyme Disease Association of New Jersey, spoke about her daughter's illness. She has been very active helping children with Lyme get assistance from their school districts with their educational needs. (Pat Smith is a tireless volunteer, lecturing at schools, assisting in legislative bills about Lyme, raising money for research, etc. This is an organization every Lyme patient should join, regardless of the state they live in. Last year this organization raised \$400,000. entirely for Lyme research. It is run entirely by volunteers. For a \$9 membership, you fund research and get their newsletter which includes listings of Lyme support groups and other organizations nationwide. Their address is PO Box 1438, Jackson, NJ 08527. A Pennsylvania chapter is being formed.

Another hard-working volunteer, Cheryl O'Connell, Co-Founder of the Chester County Chapter on Lyme, talked about her entire family who has Lyme. A question & answer panel followed. We need more of these conferences to raise public awareness. If anyone is interested in organizing in their area, I would be happy to contact speakers.

Patricia Ann Smith, RN, is one of two coordinators of the Central Pennsylvania Borreliosis Lyme Disease Support Group.

Research

Steere and Fallon teams find antibiotics improve thinking, mood disturbances in children with Lyme encephalopathy

This is the first in a series of four articles in this issue of the Lyme Times on Lyme encephalopathy in children.

by Jean Hubbard

“I’m too tired and too dumb,” 16-year-old David told his doctor, explaining why he’d quit dating a new girlfriend [1]. “I wish I could just die in my sleep.”

David had been having strange, mostly invisible symptoms on and off for about 4 years by that time. They began when he was in the 7th grade, when his knees often hurt and he quit playing sports. That year his school grades dropped slightly as well, from A and A- to Bs. He was doing his homework, but often forgot to hand it in. A medical evaluation at the time found no signs of illness, and it was thought David had a low level depression or was just lazy.

By the 10th grade David was nearly failing his classes. His depression had worsened and he was having trouble staying awake. Extensive evaluation revealed a profile of symptoms, lab findings and deficits on tests of cognitive function that were highly suspicious for Lyme disease, and he was treated with 12 weeks of intravenous ceftriaxone.

After the antibiotics his school work improved dramatically. So did his cognitive and physical symptoms, and his depression was gone. Repeat psychometric testing revealed an amazing gain of 22 full-scale IQ points.

David is one of a small group of children described in two reports published last year—one by psychiatrist Brian Fallon and colleagues [2]

and the other by a team led by rheumatologists Bradley Bloom and Allen Steere [3]—looking at cognitive, mood and attention changes in children with Lyme disease. Changes like these, due to a disruption of brain functions called encephalopathy, are now known to occur in many adults with late Lyme disease, but conservative experts still believe that children somehow escape this especially devastating consequence of the infection. These two groundbreaking reports challenge that perhaps comforting but implausible belief. Both reports describe bright, capable children with very specific types of cognitive problems that developed only after they got Lyme disease. Like David, most of these previously successful children had developed trouble doing school work. Several had had a drop in their grades from once-high levels, but in other children the school problems had been “more subtle, such as increased difficulty following directions.”[3]

Sometimes they appeared easily distracted or as if they just weren’t paying attention. They forgot things one would expect them to remember. They found it newly hard to do things or finish assigned tasks. Homework might appear disorganized and sloppy, or like David’s, just get lost. Several had disturbances in behavior or mood as well: some became newly irritable or fearful, and another adolescent besides David had

become depressed. The children also had an assortment of physical symptoms that, again like David’s, were often subtle and typically lasted only briefly.

Importantly, however, although most of the children had already been treated with antibiotics, every one of them improved—sometimes dramatically—with further aggressive antibiotic therapy. Although David’s was the only documented increase in IQ, all children returned to being successful students, earning the same grades they had earned before they got Lyme disease, once again attaining their pre-illness grade average of A/A+.

The cognitive and emotional disturbances experienced by these children weren’t just artifacts of parental fears or overreactions, and they were much more than the normal fluctuations in behavior and attentiveness many children display—they were scientifically proven abnormalities. Sophisticated neuropsychological tests (tests of cognition, achievement and emotion) objectively documented them as statistically significant deficits that were very specific, in a pattern very similar to that seen in adults with Lyme encephalopathy. And in every case the same neuropsychological tests, repeated after further treatment with antibiotics, documented improvements that again were large enough to be statistically significant.

The children also had strong laboratory evidence of brain changes. All the children described in the Bloom/Steere report had spinal fluid findings showing that *B. burgdorferi* spirochetes had invaded their brains, and David had brain abnormalities, apparently due to a decrease in blood perfusion to brain tissues, that were visible on a SPECT scan.

Based on these findings, especially the documented improvement after further antibiotics, both reports conclude—a remarkable agreement given the well-known differences in point of view between Dr. Steere and

Dr. Fallon, both award-winning academic researchers—that the problems the children had been suffering most likely had been due to latent or persistent infection of their brains by *Borrelia burgdorferi*.

Bloom, Steere et al report a study limited to 5 children with confirmed Lyme disease—children who had had so-called “classic” symptoms and positive blood tests for Lyme disease by CDC criteria—in addition to carefully proven infection of the central nervous system by *B. burgdorferi*. The results of the children’s neuropsychologic testing and responses to antibiotic re-

treatment are described in detail.

Most of the children they studied had developed symptoms of ongoing brain disturbance soon after their infection with Lyme disease, all but one within a year, making the relationship between Lyme disease and their cognitive problems unusually clear. We’ll examine this important study in detail in the second article in this series on children’s neurologic Lyme disease [please see “*Neurocognitive abnormalities ...*” on page 39, this issue], but first we return to David and review the report by Fallon and his colleagues.

to say, which made it hard for him to finish sentences. Or he might inadvertently misuse a word or say the wrong word (when asked the date, for example, he said 1977 instead of 1997). He thought he had memory problems that got in the way of his remembering conversations. He was hypersensitive to noise (hyperacusis) and easily distracted. He also mentioned that he’d quit dating a girl after only two weeks because he was “too tired and too dumb.” [1]

When asked—and only when asked—David also acknowledged having a number of episodic physical symptoms: headaches, little twitching things under his skin, and sometimes numbness, tingling and electric-shock like pains, especially about his face and hands. Now and then he had foggy vision, pains in his knees and other joints, and pain in his muscles. His appetite was poor and he’d even lost some weight. He had occasional sore throats and sometimes his neck was stiff. Sometimes he’d have episodes of sudden sweating, sometimes heart palpitations. And sometimes he had pain in his testicles.

This profile of symptoms, so like that of adults with chronic Lyme disease, led to further testing. Although 3 months earlier his Lyme ELISA had been negative, this time an IgG Western blot of his blood performed at Stony Brook was highly suspicious for Lyme disease: it showed 4 of the CDC’s 10 preferred *B. burgdorferi*-specific bands—just one less than the 5 bands the CDC requires for proof of late Lyme disease. Lab tests for other diseases were all normal, as was an MRI of his brain.

A SPECT scan, however, showed moderate to severe decreases in the perfusion of blood within his brain—patches of hypoperfusion diffusely distributed throughout the brain’s central white matter (subcortical areas) and in parts of the gray matter (cortex). According to Dr. Fallon it is

“Underdiagnosis of chronic Lyme disease in children and adults,”

by **Brian A. Fallon, MD, MPH; Janice M. Kochevar, NP; Andrea Galto, MD, and Jenifer A. Nields, MD.**

The report by Fallon et al [2] differs in its approach. It’s a wide-ranging discussion designed to alert psychiatrists, neurologists and psychologists to the kinds of problems that can develop later in the course of undiagnosed, and hence untreated, Lyme disease. It tells the stories of three patients—David, the adolescent thought to have depression; Susan, a young girl thought to have attention-deficit disorder, and Mr. B, a man diagnosed with multiple sclerosis—to illustrate some of the most common cognitive and emotional effects of late central nervous system (CNS) Lyme disease. It explores the diagnostic dilemmas likely to be encountered when symptoms emerge long after the early illness, at a time when *B. burgdorferi* infection of the brain may have to be inferred rather than proven.

David’s story:

At first it wasn’t at all clear that David had Lyme disease. His mother thought so—she had chronic Lyme herself and knew its symptoms well [1]—but there was no objective

evidence for it in David. Although he lived in a Lyme-endemic area and had had tick bites, no one had ever noticed an erythema migrans rash, nor had he had the obviously swollen knees that would suggest Lyme arthritis. ELISA blood tests for Lyme had been negative on two occasions.

As noted above, David’s most obvious symptoms had been a low-level depression and a slow decline in his grades to low Cs and Ds from the A to A- range he’d maintained during his first 6 years of schooling. At age 16, when after about 4 years of symptoms he was on the verge of failing his classes and his depression suddenly worsened, he underwent a more extensive evaluation that began with a long interview.

When asked about his school difficulties, David said he had trouble concentrating, that he felt “spaced out all the time.” [1] He was having trouble sleeping and trouble staying awake in school. He was having a little trouble talking too: sometimes, he said, he found it difficult to find the word he wanted

“very, very unusual for an adolescent to have that kind of brain; it’s unusual even for an adult to have that kind of brain. Certainly depression did not cause that; it showed that he had diffuse brain disease.” [1] It is also precisely the kind of hypoperfusion pattern seen in the brains of adults with Lyme encephalopathy.

Psychometric tests showed him to have cognitive problems as well. The neuropsychologist estimated his pre-illness intelligence to be at about the 85th percentile (the report doesn’t specify which test this figure was based on, but reading comprehension and vocabulary tests are often used for this purpose [4,5]. However his mental processing was significantly slower, and his memory for visual-spatial configurations was significantly impaired.

David was diagnosed with probable Lyme encephalopathy and treated with 12 weeks of IV ceftriaxone. His school work markedly improved, his short-term memory was better, and he was less distractible. His sleep, appetite, headaches, joint pains and numbness all improved as well. His depression lifted (he had been prescribed antidepressants but chose not to take them), and, as noted above, repeat IQ testing after antibiotics showed a gain of 22 points.

David also benefitted from counseling to help him revise how he saw himself. As the authors put it, “rather than being lazy and incompetent, he had been sick.” He needed to learn that “an undiagnosed infectious illness had been draining his energy.” As his health improved and he began to perceive himself in this new light, David regained confidence and worked hard at his studies to make up for his years of illness.

Susan’s story:

Susan too had been a superior student and apparently completely healthy before her school work began to deteriorate at age seven.

That year she began having trouble focusing on her work at school. She seemed inattentive and forgetful. She was clearly very bright but suddenly began not to do so well. A neuropsychologist thought she had attention-deficit disorder (ADD), but Susan also had symptoms not typically seen in ADD—including lethargy, headaches, joint pain, irritability, and heightened sensitivity to both sounds and light. She also had some word-finding difficulties like those David reported, and she was less coordinated than she’d been. Because these symptoms suggested a physical illness, she had a comprehensive medical evaluation (including EEG and MRI) that was entirely normal except for a positive Lyme ELISA.

During antibiotic treatment for the Lyme disease her concentration improved, her attention-deficit symptoms disappeared and her school grades came back up to their pre-Lyme level of A/A+. When the antibiotic was stopped, however, her symptoms returned. Again she was placed on an antibiotic, and again rapidly improved. This pattern—relapses while off antibiotics, improvement again when antibiotics were restarted—continued over 2 years before she could be weaned off the antibiotics without relapsing. After that she remained symptom-free for 3 years, maintaining her excellent (A/A+) grades.

Symptoms emerged again when she was 12. Again she had knee pain and headaches as well as problems concentrating, and on retesting for Lyme disease her serologies met CDC criteria—a positive IgG ELISA plus an IgG Western blot with fully diagnostic bands. Again she quickly improved when given an antibiotic; and again, when the antibiotic was stopped after 2 months, her symptoms returned.

Again she started to show problems with attention and concentration in school. Her parents noticed that she was taking her homework to

school in her bag, but she often didn’t turn it in when she got there. Often she couldn’t remember where she’d put her completed homework, and sometimes she couldn’t even remember whether or not she’d done it. Her teachers noticed this too, and began commenting in Susan’s records: “trouble with consistency in day-to-day work; careless; head in the clouds; scattered and sloppy work; assignments are late, forgotten or lost; difficult time following directions; more forgetful and disorganized.”

In addition to the trouble focusing on her work, Susan had become “frustrated, overwhelmed, tearful, aggressive and fearful, with new-onset phobias and nightmares.”

She was medically evaluated again after being off antibiotics for 4 months. This time she met full diagnostic criteria for attention-deficit disorder, reporting 6 of the 9 signs of “inattention” listed in the DSM-IV Diagnostic Manual. When asked, Susan denied the feelings of depression and thoughts of dying that David reported, but acknowledged she felt “overwhelmed.”

She was intolerant of noise. She had moderate fatigue, insomnia, headaches and the same kind of paresthesias (numbness, tingling and shooting pains) that David had had. By now she not only had knee pain but a slight swelling of her knee as well.

Psychometric tests showed her to have a “very superior” baseline intelligence, with a verbal IQ of 132. But despite her intelligence, she had statistically significant deficits in attention, visual motor planning, visual scanning, visual memory and learning. Like David, she had slowed significantly when timed on a simple task requiring mental processing, but unlike him she had a normal brain SPECT scan.

She was diagnosed as having a persistent encephalopathy due to Lyme disease, and again she was treated with antibiotics (oral

cefuroxime). Again she returned to her previous level of health and academic excellence and remains there, continuing on the antibiotics.

Why is Lyme encephalopathy underdiagnosed?

Laboratory tests that cannot reliably determine whether or not a person is actively infected with Lyme disease—or whether or not the brain is infected—lie at the root of both underdiagnosis and overdiagnosis of Lyme encephalopathy, according to Fallon and his coauthors. And what they call its “vast array” of symptoms—as seen in the stories of the two children described above—involve many systems of the body and overlap with other diseases that also are hard to diagnose, further confusing diagnosis. In fact, they remind us, Lyme disease has been dubbed “the New Great Imitator” because in its multiplicity of symptoms it is akin to syphilis, the original “Great Imitator.”

Lyme is like syphilis in other ways as well. In his talks with people who aren't medical professionals, Dr. Fallon explains: “Like syphilis, Lyme is a spirochetal disease. Both can cause an early skin reaction. Both cause multisystem illness. Both rapidly invade the central nervous system (brain and spinal cord). Both can cause a wide spectrum of neuropsychiatric problems. Both can cause what's called a Herxheimer reaction, a flareup of symptoms when you first start antibiotics. And both can exist for a long time in the body before the symptoms actually manifest. You may get infected last summer but not show symptoms for a year, 3 years, 5 years. If someone asked you 5 years from now, ‘Do you remember the rash you got in the summer of 1997?’ you probably wouldn't.”[1]

“Approximately 15% to 40% of patients with Lyme disease develop neurologic problems,” according to the authors. They describe “a plethora” of manifestations that have been associated with the infection—

too long a list to be included in this review. Many symptoms, or patterns of symptoms, are like those seen in neurosyphilis, but they also mimic other conditions (e.g. chronic fatigue and multiple sclerosis), and thus laboratory support, despite its limitations, is important in differentiating Lyme disease from other diagnoses.

The lab tests

Polymerase chain reaction (PCR), if positive, can prove active infection but is insensitive in late and central nervous system Lyme disease. Blood tests—serologies—can indicate a history of infection, but often aren't positive in Lyme encephalopathy. Fallon and his coauthors cite a recent study by Logigian et al [6], that showed that “of 8 patients with late Lyme encephalopathy who had cerebrospinal fluid [CSF or spinal tap] evidence of active central nervous system infection, half of the patients had equivocal serologic results and one quarter were seronegative.” Western blot serologies seem to be more sensitive in detecting Lyme encephalopathy, but the CDC's list of accepted antibody bands for the Western blot doesn't include two that appear to be particularly important in late disease—31kDa (Osp A) and 34kDa (Osp B)—not because they aren't specific for Lyme disease (they “are in fact highly specific”), they note, but because they're less commonly seen. Because of the CDC's “overly restrictive” case-reporting criteria, most laboratories don't report these bands to physicians unless specifically asked, and many don't even test for them, thus throwing away potentially valuable information. Fallon et al recommend that both ELISA and Western blot serologies be performed if the clinical history warrants.

Spinal taps (cerebrospinal fluid or CSF tests) are useful in ruling out other diseases. They also may reveal indications of Lyme encephalopathy, but negative spinal taps can't rule it out, the authors state. Citing a study

by Coyle et al [7], they observe that “CSF tests in early neurologic Lyme disease may demonstrate intrathecal antibody production, although in later Lyme disease the results of [these] CSF antibody studies may be negative up to 43% of the time.”

New tools aid diagnosis

Several new tools have shown promise in providing useful information. The authors point to newer imaging techniques for studying the brain, like SPECT scans (Single Proton Emission Computerized Tomography), which seem to be more sensitive in visualizing the kinds of brain changes that occur in Lyme encephalopathy than are MRI scans (Magnetic Resonance Imaging), although occasionally MRI scans will show suspicious white patches in CNS Lyme disease. Differences in SPECT patterns can also help distinguish organic from primarily “functional” psychiatric changes (like depression). But even SPECTs aren't perfect: unfortunately Lyme-like patterns are also seen in other conditions, and sometimes, as in Susan's case, SPECTs fail to detect changes even when disease is present.

Neuropsychological testing (including cognitive and psychometric testing) can “detect objective evidence of cognitive dysfunction that may not be immediately observable on clinical exam.”

Perhaps the most important tool in assessing a child for Lyme encephalopathy, however, is an old one—a good interview. Important clues can emerge from in-depth interviews based on ever-expanding knowledge about the symptom profiles associated with Lyme encephalopathy. A profile of fluctuating symptoms in multiple body systems, combined with a history suggesting possible infected tick exposure, helps differentiate Lyme encephalopathy from other conditions. These authors believe that “in the absence of such a history, Lyme disease is not likely to be the correct

diagnosis.” But in David’s case, “the diagnosis of Lyme disease would have been missed had the physician not asked explicitly about specific cognitive and physical symptoms.”

Rather than providing specific criteria for diagnosis, the authors suggest that informed interpretation of the results of all these diagnostic tools—interview, serologies that

include Western blots as well as ELISA, neuropsychological test results, SPECT scans and in some cases spinal taps—may suggest a provisional diagnosis that might then lead to a trial of antibiotics to assess treatment response.

As Dr. Fallon has said elsewhere [8], “We know some, but we don’t know enough.”

tasks “auditory sequential processing” tests, and 4 of the 5 children had trouble with them.

Three of the 5 children (including 2 of those who had trouble with the auditory sequential processing tasks) performed poorly on a test of “visual sequential processing” called the Trail-Making Test. They took significantly longer than expected to draw a path connecting a series of alternating numbers and letters, as indicated by an increased ratio of time on Trail B (which alternates between numbers and letters) compared to the simpler Trail A (which has letters only).

Two children also had significant spelling deficits—again severe enough to fall below the normal range for their age—on the spelling scale of the Wide Range Achievement Test-Revised (WRAT-R). One of these two also had significant deficits on the reading scale of this test, and the other on the arithmetic scale.

Having “significant deficits” or falling “below the normal range” on these tests implies a truly serious difficulty—considerably more severe than just scoring “below average.” In fact it means that the children performed 2 standard deviations below the average, i.e. that their scores fell in the bottom 2.5% of children their age (i.e. below the 3rd percentile)—quite startling given their normal IQs.

On the spelling achievement test used in this study, the “average score” nationwide for this age group is 100; the “normal range” is from 85 to 115. In this study the two children who scored “below the normal range” had scores of 70 and 80. Similarly, on the Digit Span test, the “average” number of digits recalled is 12.3; one child in this study was able to recall only half as many—6, while another could recall only 9. The investigators emphasize that performing so poorly on such specific tests is highly unusual in children with average intelligence. Usually

“Neurocognitive abnormalities in children after classic manifestations of Lyme disease,”

by **Bradley J. Bloom, MD; Patricia M. Wyckoff, PhD; H. Cody Meissner, MD and Allen C. Steere, MD. [3]**

Bloom, Wyckoff, Meissner and Steere describe a case series of 5 children who were referred to Tufts/ New England Medical Center between 1988 and 1993 specifically for evaluation of Lyme disease of the central nervous system (brain or spinal cord). Mostly, like Susan and David, they were referred because of declining school performance.

As a prerequisite for evaluation, these children, ages 8 to 15, all had known Lyme disease with central nervous system *B. burgdorferi* infection proven by strict CDC criteria. Specifically: 1) All had had “classic” signs of early Lyme disease (some combination of EM, cranial nerve palsies, or Lyme arthritis) that preceded their central nervous system symptoms. 2) All then developed behavioral changes, forgetfulness, or declining school performance that suggested cognitive problems. 3) All had Lyme disease blood tests that were positive by the CDC’s rigid two-tier criteria (including both positive IgG ELISA and IgG Western blots with at least 5 bands). And 4) all had spinal taps that showed that IgG antibodies against *B. burgdorferi* had been produced within their CNS. (Their spinal fluid showed “intrathecal production” of IgG antibodies to

B. burgdorferi by an IgG CSF:serum antibody index of more than 1.0, meaning there were more *B. burgdorferi* antibodies in cerebrospinal fluid than in blood).

Neuropsychological test results

On neuropsychological testing, all 5 of the children who met the selection criteria were found to have normal or above-normal IQs, but every one of them performed significantly below their age level on at least two kinds of neuropsychological tests.

Their most consistent performance problems—seen in all 5—appeared when they were tested on tasks involving strings or sequences of information they either listened to (4 children) or looked at (3 children), or both (2 children). Specifically, they showed substantial trouble on one or more of the following tasks:

1) following spoken directions that had multiple steps 2) repeating back a series of spoken numbers (recalling shorter number sequences than expected for their age on the Digit Span test) 3) performing oral arithmetic problems 4) identifying similar pairs of sequential rhythmic beats (Seashore Rhythm Test)

The investigators call the above

they are found only in association with other cognitive deficits or in children with learning disabilities. And all these children did have at least average intelligence, confirmed by their scores on all subsections of IQ tests for intellectual functioning (Wechsler Intelligence Scale for Children-Revised III—the WISC-R), which were uniformly within normal limits.

Their reading comprehension scores were also normal (on the Gates-MacIntie Reading Test) in every case, and their teachers all reported that their school work had been at average or above-average levels before they got Lyme disease, with no suggestions of previous difficulties.

Surprisingly, given that most of these children had been described as forgetful, neuropsychological tests for memory were able to detect a memory deficit in only one boy, and it was slight. When asked to recall words after a short delay, he recalled only 7 words instead of the 8 to 12 words defining the normal range for his age (Children’s Version of the California Verbal Learning Test). He and the others performed within the normal range on two other tests of memory as well—the memory subsets of the Stanford Binet Intelligence Scale Fourth Edition and the Weschler Memory Scale.

Symptom histories

What symptoms or signs had aroused suspicion of possible brain infections in these children, prompting their extensive evaluations at Tufts? Nearly all (4/5), like David and Susan, had shown a decline in school performance after their first signs of Lyme disease, although this was dramatic in only one child. In the others, according to the investigators, the change in their school work was “more subtle, such as increased difficulty following directions.” They seemed forgetful, failing to remember names or forgetting to do tasks. Two reported headaches. Two showed signs of

fatigue, including sleeping more at night or falling asleep in the afternoons. Two had behavioral problems, described as “moodiness, emotional lability, irritability or becoming easily frustrated;” one adolescent girl had become depressed.

As noted above, all had first shown “classic” signs of early Lyme disease (those recognized by the CDC). Three children then developed symptoms suggesting CNS infection (headache, back pain, fatigue, forgetfulness, behavior changes or new difficulties with school work) within a month or two. Only one had neck stiffness, a symptom suggestive of meningitis, and the stiffness had been only mild and transient. The evaluations for *B. burgdorferi* brain infection in these 3 children were done at 2, 3 and 5 months following their first symptoms. By then 2 had already had their first courses of antibiotics (10 days of Pen V in one case, 16 days of IV ceftriaxone in the other).

Two other children, both girls, were evaluated later in the course of disease—one at 11 months and one at 9 years after their first signs of Lyme disease. In the meantime both had had intermittent episodes of arthritis and neurocognitive problems that had affected their school work. They also had developed partial complex seizures which were unusually obvious: one had staring spells accompanied by lip-smacking, and the other had staring spells accompanied by head-shaking that were sometimes followed by generalized tonic-clonic seizures. Their EEGs showed changes typical of seizures.

The girl evaluated at 11 months post-EM had been treated with 4 days of IV ceftriaxone plus 30 days of amoxicillin prior to her neuropsychological evaluation and subsequent re-treatment. The girl evaluated 9 years after her first signs of infection had never noticed a rash; her only early symptom had been a flu-like illness at age 6. Joint swelling

developed months later, and her neurocognitive symptoms, recurrent arthritis episodes and seizures had developed about 2 years after that; she was treated with two 2-week courses of IV ceftriaxone. When evaluated for this study 7 years later, at age 15, her seizures and neurocognitive symptoms persisted, she had developed headaches and fatigue, and her school work had worsened. She also had developed emotional problems like David’s: her neuropsychological tests revealed low self-esteem and depression (on the Piers-Harris Self Concept Scale) as well as self-reported “behavioral abnormalities” (on the Achenbach Child Behavior Checklist or Youth Self Report).

Treatment histories and results

Four of the children had received antibiotics prior to their neuropsychological and cerebrospinal fluid evaluations—2 within 5 months of their first signs of Lyme disease—but typically the treatment course had been brief (one month of oral amoxicillin, or 2 weeks or less of IV antibiotics). Otherwise there is no clear pattern in their histories to suggest what kinds or durations of antibiotic treatment would have prevented the development of neurocognitive problems.

After their evaluations proved positive (both for intrathecaly produced *B. burgdorferi* antibodies and for neuropsychological deficits), all 5 children received re-treatment with either 2 or 4 additional weeks of IV ceftriaxone (Those who entered the study in later years benefitted from Tufts’ gradual realization that shorter courses of antibiotics resulted in lower rates of improvement and more relapses.)

One, the girl whose neuropsychological evaluation came 9 years after her initial Lyme symptoms, then became unavailable for followup.

The 4 children who remained in the study all clearly improved, although slowly and gradually over

months. Neuropsychological reevaluations after treatment documented significant improvement in every one of these children. Two returned to or surpassed their pre-Lyme level of school performance, and one boy treated with a 2-week course of IV ceftriaxone improved only transiently, then relapsed and was treated again with a 4-week course of IV ceftriaxone, once again improving. Still, 3 children continued to have problems after treatment. Repeat neuropsychological testing on 2 children, 1 to 1 1/2 years after their re-treatment, again documented significant “auditory sequential processing” deficits in both. The girl first evaluated at 11 months first improved, as documented on post-treatment neuropsychological testing, then had recurrence of intermittent seizures and headaches.

The 4 children who had remained in the study were contacted by telephone 2 to 7 years later (in 1995). At that time 3 of the 4 reported that they were still having difficulties following spoken directions. They had learned to compensate by using written lists—a tactic often used by adults with chronic Lyme encephalopathy as well.

Apparently none were given further treatment.

What caused the children’s deficits?

Bloom, Steere and their colleagues believe that the cognitive difficulties in the children they studied resulted from direct invasion of the brain by Lyme spirochetes rather than from a remote action of infection in the body or some sort of delayed immune reaction.

The children developed their cognitive symptoms only after well-known “classic” symptoms of Lyme disease, with confirmatory blood tests and spinal tap results (the CSF:serum *B. burgdorferi* IgG antibody index) that proved that at some point spirochetes had invaded their brains. But, as the investigators note, even the CSF:serum index doesn’t prove

continuing infection in the brain by living spirochetes; it remains possible that deficits resulted from “postinfectious phenomena.”

The best evidence that spirochetes remained in the children’s brains, that “Lyme encephalopathy may sometimes result from active spirochetal infection,” they argue, was the children’s “gradual, sustained improvement in symptoms and test results after 2- or 4-week courses of intravenous antibiotic therapy.”

Like Fallon and his colleagues,

the Tuft investigators note the similarity between *B. burgdorferi* and syphilis. They think it most likely that, “as happens sometimes with another spirochetal disease, syphilis,” *B. burgdorferi* spirochetes had spread to the brain during the children’s acute Lyme infection and, even after antibiotic treatment, remained there as a “low-grade latent or active infection” which was continuing to cause changes in their brain functions as well as production of the antibodies seen in their spinal fluid.

Opinion

“We know some, but we don’t know enough.”

by Jean Hubbard

The similarities between the stories of Susan and David and the children studied at Tufts are too striking to be ignored, especially since their paths to diagnosis were so different and their cognitive gains after antibiotic treatment and re-treatment so profound.

The Tufts study, with its detailed documentation that children 1) first displayed CDC-approved and easily visible Lyme disease signs (EM, facial palsy, arthritis) that were treated with antibiotics, 2) then developed fairly obvious neurocognitive symptoms, 3) still had serologies that met CDC diagnostic criteria for late Lyme disease (less likely after early antibiotics), 4) still had laboratory evidence that spirochetes had invaded their brains (also less likely after early antibiotics), 5) then demonstrated a shared unusual pattern of neuropsychological test deficits, and 6) then in each case improved on neuropsychological testing after antibiotic treatment, has proven that Lyme disease evolved

into treatable Lyme encephalopathy in those children, just as it can in adults.

Two to seven years after re-treatment, the three children who “told of continued difficulty following verbal directions” certainly had Lyme encephalopathy; in fact they had what in adults is now called “chronic” Lyme encephalopathy. Unfortunately we don’t know whether they would have improved further with more antibiotics.

Symptoms of Lyme disease and immune responses to the spirochete don’t always evolve so tidily, however, and Fallon and his coauthors have taken the urgently needed next step, showing that Lyme encephalopathy can also occur in children who don’t quite meet such restrictive diagnostic criteria. Susan and David weren’t lucky enough to have CDC-approved “classic” signs of early Lyme disease—EM, facial palsy, etc.—before they developed persistent cognitive problems. David didn’t have a positive Lyme ELISA, and his Western blot was one band

shy of the required CDC number of five. But could anyone argue he should not have received the antibiotics that enabled him to gain back 22 IQ points, his health, his energy and his self-confidence?

Susan and David were able to obtain the help they needed, and able to return to being the bright children they once were, only because they encountered physicians whose eyes and ears remained open to less obvious symptoms and laboratory findings which—while not yet designated “classic”—are known to be common in adult Lyme encephalopathy. Their physicians were willing to seek additional information from neuropsychological tests, SPECT scans and Western blots, and courageous enough to try longer and even continuing courses of antibiotics. For these two children at least, their doctors’ courage paid off in cognitive recovery that seems to have been even more dramatic than that experienced by the Tufts children.

We don’t know how often encephalopathy develops in children with Lyme. The Tufts group reports that 14% of all children seen there for evaluation of symptoms of late Lyme disease during the years of their study (86 children between 1988 and 1993) had been referred because of “neurocognitive symptoms associated with or after classic manifestations of Lyme disease.” This seems a substantial percentage to be seen in a rheumatology clinic specifically famous for its expertise in Lyme arthritis [9], but we can’t know if they all had treatable cognitive problems because more than half weren’t further evaluated or re-treated. In all but one case this was because they didn’t meet the study’s restrictive diagnostic criteria.

Unrealistic diagnostic criteria clearly are a major obstacle to the diagnosis of Lyme encephalopathy in children. It seems likely, though, that an even bigger obstacle is that few parents—except those who experience Lyme encephalopathy them-

selves—recognize its symptoms.

In fact brain disturbances—encephalopathies—in general seem to be difficult to recognize in children, by both parents and pediatricians. Several decades ago, from the 60s through the 80s, a virulent epidemic of *Hemophilus influenzae type B* infection caused a very severe meningitis in young children that could sometimes “strike like lightning.” It killed between 3% and 8% of those infected. Children who lived through it sometimes had

All of these children were said to be totally normal by their parents, their teachers and their friends. Their doctors too thought they had completely recovered.

obvious problems after the infection had subsided—hearing loss, mental retardation, blindness, paralysis and seizures—but until 1972 it was thought that about half of them recovered completely [10].

That year pediatrician Sarah Sells used psychological testing to study a small group of “normal” survivors of septic meningitis—25 children between the ages of six and ten who had had documented meningitis (mostly *H. influenzae*, a few with meningococcal or pneumococcal meningitis) before they were four years old. All of these children were said to be totally normal by their parents, their teachers and their friends. Their doctors too thought they had completely recovered. However, when compared with a control group of children *without* a history of meningitis (from the same classroom and matched for age, sex and family income), the children who *had* had meningitis performed at lower levels on tests of “knowledge of their school work” (probably

achievement tests), language development, visual-perceptual development and instructional receptivity. [10,11]

Their school records showed that, as a group, they had “lower scholastic ratings, read at a lower reading level and a slower rate” than their classmates, and that they had “uneven academic profiles,” although “these learning problems were not previously recognized.” They also had lower ratings on “motivation, attentiveness, gait and fine and gross motor coordination,” [10] Other researchers found similar problems in apparently normal post-meningitis children; average IQs were lower, for example. Again—Dr. Sells repeats it so I will—these children were all “considered to be normal by parents, physicians, teachers and peers.”

Septic bacterial meningitis causes a much more intense meningitis than is usually the case with Lyme disease [12], which doctors call an “insidious” or “insidious” infection [13]. Organisms reach high densities and can be cultured from both blood and cerebrospinal fluid (CSF) with ease [14], unlike *B. burgdorferi*, which is low-density in humans and rarely culturable from CSF. Cognitive disturbances in children who survived *H. influenzae-b* infection apparently were also more severe: they had lower reading levels and lower IQs, while the children described in the Fallon and Bloom/Steere papers had normal or above-normal IQs and appropriate reading levels.

It shouldn’t surprise anyone, then, if most parents—and even many doctors—fail to recognize symptoms of Lyme encephalopathy in the children they care for. Lyme encephalopathy symptoms are called “subtle” by all experts. Most are invisible. Certainly David would never have received the thorough evaluation that led to his treatment and recovery if his mother hadn’t suffered from it herself.

What about children whose

parents don't have that awareness? There are probably many because children are infected so much more often than adults. What will parents need to learn in order either to suspect Lyme encephalopathy in their children and push for good evaluations, or to be assured that there's no reason for concern? Are there patterns in the symptoms experienced by Susan, David and the Tufts children, and in the results of their tests, that can provide clues?

Neuropsychiatric vs. neurocognitive

Fallon and his coauthors call disturbances like those David and Susan suffered "neuropsychiatric Lyme disease," a term that emphasizes that they had brain-related, or neurally-mediated, emotional or behavioral problems in addition to their cognitive and attentional problems, but their cognitive symptoms and neuropsychological test deficits were much like those seen in the Tufts children.

Bloom, Steere and their coinvestigators at Tufts call the problems shown by the children they studied "neurocognitive," emphasizing aspects of the encephalopathy syndrome related to thinking, learning, memory, or mental processing, but a few of the children they evaluated showed emotional and behavioral problems as well. The adolescent girl in their study, for example, the only child whose symptoms had lasted longer than a year before evaluation, had developed both depression and low self-esteem very similar to David's.

Cognitive difficulties combined with mood and emotional disturbances are typical of generalized, diffuse encephalopathies, whatever their cause (there are many besides Lyme—e.g. closed-head injuries, drug abuse, multiple sclerosis, and some other infections and toxins that get into the CNS). The brain, after all, is the seat of both domains, and encephalopathy just means something is wrong with the brain.

The problems these children showed in their everyday lives don't look much like signs of illness—Trouble doing school work? Declining grades? Being inconsistent in day-to-day work? Not paying attention? Not following directions? Doing sloppy, disorganized homework? Often losing homework? Forgetting to do chores? Being irritable or depressed?

These behaviors look more like just not trying, or maybe like having

Children with Lyme may try to hide what's going on, but they can't control it. David wasn't lazy and incompetent, he had been sick.

a bad attitude. Even worse, most Lyme symptoms change from day to day, or even minute to minute. They may disappear altogether for long periods of time before returning. It takes great understanding not to become annoyed when children show such inconsistency in how they handle their school work and home chores, how responsive they are and how well they remember what you say. It's hard not to believe everything would clear up if they'd just "pay attention" or "try harder."

But these seven children with Lyme disease had profound neuropsychological test deficits that explain their behaviors. From everything we know about Lyme encephalopathy, they are symptoms of the brain infection, not of the child's attitude. Children with Lyme may try to hide what's going on, but they can't control it. David wasn't lazy and incompetent, he had been sick.

Formal testing, for example, showed that it was hard for the Tufts children to follow spoken directions that had multiple steps. They didn't

do well on tasks that required "sequential processing" of information they heard or saw. And this was true even when the tasks were interesting ones, game-like tasks children usually enjoy, like listening to rhythms, or connecting a series of points to make a trail. Yet in the same testing sessions these children did *not* have trouble answering questions about the meaning of what they were reading, nor those on tests of verbal IQ. Clearly they *were* trying. And they were also smart.

Why did they do well on some tasks and not others? The Tufts investigators said the specific deficits they found were "uncommon," usually seen only in children with learning disabilities. But the Lyme children weren't learning-disabled. Looking at the pattern of their test results we see: All did well on IQ tests and reading comprehension tests, some did badly on tests of spelling and oral arithmetic, and all did very poorly on tests of either auditory or visual sequential processing. Similarly, Susan and David tested high on IQ tests (Susan's verbal IQ was 132) but poorly on tests of visual motor planning, visual-spatial memory and speed of mental processing.

This turns out to be a significant pattern. According to psychologist Felice Tager [4], the tests the children did well on—reading comprehension, verbal IQ, and vocabulary—"tend to be less susceptible to subtle brain dysfunction" than other mental skills. As a result, those tests can give an estimate of how intelligent and capable a child was before becoming ill.

Neuropsychologists know this well. When they're looking for evidence of *acquired* mental impairment, they use scores on "over-learned" skills—vocabulary and reading comprehension—as well as IQ tests as baseline measures to indicate a patient's pre-illness mental capacity. Mental impairments are likely to have been acquired (through

disease or injury), rather than to have existed all along, only if the patient's performance on tests of specific brain functions is significantly lower than would be expected given their estimated baseline intelligence [5,15]. The pattern of test results seen in the children with Lyme encephalopathy showed that their deficits were acquired.

Evidently it's the pattern that counts. Dr. Tager adds that there are other indicators of how well a child had been doing before a Lyme infection: report cards, teacher assessments and standardized achievement tests from before the illness [4]. For Susan, David and the Tufts children, it was teacher reports and school grades that indicated the suspicious "change for the worse" that allowed the children to obtain such in-depth evaluations. They provided the evidence that these children were, to use Dr. Fallon's phrase, "bright children who began not to do so well." [1]

Could the standardized achievement tests Dr. Tager mentioned provide the same kind of information? So far no one has looked at the long-term patterns of achievement test results in children with Lyme disease—a study we hope will be done soon—but it seems a promising avenue for parents of school-age children to explore. Most school districts now test children regularly, often yearly, on nationally standardized achievement tests. Probably all have scales for vocabulary and reading comprehension in addition to scales for specific academic skills, and parents have ready access to their child's scores, expressed as percentile rankings comparing each child to other children in the same grade. These commercially developed tests, usually administered by teachers, are almost surely clumsier and less reliable than the standardized achievement tests used by professional neuropsychologists, but they give information few teachers or report cards can provide and might reveal patterns that could give

parents important clues.

Given what we've learned above, it seems likely that if children achieved impressively higher percentiles on vocabulary and reading comprehension scales than they achieved on scales for specific academic skills, there would be justification for further evaluation—although of course Lyme disease isn't the only thing that could cause that kind of pattern.

Children who had Lyme disease that had gone undetected for years might also show patterns of change over time, although we don't know yet what they would be.

What academic skills might be disturbed in children with Lyme encephalopathy? Based on the little information we have now, spelling looks like the most likely candidate.

Problems involving language

Spelling: Two of the five Tufts children scored below their grade level—one way below—on the

spelling achievement test used in that study. Several years ago pediatric neurologist Dorothy Pietrucha of New Jersey, who has seen more than a thousand children with Lyme disease, mostly because of neurologic problems, told science writer Denise Lang that many had "difficulty spelling words they could spell before the illness." [16] Dr. Tager says that some of the children with late Lyme disease she and Dr. Fallon are seeing also report having difficulties on spelling tests, although we don't know how many [4]. (They also report auditory tracking problems and dyslexic-type errors).

No one knows why spelling is difficult for people with Lyme encephalopathy, but even some adults with chronic Lyme experience it. Superficially at least, spelling involves handling sequences of information: one has to arrange each letter in a word in its correct sequence, and children who are just learning to spell have to be able to

Continued on page 46

Memorial donations given to LDRC

A donation in memory of Freida Gaultney was given to the LDRC by Kathy Hewko. Gaultney, who suffered from complications of Lyme disease, died at age 71 on December 28, 1998 at Petaluma Valley Hospital in Sonoma County, California. She had been active in the Lutheran Church and a member of the Christian Women's Club. She was an accomplished china painter, but her painting and other activities were curtailed after she caught Lyme disease.

According to Jim, her husband of nearly 55 years, she had Lyme disease long before people knew what Lyme disease was.

"It crippled the quality of her life, and it was more than six years before she had a diagnosis," he said. "Undiagnosed Lyme disease does much damage to the body."

The Gaultneys attended the Sonoma Lyme Disease Support Group from 1991 to 1996.

A donation in memory of Charles Hahn, husband of Barbara, of Walnut Creek, California, was given to the LDRC by Andy, Marian, and Gerry Hansen, to help support the LDRC's efforts in the prevention of Lyme disease.

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discriminate between similar auditory patterns, remembering the sound of the word and the sounds of each letter while putting them all together in the right sequence.

On the other hand, and perhaps more importantly, the brain has evolved very special systems and specific structures to handle language. It's possible *B. burgdorferi* can somehow preferentially attack them or that they're more susceptible to attack.

Importantly, this is a specific skill that parents can observe by teaching children how to spell new words, helping with their homework, etc. Does it seem a child's poor spelling is way out of line with his other skills? Is his spelling much worse at some times than others? How does he act when doing spelling homework? And, conveniently, most standardized achievement tests used by elementary schools contain spelling scales starting at about the second grade.

Dyslexic-type errors: Dr. Tager says dyslexic-type errors are reported by some of the children seeing Dr. Fallon for evaluation of possible Lyme encephalopathy. Again, we don't know how many of them do it, how often, or the most common types. Dyslexic-type errors aren't the same as dyslexia itself, which is a developmental reading disability. In Lyme patients these errors are just ones that are also common in dyslexia and typically involve some sort of reversal of language elements. Adults with Lyme encephalopathy, including very eloquent and literate adults, may reverse the order of words when they're talking, or may reverse letters within words—it happens both when writing and when talking. Obviously this interferes with spelling, although dyslexic-type errors aren't the only kind of spelling error Lyme patients make, just a very common one.

Dyslexic-type errors also happen with numbers, so that now and then—especially early in infection or

during what they're sure are relapses—patients will have a hard time writing down phone numbers. One can imagine that this would hamper children trying to write down dictated arithmetic problems, or even those displayed on a blackboard, but so far we have no specific information about how it affects their school work or achievement tests.

Young children with Lyme, even after they've learned to reliably print letters correctly, may suddenly start reversing letters right-to-left, so that they print d instead of b, or q instead of p. Some may have trouble with digits as well, writing a 2 when they meant to write a 5 or vice versa.

Right-left confusion: In fact there's evidence that dyslexia, and quite likely dyslexic-type errors, involve some disturbance of the brain's systems for helping us distinguish left and right. Left-right confusion can show up in non-language activities too. Young children with Lyme encephalopathy who seem quite clear about telling left from right may suddenly no longer be able to; they may put their shoes on the wrong feet, forget which hand is their right (or left) one, or turn the wrong way when told where to look for something or how to go somewhere. Even adults with Lyme encephalopathy have been known to put their shoes on the wrong feet.

Word-finding difficulties: Susan and David both had word-finding problems, and the Tufts investigators report that some of the children they studied failed to remember names. David's trouble in finding the words he wanted had grown to the point where sometimes he couldn't finish his sentences. As Dr. Fallon says [1], "They know the word they want to say but they can't pull it out."

It's well known that many adults with Lyme encephalopathy have word-finding difficulties, since they often inadvertently demonstrate them during interviews with their doctors. Sometimes it becomes a serious problem, making it hard to explain

anything or ask for what we want. Most of us can tell that it makes us sound "slow." Some people use compensatory tactics, like making lists of words and related notes before important phone calls.

In children word-finding difficulties are particularly noticeable when they can't remember number-names. One 5 1/2-year-old girl with Lyme—who had been proudly counting to 100 since she was 3—was trying to tell someone about an older friend who was 12, when she stopped, frowned, and asked "what's that number that comes after 11?" [17]

How else might word-finding problems appear in a child? Pauses occurring for no apparent reason while they're talking might suggest they're waiting to remember the word they want. Their eyes might shift away from their listener while they're searching for the word. And of course sometimes they might not find it and the sentence will trail off into silence. Or they might give up on that word and try another way of getting their point across: trying to remember the word "observatory," for example, they might say, "you know, the star place."

Younger children might actually mention they're waiting to remember the word, or ask you to tell them what they mean, but older children, who tend to be less forthcoming about things that embarrass them—and it does get to be embarrassing—might need to be asked what's going on when they stop in the middle of what they're saying.

Many of us who have this problem have learned that people begin trying to help us out with a word. If a parent or teacher often finds they're tempted to supply a child with a word when they pause inexplicably while speaking, maybe it's a clue the child is having trouble finding words more often than feels natural. One can imagine that word-finding difficulties would influence many activities in a child's life—perhaps they'll be less active in

school discussions, less often raise their hands to answer questions that are asked, etc, but this is just surmise.

It seems very likely, however, that eventually, if Lyme encephalopathy remains untreated in children, word-finding difficulties would cause a decrease in their vocabulary, and a decline from their earlier percentiles on vocabulary scales of standardized achievement tests. Maybe even on tests of their verbal IQ. Vocabulary, reading comprehension and IQ are only “relatively susceptible”—not entirely resistant—to the effects of brain injuries and diseases. In fact exactly this kind of pattern—slight declines on vocabulary, reading comprehension and/or IQ tests with much more dramatic declines on other specific cognitive tasks—has been seen in adults after astrocytic tumors [18] and asymptomatic HIV infection [19].

Hopefully, now that children’s Lyme encephalopathy is finally being taken seriously, we’ll learn more useful examples of how children display this symptom, and how it affects them, so it can be more easily recognized in children and they can be treated before such declines would occur.

Odd misuse of words - paraphasias: Lyme encephalopathy affects language in another curious way—using a wrong word that is oddly related to the word one meant. The neurologists’ name for this is “paraphasia.” These oddities are hard to explain without examples, so here are a few:

A Lyme patient might say “map” for “calendar,” or “crutches” for “chopsticks.” [20] A woman wanting to say “I’m putting the dinner in the microwave” instead said, “I’m putting the dinner in the radiator.” As Dr. Fallon comments, “it’s an odd misuse of words—wrong, but it’s kind of right because it’s hot.”[1]

A Lyme patient on the Internet Lyme disease newsgroup posted:

“How about all that word-switching stuff? I’m asking for paper plates when I need paper clips, say please close the light when it should have been the blinds. I’ve referred to cargo tie-downs as rubber bands ... And here’s a good one ... I’m a big fan of football and while watching the games last year I found myself calling their helmets ‘hoods.’” [21]

A special type of paraphasia, called a “literal paraphasia,” is when a letter or sound from one word intrudes into nearby words, and Lyme patients do this too. For example one child repeated the phrase “Let’s park in bark” several times, then commented, “I keep saying that.” (She meant “park in back.”) [22].

Lyme patients have learned that these word oddities all make the listener laugh, which can be a clue that a paraphasia has occurred. But there’s a reason why neurologist have troubled to classify and name the separate types—they take them seriously as potential indicators of a disturbance in the brain.

* * *

There are many more symptoms to talk about, but this list is already too long. In the next issue of **the Lyme Times** we’ll continue this survey of cognitive symptoms, starting with a look at the attention problems that are so common in children’s Lyme encephalopathy, then look at emotional manifestations and finally some of the physical symptoms.

Parents wanting more information about symptoms of children’s Lyme encephalopathy in the meantime might review the symptoms of David, Susan and the Tufts children listed earlier in this issue. We also strongly recommend two thoughtful and informative chapters from Denise Lang’s book, **Coping with Lyme Disease**—chapter 7 on “The Young Child” and chapter 8 on “The Teenager.” [16]

We believe examples of how

children display symptoms of Lyme encephalopathy are the best way to help parents recognize them, but few have been published. If any parents of children with Lyme, or the children themselves, are willing to share stories of children’s Lyme symptoms, we would warmly welcome them. Send letters to Jean Hubbard c/o LDRC, P.O. Box 707, Weaverville, CA 96093-0707, or email: jeanhub@earthlink.net.

... to be continued

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* * *

"Since the days of revelation, in fact, the same four corrupting errors have been made over and over again: submission to faulty and unworthy authority; submission to what it was customary to believe; submission to the prejudices of the mob; and worst of all, concealment of ignorance by a false show of unheld knowledge, for no better reason than pride."

-Roger Bacon

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The Lyme Disease Resource Center would like children's doctors to read these these important, peer-reviewed publications on children's Lyme encephalopathy (Fallon et al's article on "Underdiagnosis of neuropsychiatric Lyme disease in children and adults" and Bloom/Steere et al's article on "Neurocognitive abnormalities in children after classic manifestations of Lyme disease").

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