



the

Lyme Times

NUMBER 35

Education, Support, Advocacy, Research

FALL 2003

LDA News

Time for Lyme gala supports Columbia Research Center

by Ellie Becker and Melissa Diamond

Greenwich, Conn. - More than 400 supporters had a great time while helping to raise close to \$450,000.00 to help fight Lyme disease at the 1970's disco-themed Time for Lyme® at the Lymelight, held in May at the Greenwich Hyatt. The annual gala is sponsored by The Greenwich Lyme Disease Task Force, (GLDTF), a Lyme disease research, education and advocacy network. Holding the event in the spring underscores the beginning of the tick season.

This year's event took on special significance when GLDTF co-presidents Diane Blanchard and

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Inside...

Join LDRC's New National Survey Program!
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Rhode Island passes bill mandating insurance coverage

Providence - An hour before midnight on July 2, the Rhode Island General Assembly passed a groundbreaking bill requiring health insurance companies to cover long-term intravenous antibiotic treatment for Lyme-disease patients, beginning in 2004. The bill's passage marks a victory for the Lyme Disease Association, Rhode Island Chapter (LDARIC), whose co-chairs Lisa Larisa and Julie Merola, along with support group leader Janice Dey, were present when it passed. Governor Donald Carcieri signed the bill, Lyme Disease Diagnosis and Treatment Act (H6136 SubA/S1173), on July 7. The vote followed testimony before the committee by LDARIC, patients and a physician advocating for the passage of the bill.

The state's leading health insur-

ance companies, Blue Cross & Blue Shield of Rhode Island and UnitedHealthcare of New England, opposed the bill, saying there is no evidence that long-term treatment is effective.

Rep. Raymond E. Gallison Jr., D-Bristol, one of the bill's sponsors, told the Providence Journal that the bill almost fell apart during the last week as insurance company representatives proposed amendments that would limit the length of treatment to 12 weeks and narrow the type of doctors who could prescribe intravenous antibiotics. Covered treatments typically last four to six weeks. Promoters agreed to a compromise to enable the bill to pass with no amendments - a sunset provision will cause the bill will expire at the end of

See Rhode Island Bill on page 32

Patients win major victory against HMOs

Court allows suit for wrongful denial of care

Patients have just won a monumental victory they have been seeking for so long - the ability to sue their HMOs when the companies deny recommended treatment. In the past, the federal law, ERISA, had thrown

these claims out of court, leaving patients and their families no right to hold HMOs responsible for their actions, regardless of the harm they caused. But in a recent decision

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From the Editor

Dear Readers,

In terms of size, this issue is another record-breaker at 64 pages. It really is our intention to produce smaller, more frequent Lyme Times, but it happens that the longer we wait, the larger it grows. This year our planned Summer issue was preempted by a collaborative effort that resulted in a new lay journal, **EuroLyme Times**, which we created with British and German Lyme activists and which was distributed only in Europe. Issue #1 will eventually be accessible on our lymetimes.org website. We do not plan another issue until we (and they) have a surplus of volunteer time, and that is usually in short supply here as well as there. But if you have friends or relatives abroad, please tell them about this new resource. The Europeans are also organizing medical conferences to educate their healthcare professionals, and setting up patient support groups. There are several active internet discussion groups, too. We are pleased to have been able to assist them on this project.

Meantime, on the home front, our plates are full. Legislative efforts were successful in Rhode Island (*page 1*) and are under way in California, New York, and Washington, DC (*pages 44, 45*). In our next issue we should have an update of our new California reporting bill. People are organizing new support and advocacy groups in Oregon (*page 39*) and North Carolina

(*page 41*); people are raising money for research in Connecticut, New Jersey, and Illinois (*pages 1, 34, 39*). Newsletters are being mailed regularly from Michigan, Kansas, New York, Connecticut, Ontario (Canada), and of course, California. The Internet facilitates communication and information-sharing on a multiplicity of chat groups, E-lists, and websites. It is an exciting time to get involved. We encourage you to seek out and support your local support group. If there is no group near you, start one. It can be as simple as deciding to meet at a restaurant and putting a notice in the newspaper. State-wide groups like LDRC depend on active support groups at the local level to boost our numbers and to make our voices heard in our legislatures.

On a somber note, one of our dear Lyme friends and a long-time ally of Lyme patients died in May after a long and courageous battle with cancer (*see page 4*). Betty Gross had amazing spirit and optimism through all her ups and downs. Many people will miss her terribly. Everyone loved the idea for an award, which came from Massachusetts Lyme Coalition director John Coughlan several months before Betty died. Since we were too late to give it to Betty, we named it for her instead. If you would like to nominate a patient leader for this special award, please write to us.

Until next time, be well.

Phyllis Mervine, Editor

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

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Number 35**Editorial**

Investigator bias rampant in medical research

In the past year major medical journals and other media have addressed the issue of conflict of interest in industry-funded research. Studies have confirmed that funding sources have a perfidious effect on the outcome of so-called "scientific" studies.

"Commercial funding," said the Los Angeles Times, "once anathema to ivory-tower academics, has become the lifeblood of biomedical research, fostered by federal laws and regulatory changes since 1980 that give scientists and schools more freedom to profit from work once considered in the public domain." A survey of 47 of the most influential biomedical journals showed that fewer than half had disclosure policies.

A recent review article published in JAMA showed that industry-sponsored research is 3.6 times more likely to produce results favorable to the company that helped pay for it. The authors pointed out that financial incentives are not the sole factor influencing investigators' professional judgment. Other pressures include desire for professional recognition and the need to compete successfully for research funds.

The most important article was "Investigator bias and false positive findings in medical research," published by Elsevier Science Ltd. Authors Edzard Ernst and Peter H. Canter who found that "bias is ubiquitous, and medical research is no exception." Investigator bias, which they define as bias resulting from a conflict of interest arising from passionate beliefs held by the investigators, can influence all stages of a research project.

"From the very outset, investigator bias can influence the general attitude towards a research project," they write. "Research is at its best when it tests (or, more precisely, falsifies) hypotheses. The biased researcher, however, has preconceived ideas and is likely to approach a project to 'prove' a point. ... Experimenters have great scope to influence the likelihood that a trial will give a positive or negative result through their choice of outcome measure and design of key features of the research protocol. Perhaps the largest scope for bias exists when the results are evaluated."

Nowhere have we seen this diabolical scenario borne out to more damaging effect than in the published results of the NIH-funded treatment trial conducted at New England Medical Center that currently guide clinical practice in the treatment of chronic Lyme disease, and provide ground for insurance companies to deny treatment to sick people.

Neither do the government agencies designed to protect the public health do their job. A recent UPI report quoted Stephen A. Sheller, a Philadelphia attorney who has sued vaccine makers for what he says were bad vaccines. "The CDC is a disgrace," he said. "It is a corrupt organization. The drug companies have them on their payroll."

Before physicians accept the 3-week treatment protocol, we recommend that they seek guidance from the professional association of Lyme disease experts at ILADS who are not trading their patients' lives for lucrative contracts and professional acclaim. Too many lives are at risk, including the most vulnerable in our society - children and the chronically ill and disabled.

Page 3

Heroes

Distinguished Patient Leader Award honors Betty Gross

Ukiah, California – The Lyme Disease Resource Center, an affiliate of the New Jersey-based Lyme Disease Association, has announced a new award to be given to a deserving volunteer Lyme disease patient advocate or support group leader. The **Betty Gross Distinguished Patient Leader Award** is named to honor the Irvington, NY, resident who died of cancer in May, 2003. It will be awarded annually to a person who has demonstrated leadership, dedication, compassion, and cooperation with others.

Betty always worked with patients and patient leaders from coast to coast. In the mid-eighties, after her own bout with Lyme disease, she and California Lyme patient and writer Suzanne Smith gathered and exchanged information and names, addresses, and telephone numbers.

“Before the advent of the Internet, before regional support groups were created,” Smith reminisced, “Betty painstakingly wove together a loose group of contacts across the USA. She was the glue among literally thousands of people and hundreds of organizations including researchers, doctors, patients and the press.” Smith delivered a eulogy at Betty’s memorial service on Sunday, Sept. 14.

In 1988, Betty started the Westchester Lyme Disease Support Group, which still offers monthly support group meetings. . In 1990 she helped start one of the first Lyme disease newsletters, “Lyme Letter,” now in its thirteenth volume. The newsletter became “L&E Newsletter” in 1995 after the discovery that tick-borne ehrlichiosis could infect humans.

Connecticut video-maker Dolly Curtis, who herself has created and

distributed many educational videos on Lyme disease, is one of many who cherished regular phone calls with Betty. She called her a “champion who gave of herself through heartfelt advice to thousands of people she never knew.” Another patient recalled her kindness and the extraordinary lengths Betty would go to to help people. Many remember her snappy

Betty Gross with her husband, Richard, at the time of their 50th anniversary in October 2002. She died of cancer on May 14 at age 74.



Betty Gross' Memorial Service

A Personal Account

by **Suzanne Mac Donald Fratus**

Tarrytown NY - The last time I had seen her was the fall of 2000. Our last conversation was just 3 weeks before she died. We ended it the way we always do

“God, I don’t want to hang up. But I gotta go,” she said.

“I love you whole bunches,” I replied.

“I love you and miss you like a front tooth,” she quipped.

“OK— I’ll talk to you soon.”

remarks and picturesque speech.

Lyme Disease Resource Center president Phyllis Mervine’s friendship with Betty goes back to the eighties. She credits John Coughlan of the Massachusetts Lyme Coalition, also a longtime friend, for coming up with the idea of an award for Betty. “Everyone was enthusiastic about the idea,” said Mervine. “Unfortunately, we were too late to give the award to Betty, but we hope that by naming the award for her, we will both honor her and establish a high standard for volunteer leaders to aspire to. Betty was an amazing person. We already miss her.”

Throughout these last three years, Betty and I had lived on hope, on prayer, on taking chances. “*Sloan Kettering is the best place for colon cancer treatment,*” she assured me. “*And I have gotten into a state of the art new therapy program using platinum,*” she announced.

I teased her. “*I always knew that you wanted to be platinum— platinum BLONDE!*” She laughed.

The trip to Westchester County Airport was old hat for me by now.

This route had been my annual pilgrimage ever since Dr. Lavoie [*San Francisco Lyme expert - Ed.*] died. On my way to Tarrytown, I stopped in Armonk to see Dr. Liegner. "Are you here for Betty's memorial service?" he asked. "Yes, I'm speaking," I told him. "Well, I'll see you there," he said. "Betty did so much for the Lyme community here. We all miss her a lot." I nodded and waved goodbye.

That evening, I met Betty's best friend for dinner and she gave me a tour of Tarrytown. It was the evening of September 11 and the second anniversary of the attack. American flags, balloons and red white and blue memorial ribbons abound. We wandered down to a park overlooking the Hudson River and sat down on a bench to talk. In the distance lay what remained of the New York City skyline post 9-11.

As the sun set over the Hudson River, it was an extraordinary site. A glowing orange orb sinking into a silver river reflecting the dark shadows and blackened buildings of New York City. When dark came, two bright blue pillars of light illuminated the site where the twin towers had been. I felt my soul adrift in the river of time, momentarily in shock, numbed by grief, trying to find my own purpose and direction.

As the two blue search lights shown into the night sky, they reminded us of the courage and caring of the firefighters, paramedics, police and other people who had given their lives to try to save others. So it is with our doctors, nurses, and support group leaders like Betty Gross. She was driven to make a difference in our lives and she fought against ridicule, personal attack, and incredible odds to save young, innocent lives of Lyme patients.

I remember in particular a story she had told me about a 16-year old girl, a ballet dancer, who had been chosen to dance with the New York City Ballet Company. That child, she told me, got Lyme disease and her life's dreams are being destroyed.

Betty would not put up with that. She fought for peoples' dreams, for their hopes, for their futures. She did so continuously, at great personal sacrifice to her health and well being. She was not afraid to confront authority figures and demand answers, accountability, and *more treatment*.....after all a child's life is at stake here. That was enough to send her on her mission.

Betty burned the candle of her own life at both ends rarely taking time to rest or renew. Time was short, she was always running late, there was always something *just one more little thing* that she just wanted to do

"I've enjoyed a marvelous existence right up to this minute, and would of course want more of it. But whatever turn life takes from here on could not be called 'shortchanging' this girl. Still - I don't know anyone who's in a hurry to wave *au revoir*. Specially when things are looking so promising at this juncture. Keep loving every day. They are all so extraordinary."

Betty Gross
July 2001

for somebody. It gave her pleasure, it gave her purpose, she wouldn't have it any other way. And she was like that with everybody from her own children to doctors and famous Lyme researchers - nobody got anything past Betty. She demanded the best. Every 'i' was dotted, every "t" was crossed. She helped you to figure out what to do, how to do it, how to correct it, how to improve it, where to park, where to sit, what to wear, what to eat and which fork to use when you ate it and she did all of that with her amazing charm and style.

Betty had that amazing ability to be polite without losing sight of her mission and goals. Nobody could pull the wool over her eyes. "Don't think I was born yesterday. Don't think I just fell off the turnip truck," she said.

"That and 10 cents will buy you a cup of coffee." "Now, let's get back to the matter at hand." She kept us on target, focused and moving in the right direction. Nipping at our heels like a lovable little collie, she gently rounded us up and brought us in for the evening staying awake herself to kept watch for wolves. We were safe, Betty was on guard and nobody got past her watchful eyes.

The night before the memorial service, I went to meet Betty's four children—Pat, a TV producer, Carey a psychiatrist, Andrew a realtor and Richard a businessman. I could see and hear little glimpses of Betty in each one of them. Her charm, her wit, her grace, her exquisite sense of timing her sense of humor, her incredible ability to organize complex ideas and events. We gathered together at Carey's home for a dinner—16 friends and family around a table all missing Betty. We talked about the good times, laughed and smiled while we divided up the duties for the next day's event.

The next morning we all met again at Sleepy Hollow High School in Tarrytown. Carey, the doctor, kept saying "I can't believe it. We all picked the same color!" Dusty rose was Betty's favorite and everybody unconsciously chose that color. The signs, the table cloths, the flowers, the napkins were all perfectly done in dusty rose.

Betty's friend Barbara made the most opulent and luxurious floral arrangements in Chinese porcelain vases. Her visual metaphor for Betty's life was a *bountiful harvest* of dusty rose peonies, white hydrangeas, red ginger blossoms, mixed with pomegranates, grapes and various greens. At the end of each seat in the auditorium was a fresh box of Kleenex—just in case.

The auditorium filled quickly with several hundred people. There were the many familiar faces of Polly Murray, Brian Fallon, Ken Liegner, Pat Smith, Pam Weintraub, Mark Kramer mixed with some people that I

had not seen in 15 years! It was the “Whose Who” of the New England Lyme scene.

Eleven speakers took the podium to talk about fond memories and recollections that they had of Betty—as a friend, as a mother, a girl scout leader, a community member and as the spiritual head of the Westchester Lyme Disease Foundation. What shone through the service and all of the words said that day, was Betty’s light, her love and her willingness to give to her fellow human beings.

We laughed, we groaned, we clapped, read poetry and celebrated together over the life of the most wonderful women any of us has ever known. She was one in a million, we all agreed. Speakers recalled the good times, the fond memories, the surprises, the love that Betty gave to us. Over and over, people commented on how Betty attended to every detail. One speaker asked, “Was there any group in Westchester County that Betty Gross did not help?” She was everywhere—girl scouts, the courts, public health, the hospital. “Community” and “extended family” were Betty’s middle names!

Her presence hung in that auditorium and I know that her spirit was loving every word! Carey said. “*Mom would have loved this!*” She was absolutely right. It was a time of recollection, fond memories, and a celebration of a life, 74 years well lived.

Betty’s daughter Pat (who was a producer for BBC) and her friend Mary composed a photographic scrapbook on Power Point to end the program. As the images passed by, we saw, heard, and felt the footsteps that Betty made in the sands of life. **It was so exquisitely done.** You could have heard a pin drop in that auditorium. Everyone felt the pain of her passing, the huge empty hole in our hearts. But there was a sense of gratitude and wonder about the life she lead. It was a bountiful life. With four children, a husband, a girl scout troop, grandchildren and all of these

community groups she coordinated - “*How on earth did she ever find time?*” In one lifetime, she lived 10 lives and touched 100,000 hearts.

Please send your donations to honor Betty to LDRC, PO Box 707. Weaverville, CA 96093

The author lives in California.

Deaths

Roberta J. Sorbello-Luongo, 62, of Hamilton, Massachusetts, died peacefully March 2 following her brave fight with Lyme Disease and ALS. Roberta has tested positive for bartonella, mycoplasma, ehrlichia and babesia as well as Lyme. She studied vocalization and for many years performed in the Boston area. She had also performed as a soloist in Symphony Hall and had auditioned for the Metropolitan Opera. Throughout the years she had performed in various art galleries, churches and music halls in Massachusetts and in New York City. Always a wonderful gourmet cook, she opened her business, The Cook Sings, giving cooking lessons in her home. She enjoyed creating products to share with her friends and to sell at the local farmer markets.

Avid horseman **Jim Sazani**, 59, died on April 18 fighting complications from Lyme disease Saturday. Up to his last hour, a local horseman remained hopeful he would beat the disease that crippled his legs, but not his spirit.

“He never gave up,” said Judi Sazani, Jim’s wife of 38 years. “He was hopeful he would get through; there was always something going on in life that kept him alive.”

Jim once predicted he would fight to the end but the pain became too much for him to bear. He spent three weeks in the intensive care unit before his death, during which time doctors had to resuscitate him. Jim finally reached a point where he said, “No more,” according to his wife, Judi.

The process of his degeneration started a few years ago. The engineer began falling 10 times a day and

eventually landed in a wheelchair. He traced his muscle-wasting to a tick bite in 1998.

“He was miserable. He was trapped inside his body and he couldn’t get out,” Judi explained.

Now, she believes her husband is riding horses in heaven. Jim bred and trained driving horses at Sazana Rosa Saddlebred Farm in Nipomo for 18 years - his passion. After Lyme disease confined Jim to a wheelchair, the view of his ranch haunted him.

“I would rather move than look outside and see everything I can’t do,” Sazani said. “That’s torture for me.”

The Sazanis sold their Nipomo ranch last summer and moved to Lompoc. There, Judi received support from family members. An independent man, Sazani was forced to rely on others for his daily survival.

Lyme disease has claimed another victim after a prolonged 23-year struggle with the disease. **Shirley Moore**, one of the original members of Lyme Disease Association of New Jersey (now Lyme Disease Association) was a wonderful human being who always had a smile and a hearty laugh. She died in June.

Shirley, along with her friend Judy DeBow, ran the New Egypt Lyme Disease Support Group (NJ). They held regular meetings and helped fellow strugglers with phone calls and emotional support. Each summer, they hosted a potluck dinner at Shirley’s, which many New Jersey and Pennsylvania Lyme patients attended. It was not just the outstanding food but the camaraderie and support that drew people there.

It was not a place to feel sorry for yourself but a place with laughter and a place where people could be themselves and exchange words of encouragement. It was even a place to talk about families and events which most people consider commonplace discussion, but which are often necessarily relegated to a lesser priority by people with Lyme.

While on the LDANJ Board, Shirley contributed positively to the organization, and in spite of her debilitation, always made the meetings and always smiled. After the trek to the meetings became too difficult, she continued her support work, touching the lives of thousands with her caring spirit. She was never too busy to attend to the needs of others.

Vicki Logan died on July 17 after her insurance company refused to pay for treatment of her Lyme disease.

Vicki's case was featured in the Aug. 24, 1993 **Science Times**. Her life was ravaged by Lyme disease and she was denied the IV antibiotics by her insurance company that could have given her both better quality and duration of life. When given this medication previously she always had improvement.

In Vicki's case this denial was an outrage as she was known to have a compromised immune system due to a splenectomy. So, Vicki suffered for years in the hospitals and in nursing homes. Vicki had a wonderful spirit and until her life tragically ended she still prayed for treatment.

Trevor Allen Wayne Ligon, aged 2, died of Rocky Mountain Spotted Fever at Kosair Children's Hospital in Louisville, Kentucky, where he was air-flighted for treatment Aug. 10. Doctors at first suspected a virus. He died nine days after becoming ill. His mother also appears to have the disease, although tests were inconclusive.

About five cases of RMSF are reported in Kentucky annually. According to CDC, the disease most often caused by the bite of an

American dog tick. Children are most susceptible, accounting for two-thirds of all cases, and the mortality rate is 3 to 5 percent.

Former West Palm Beach mayor **Pat Pepper**, 58, died Aug. 16 of amyotrophic lateral sclerosis (Lou Gehrig's disease). She was diagnosed with ALS in 1993, and was treated for a time with longterm antibiotics that kept symptoms at bay. She and her doctor were convinced she had Lyme disease, but antibiotics do not prevent progression in all patients.

Erwin Lamp, 44, of Weiler, Germany, committed suicide in September. Erwin contracted Lyme disease in 1999 after being bitten by a tick. At first, physicians misdiagnosed his condition as flu. By the time they learned how sick he was, much of the damage couldn't be undone. He could work only part time. Before he was stricken, he loved to work. Two weeks before his death, he was told to take full disability. His body was found by his 12-year old son, Patrick.

Susan Hawkes-Koons, 57, died September 18 in Sidney, Maine, after a long battle with Lyme and Lou Gehrig's Disease. Susan graduated

from Mills College and received her law degree from Golden Gate University in San Francisco. She moved to Maine in 1982, as an assistant in the Attorney General's Office and in 1983 was the Assistant DA in Farmington. In 1985, she opened private law practice in Augusta, involved in general law and specializing in governmental relations. Susan was Chair of the Maine Arts Commission for several years.

Balsorah Lamar Miller, "Marnie," age 64, passed away on Sept 22, 2003 in her daughter's home in Richmond, Virginia from complications of ALS and Lyme disease.

She led an active and creative life, enjoying her job as historical interpreter at the Yorktown Victory Center for the 18 years prior to her illness. She was "in the battlefield" (literally) and constantly exposed to ticks in her work. Some of her co-workers also developed Lyme.

The family wishes to acknowledge the loving, attentive care given to her by Dr. Sabra Bellovin, an ILADS board member. She will be particularly missed by her sister Ginger Savely, a nurse practitioner treating Lyme patients in Austin, Texas.

Lyme linked to serious neurologic diseases

Case reports have linked a variety of neurologic syndromes to late Lyme disease, including blindness, progressive demyelinating-like syndromes (mimicking Multiple sclerosis) or Amyotrophic lateral sclerosis, Guillain-Barre, progressive dementias, seizure disorders, strokes, and extrapyramidal disorders. Encephalomyelitis can be caused by *Borrelia burgdorferi* and is characterized by spastic paraparesis, ataxia, cognitive impairment, bladder dysfunction, and cranial neuropathy. Finally, although transplacental transmission of *Borrelia burgdorferi* does occur and only rarely leads to fetal injury, neonatal death has been linked with Lyme borreliosis based on culture positive frontal cortex specimens.

Neurosyphilis, also caused by a spirochete, is known to be associated with memory problems, depression, mania, psychosis, and personality changes, such as irritability, emotional lability, and apathy. Given the remarkable similarities between syphilis and Lyme borreliosis, it is possible that the full range of psychiatric symptoms seen in neurosyphilis may also soon be recognized as features of Lyme borreliosis.

From Fallon BA, Niels JA, Burrascano JJ, Liegner K, et al. The neuropsychiatric manifestations of Lyme borreliosis. Psych Q 1992;63:95-117.

Letters

Another case of Lyme misdiagnosed as chronic fatigue

Another child from one of our CFIDS support groups just went down to New Haven to see Dr. Jones. The boy, 14, sick since 4th grade, was diagnosed with CFIDS by a couple of doctors, including an expert at Johns Hopkins for the orthostatic intolerance (“neurally mediated hypotension”). The kid’s knees swell. Five dogs on their street, including their own, have Lyme. The pediatrician is adamant that the boy does not have Lyme, says he’s been on enough antibiotics for other infections that Lyme would have been treated, if he’d had it. Dr. Jones says they were not the right antibiotics for the condition, nor the right dosages. The pediatrician also claims Lyme has been ruled out with a Western blot although it turns out that the boy only had an ELISA, a lab test that is only 65% reliable.

They saw Jones last weekend. Jones is the first doctor they’ve seen (and they’ve seen plenty) to notice that the kid has a partial facial paralysis and swelling of the finger joints, in addition to the knees, which no other doctor has commented on. He orders lab tests but starts to treat with antibiotics immediately, feeling the symptoms and history are significant enough to warrant not waiting for the results.

The parents are very grateful, but I am just enraged by this. It has been staring the doctors in the face, and they didn’t see it. This boy has lost years and years of his life. I just don’t get it. Do you know that veterinarians test animals for Lyme disease routinely, at least on a yearly basis?

This is how they are screening human beings for Lyme. You’d get better treatment if you were a dog.

Sheila Statlender
Boston, Massachusetts

Patient does not need plot - yet

Last year, I got a phone call asking if I wanted to purchase a cemetery plot. Coincidentally, it was during one of the many severe relapses. God, what a call to get. It was probably one of the employees at one of my medical insurance companies, moonlighting. They get all the inside info. I guess he needed the extra money, too

Denise Chapman
Brooklyn, NY

Denise Chapman was featured in the Lyme Times # 34 when she won her lawsuit against NYPD.

Teen patient and mom go public to fight Lyme

I wrote an article about Lyme disease for the Inland Empire Magazine for the July issue. I got the Lyme Disease Resource Center president and the editor of the Lyme Times to help me. Tiff’s doctor also checked it over to make sure my facts were correct. Cool, huh? I’m finally published!

They also interviewed Tiffany and me about all she has been through. Then they found out that I had had a brain tumor, so they interviewed me. Just call us “The Fight Back Family.”

The magazine article and interview shows Tiff and me in a picture with a caption. I got so tickled when I saw it. Tiff looks so cute, of course. She is getting better now. She has been going back through ALL of the symptoms since May. She can really feel the difference now, and the Rifampin is being carried by her Biaxin and Ceftin to the little nooks and crannies. She even had one good day recently when the brain fog almost lifted completely.

Please keep praying for Tiffany. She’s almost at the end. Then we will have one big bash party to celebrate!

Carol Smith
Redlands, California

The Smiths’ picture and article can be viewed at <http://www.inlandempiremagazine.com/july.html>

“TBDs” gets more attention than Lyme

I have started referring to “Lyme” and the rest of these buggers (pun intended) as Tick-Borne Diseases, or TBDs! Have you met anyone with *only* Lyme? Virtually everyone has more than one TBD. If they have Lyme, they most likely have co-infections.

How many times have you seen the glazed, far away look or the eye roll when you mention “Lyme”? I have gotten a much better response when I say Tick-borne disease. Try it! Or TBD!

When you say to the doctor (or acquaintance, family member or friend), “Doc, I think my kid has Lyme,” you know what you’ll hear/see: the eye roll, the sigh, the “not another one with Lyme hysteria” look.

“My child has Tick-Borne disease,” seems to keep them listening.

People say “TBD” sounds like a sexually transmitted disease. (It is, isn’t it? I believe it is.) Anyway, what interests the general public more than something sexual? Ask anyone in advertising or any form of media: sex gets the viewer’s attention.

I don’t know how you feel, but I am sick of the eye roll, sick of being treated like an idiot, tired of little kids being turned away by doctors when they need help!

I have tried it, and it works! I hope you will too! Spread the word!

Kay Lyon
Wenham, Massachusetts

Ms. Lyon is the mother of a child with Lyme disease and editor of www.lymesite.com.

Patients appreciate Lyme Times

To be able to relate Lyme experiences and share with others is heartening to someone afflicted for nine years. Such ignorance and closed doors by the medical practitioners and insurance companies is most disheartening. These people should be infected by the most virulent spirochete, to understand what a debilitating disease feels like. It sure has made our life an unexpected hell in so many ways. Thank you for your publication.

**Florence and Edward Elian
Columbus, New Jersey**

Patient confronts HMO about failure to diagnose

Mr. Perez-Lizano sent this letter to Denise L. Honzel, Vice President and Health Plan Manager of Kaiser Foundation Health Plan of the Northwest in reply to her letter to him dated June 16, 2003.

Dear Ms. Honzel,

Thank you so much for writing regarding my letter to the Centers for Disease Control. I was not expecting a response. I simply did not want you to not be aware of problems in your organization. The (non) diagnosis of Lyme disease is a systemic problem at Kaiser. The delegation of this matter to you, first by David Lawrence and now by George Halvorson, is inappropriate. Delegation does not relieve them of responsibility.

I must take issue with your comment that my complaint was reviewed by "appropriate" personnel. To me, an appropriate reviewer would be a person who is unbiased, honest, and competent. People who are on Kaiser's payroll and who know little or nothing of the subject of the complaint do not fit these criteria.

In the news some months ago, I noted that one of your doctors was

charged with sexual abuse. This same doctor was my former primary care physician who repeatedly refused to see me when I told him I suspected I had Lyme disease. A friend of mine who is an M.D., JD, Ph.D., and a professor at a major medical university made the observation to me that there really is no distinction in the mentality of a sexual predator and a doctor who denies care. I did not file a complaint against this doctor. The doctor I did complain about was far worse. His denial of care was blatant, cruel, and unjustified.

If you hire and protect ethically challenged doctors, you must also be ultimately culpable for their actions.

Incidentally, the CDC did respond to my letter. They apologized for the experiences I went through. Surely, when the CDC feels an apology is in order, this must give you some kind of a message.

**Miguel Perez-Lizano
Battle Ground, Washington**

Insurance company demanding money back

I am writing because I am having problems with my Blue Cross medical insurance. They have refused to pay for my Lyme intravenous treatments. They actually paid the IVs for 90 days, but now they are demanding the money back. I have appealed and that failed. I have my last appeal to go. Do you know of an attorney or any research articles that deal with this?

Blue Cross claims that the CDC says 30 days or one month of IV is sufficient. How can I fight them on that?

**Marion Spinelli
Los Angeles, California**

We can send you an annotated bibliography of 10 scientific articles proving persistent infection in spite of "adequate" antibiotic treatment. For an example of one successful approach, read Carolyn Cramoy's article on page 49.

NIH-Columbia research study needs fifteen more patients

by Adam Lessler and Brian Fallon, M.D.

The Lyme Disease Research Program at Columbia University, under the direction of Dr. Brian Fallon, is conducting a chronic Lyme disease re-treatment study, sponsored by the National Institutes of Health. We are now three years into the study, and we have one year left. We still have room to accept about 15 additional patients with Lyme disease. We also need about 5 good healthy controls; (for those of you whose healthy relatives wish to help Lyme disease research and earn compensation for their time). The study provides an excellent opportunity for those suffering from the persistent symptoms of chronic Lyme disease to get state-of-the-art evaluation using a

variety of modalities if they qualify for the study. In addition, all patients eventually get treated with antibiotics – two-thirds receive 10 weeks of IV antibiotic therapy in the double-blind phase of the study, and one-third receive 6 weeks of IV antibiotic therapy openly after the end of the double-blind phase. The study testing, hospitalization, and treatment are free of charge. We estimate that each patient receives over \$25,000 in medical care. We are able to provide this study free of financial cost to the patient thanks to a \$4.7 million grant from the National Institutes of Health. We also receive support from private foundations, such as the Lyme

Continued on page 40

Disease Association, the Wilton Lyme Disease Task Force, the Greenwich Lyme Disease Task Force, Time for Lyme, Inc., and the National Research Fund for Tick Borne Diseases.

Our study is a treatment study that will evaluate response to treatment using neuropsychological testing and state-of-the-art brain imaging. Evaluations include neuropsychological testing of memory and attention, brain imaging to look at blood flow in the brain and nerve cell structure and metabolism, a neurological exam, a rheumatological exam, and studies of the fluid that surrounds the brain (“the cerebrospinal fluid”). The brain imaging includes both MRI’s and PET scans. An MRI is basically a picture of the brain to examine its structure, whereas a PET scan looks at how the brain functions. This study is the largest ever to focus on the neuropsychiatric aspects of Lyme disease and utilize PET scan brain imaging technology. We have several important goals:

- 1) to determine whether 10 weeks of IV antibiotics result in further improvement among patients who have already received the standard amount of treatment,
- 2) to determine whether brain abnormalities in Lyme disease are primarily due to blood vessel inflammation or a nerve metabolism problem,
- 3) to identify clinical and biological markers that may be associated with a treatment response,
- 4) to determine whether the brain imaging abnormalities improve with time, and, if so, whether the time course of change in brain imaging is similar to that in the neuropsychological testing, and
- 5) to see whether patients, when off antibiotics, improve over time, stay the same, or relapse

Patients must come to Columbia for evaluations on at least five occasions throughout the course of about a year. The study is officially

24 weeks, but there is a follow-up visit at week 48. Patients will be screened over the phone and in person to confirm study eligibility. The treatment involves 10 weeks of either intravenous antibiotic (ceftriaxone aka “Rocephin”) or intravenous placebo (inactive substance). There is a 2 out of 3 chance of getting the real medicine and a 1 out of 3 chance of getting the placebo. (At the end of the 24 weeks, patients who received placebo will be given the option of getting 6 weeks of the actual medicine at no cost.) After the first visit, the remaining treatments will be done in the patient’s home. The neuropsychological tests will be done four times (screening, baseline, week 12, and week 24), and the brain imaging (MRI and PET scans) and physical exams will be done three times (baseline, week 12, and week 24). Blood tests and self-report ratings will be done more frequently from the patient’s home. Each patient will have one lumbar puncture at the start of the study in order to examine the cerebrospinal fluid for markers of infection. As mentioned above, there is also a 6-month follow-up at the end of the study (i.e. week 48) at which time neuropsychological testing will be repeated. If requested, the patient’s physician will receive a report at the end of the study summarizing the results for his or her patient.

We are looking for patients who meet the following four criteria:

- Presence of classic Lyme symptoms in the past
- Treatment with at least 3 weeks of intravenous (IV) antibiotics
- Persistent cognitive symptoms, including memory problems
- Ages 18-65

If you meet these criteria, we encourage you to contact us at (212) 543-6510 or CULyme@aol.com so that we can begin the screening process. We also require that all participants in the study have a current, positive IgG Western Blot blood test at our research lab. Please go to our website for more information about our study at www.columbia-lyme.org.

Please do not hesitate to call. This study will only be recruiting patients for another 6-12 months, and enrollment will stop once we reach our goal of 15 additional patients. So please contact us soon. Also please note that patients from around the country have participated in this study. Given that we help with travel costs and work with local physicians, participation in this study is possible even for those who live far away. And remember, New York is beautiful and worth a visit!

Entry criteria for Columbia chronic Lyme study

- § Presence of classic Lyme symptoms in the past
- § Treatment with at least 3 weeks of intravenous (IV) antibiotics
- § Persistent cognitive symptoms, including memory problems
- § Ages 18-65

Call (212) 543-6510 or email CULyme@aol.com

Beginners' Pages

Lyme Disease in Children

Diagnosing Lyme disease in children can be difficult, because: they may not look sick; children may be unaware that a constant headache, ringing in the ears, and numbness and tingling aren't normal, and may not report it; they may be unable to describe their symptoms; and frequent complaining may cause adults to think they are just trying to get attention. Pains can come on suddenly and be very intense, and then suddenly be gone. This may be difficult for adults to understand and believe.

Children with Lyme disease often complain of headaches, stomach pain (sometimes accompanied by an ulcer), chest pain, ear aches, sore throat, and joint and muscle pains. Swelling of joints is less common in the central states than on the east coast. There can be episodes of stiffness. Headaches can be frequent or constant, lasting months or years. They can be mild, or so severe that medication doesn't totally relieve them. Sunlight can cause eye pain and make headaches worse. Children with Lyme disease may need to wear sunglasses at recess, even on cloudy days. They may need to go to the bathroom frequently and suddenly, and may not be able to wait for the teacher's permission. There may be vision and hearing problems, which may come and go.

Cognitive problems can also come and go throughout the day. Concentration and memory problems can make math especially difficult. Slowed thinking can make it difficult to comprehend oral and written language. A child with Lyme can suddenly not recognize familiar places and can get lost in the school. The disease can cause learning disabilities and low IQ scores. Word, number and letter reversals in written and oral speech (dyslexia) are common.

Sometimes IQ scores jump after a child begins antibiotic treatment.

Children with Lyme can be too tired to go to school and may need to go part-time or receive home schooling. The symptoms and severity of symptoms can vary from day to day. A child may feel well enough to go to school one day, but not the next. Absences may be frequent.

The children can also have social problems, being too tired to play with friends, and being teased if they have trouble walking, talking, or learning. Other children may avoid them, because of an unfounded fear that the disease is contagious. Lyme disease can cause a child to have sudden panic attacks, and to be irritable and to have mood swings. Children with Lyme may have only mild problems, or the effects can be severe enough to put a child in a wheelchair. Children whose mothers have active Lyme disease during pregnancy can be born with damage to the brain, heart, liver, and other organs. They can have a variety of problems, including frequent illness, speech delays, other developmental delays, or severe multiple disabilities. Antibiotic treatment during pregnancy can often prevent congenital Lyme disease.

Lyme Disease in Teenagers

Teenagers with Lyme disease also have special problems. The disease can cause a sudden drop in grades, mood swings, depression, suicidal thoughts, personality changes, sleep problems, poor concentration, cognitive problems, and a loss of interest in school and school activities. These changes can be mistaken for drug abuse, which may cause a delay in diagnosis. A drug test is often ordered to rule this out as the cause. Hormone changes can also be blamed, or teenagers can be accused of being lazy or rebellious and not

trying hard enough in school. All these problems can make it more difficult to get diagnosed.

The teenagers may be too tired to attend school or to complete their work. They may need to go to school part-time or not at all. Home teaching may be necessary. The subjects in which they are most likely to experience a drop in grades are those that require a person to remember previously learned concepts, such as math, foreign language, and chemistry and other science courses. They may do fine in history and English.

Loneliness can be a problem for teenagers with Lyme. They may be too tired to participate in social activities with friends. It's hard for them to predict how they will feel from day to day, making it difficult to make social plans, which often have to be canceled. (This withdrawal from friends is not typical of drug abusers, who may change friends, but will socialize.) Students who are ill with Lyme disease in high school are often feeling better and performing better by the time they go to college. They can arrange for an extended-time SAT test with a letter from a doctor. If a Lyme patient has a year or so of poor grades from illness, the doctor can write a letter explaining the health problems and asserting that the patient's health is improving with treatment. This letter can be included with a college application.

Summary for Children & Teens

- They don't realize what is "normal"
- They cannot always articulate symptoms
- They cannot remember sequences of events
- They need someone to listen
- They need an advocate
- They need to be believed

This essay is part of an educational packet developed for schools by the Lyme Association of Greater Kansas City, PO Box 25853, Overland Park, KS 66225.

Front Lines

A Window for Pain

by Virginia Sherr, MD

Thirteen-year-old Bridey looked like a small, angry, caged, and frightened wild animal as she grimaced into the face of her patient mother and voiced a loud howling noise. They sat together in my office, hoping I could help her behavioral problems. Both mother and daughter were used to her episodes of screaming at home – sometimes for hours at a time and of such volume that neighbors several houses away were alarmed. Often asked why she behaved in this seemingly feral way, she always moaned that she was in pain. There were few specifics in her description of pain – both she and her mother defined it as a kind of “psychological pain” because it took no form that she could describe and they had no reason to doubt her very real emotional anguish.

Bridey recently had been discharged from a children’s psychiatric hospital. She had been treated with antipsychotics and mood-stabilizing medications and was described as somewhat improved. Her conceptualization of pain continued, unexamined. After several months she stopped the medications and returned to her usual isolation, utterly miserable, angry, and fearful of leaving the house.

Home-schooled for the last three years because of her “strange behavior” with seemingly paranoid features, she thought people didn’t like to be around her, never believed her and looked at her strangely—probably all actually true then) and an undefined learning disability, Bridey had lost her previously keen scholastic skills, lost all social confidence, could no longer concentrate to read or to focus on her studies. Eventually, even the teacher for homebound

children gave up trying to educate her.

Most of the time Bridey was alone while her Mom’s job kept the family together and her siblings went to school. Her father had remarried and lived far away in Florida. Like everyone else but her Mom, he seemed to be leery of relating to his daughter – a situation that grieved the patient.

When asked about a history of tick encounters because of her cognitive losses, tick-borne disease was a prime suspect.), Bridey vividly recalled being bitten in the ear when she was in the 3rd grade. It caused little concern at the time. But it was not long after, at the age of 8, that Bridey began lamenting to teachers, parents, and anyone who would listen: “I know something is wrong with my mind – I can’t think the same as I used to anymore. I can’t remember things anymore. I can’t read like before.”

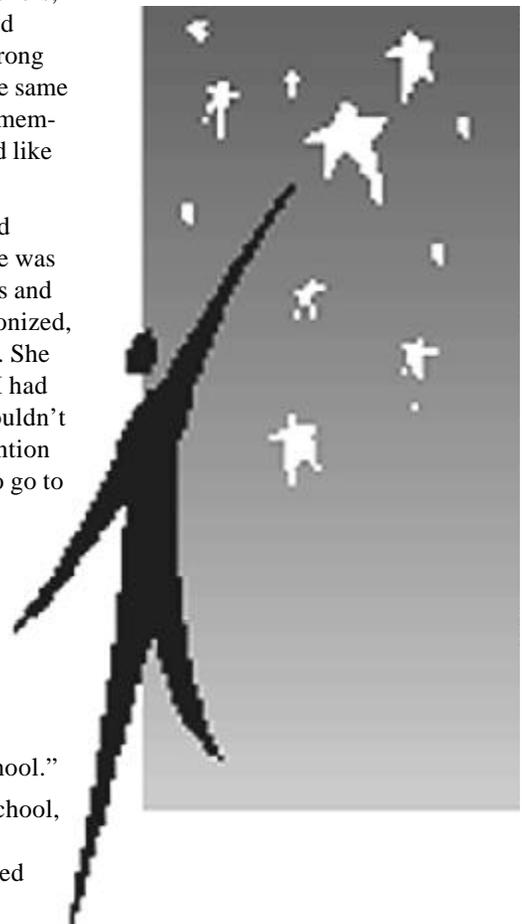
Well-meaning teachers tried reassuring the little girl that she was imagining her mental foggy and that she was fine. She felt patronized, knowing that they were wrong. She added, “Then soon after that, I had such pain in my knees that I couldn’t walk. They said I was just attention getting, but for a while I had to go to school in a wheelchair. I knew people weren’t listening to me and had started to look at me strangely, so I began to avoid people. Finally, by the time I was 10, it all was unbearable. I couldn’t think clearly and had no confidence anymore, so I quit going to school.”

Three years after she left school, I was asked to help with her emotional problems. I also tested

her blood and urine to determine if her cognitive losses could have an infectious origin. Ten years after the known tick-bite, labwork revealed the active presence in her body of *Borrelia burgdorferi*, the bacterial cause of Lyme disease.

I hypothesize that over the years, that Bridey’s pain intensified and generalized to her whole body, becoming more focused when antibiotics were begun. When a deep pain in her back became unbearable, her mother would take her to the local ER. The physicians there were certain that anyone who writhed, screamed, and gyrated as Bridey did couldn’t be experiencing real pain –they insisted that “real” back pain caused people to be stiff, not limber as she was. Luckily, at this point she was under the care of Connecticut pediatrician Dr. Charles Ray Jones, who disagreed.

“Children are different from adults,” he said. “She has deep bone pain from Lyme disease and, like most



kids, isn't guarding against it by stiffening up like grown-ups do."

I had never before treated a child with heavy-duty pain medications, especially a child who was now on antibiotics and psychotropic medications. Relief was clearly called for because Bridey at this point was non-functional due to her pain, and the ER had made it clear that she would not be welcome there again. Conventional painkillers gave her no relief. To everyone's surprise, as opioid pain medication succeeded, Bridey began to be more interested in self care, the screaming episodes phased out, and she had mental energy to devote to her home-schooling. I gradually increased her dosage to adult levels, yet she experienced almost no side effects.

At her most anguished, Bridey had threatened serious violence to her siblings and herself, but now she keeps "forgetting why I was so angry," is solicitous of them and enjoys their company, at least part of the time. While on pain medication she successfully attended a private school part-time and now plans a future that includes full-time public school. She no longer has pain or takes any pain medications, and she still takes needed antibiotics for treatment of her chronic neuro-Lyme disease. At last, my psychotropic medications (Seroquel and Wellbutrin) finally do work. Psychotropic meds offered earlier had not worked optimally before antibiotics and pain meds were begun.

There is, in treatment of chronic neurologic Lyme symptoms, a window in which pain has to be addressed or the social, maturational, educational, and biotoxin damage to the psyche may go beyond repair. One should not expect to be able to work well with a child who is distracted by unfathomable pain. I suspect that in addition to her bone pain, Bridey experienced a kind of generalized "Central Pain Syndrome" as it is called. It is very hard for adults to define this central pain in them-

selves. It is virtually impossible even for such bright youngsters as Bridey to put this pain into words. Thus, we had this description by mother and daughter – "a kind of emotional pain that is physical." Sometimes a howl was the only way to express it.

Today Bridey no longer looks hunted and cornered. She appears as and behaves like the young teenager that she is. Our main challenge lately is to deal with her concern over appetite. Pain is no longer in the picture.

Bridey serves as a valued example

of why we health professionals need to listen carefully to children for clues to the presence and effects of invisible chronic pain, understanding that they do not have the life experience to describe it adequately in words. We must not fear offering pain medications that, judiciously given and carefully followed, can offer adequate relief when they are indicated and when lesser measures no longer suffice. Powerful pain medication launched Bridey in the direction of reopening her own personal window on the world.

No Lyme child left behind!

Lyme-literate Psychotherapist talks to teachers

by Sandy Berenbaum, CSW-R, BCD

For 12 years, children with Lyme disease have come to me for individual and family therapy. Some already knew they had Lyme. Others came for other reasons, with problems that turned out to be, in whole or in part, due to Lyme and coinfections.

Over the years, I have written and spoken on topics related to kids and Lyme, developing a protocol for screening for Lyme, a collaborative approach for physicians, psychotherapists and schools to work together, and a handout to educate parents. And for 12 years, I have seen a spectrum of Lyme symptoms in children and adolescents – mood and eating disorders, psychotic symptoms, mild to severe cognitive problems, and of course fatigue, headaches, stomach aches, with any and all combinations of symptoms. I've seen families jump through hoops to get and pay for the right diagnosis and treatment for their children, and seen families suffer from the fact that Lyme has hit more than one family member. The struggles faced by families with Lyme are enormous, and multi-faceted.

One of the most complicated problems I see families struggle with is how to help their child function as a normal child, in the healthy stream of life, despite the fact that he or she has a serious chronic illness, that is, at times, disabling. Parents of children who were born with Lyme, or who acquired it at a very young age, wrestle with the question of what normal is – would the child have been learning disabled, or have an anxiety disorder, or ADD, if he did not have Lyme? Will the child be free of mental and cognitive disabilities following treatment? What do they do TODAY to optimize their child's chances?

Schools play an essential role in assuring that these children have the opportunity to lead a normal life. From the attitudes that school administrators and teachers have toward these children, to the supports and accommodations the children are given, individualized and based on the need of each child, schools have an enormous impact on the ability of children to be successful students, and ultimately feel good about themselves and their abilities.

School has a special place in our society. As Americans, we take great pride in our commitment to providing free public education to all children. Every President includes an agenda for improving the quality of education in this country. We stress literacy and promote learning.

The process of learning, however, is complicated for some children. Those who have chronic Lyme disease are particularly challenged. I'd like to address some of those challenges, and look at some of the ways those children can be helped.

We know that, in addition to physical symptoms, Lyme disease can cause impairments in the brains of children, affecting mood and behavior. We know that the cognitive problems caused by Lyme can impact learning in a variety of complex and profound ways.

You, as teachers, might very well be the first ones to see these problems in your students. You therefore have a unique opportunity to identify the changes that might point to this illness. Experienced as you are at observing behaviors in your students, you could pave the way for early diagnosis and early treatment, thus helping a student return to functioning, his ability to concentrate and learn in tact. And with those students who have chronic Lyme, you could help them to develop competence at working *around* their disabilities, to be able to succeed *despite* their learning problems.

What is it that you might see in your classroom, the infirmary, or the guidance office?

Often there was a *discreet point in time* when a child changed in a dramatic way. Did he appear to have *acquired* a learning disability or ADD in 4th grade, for example? Did he start to complain more about headaches right after Christmas break?

You might also see *symptoms* causing *behaviors*. Here's an example: One symptom is an extreme sensitivity to light or sound. The

behavior change might be the student's withdrawal, or refusal to be in class when the lights are turned up, or there's a lot of noise or motion in the room, but be perfectly *fine* when there is no excessive stimulation. *Lyme disease calls on us to be keen observers of behaviors, good listeners, actually detectives, so that we can see these signs. We need to put the pieces together. The complexity of this illness is truly astonishing!*

What can you do to help these children?

If you *see* the behaviors, *track* them for a period of time. Notice whether they continue, or if the unusual behavior was an isolated incident. If symptoms come and go, with different arrays of symptoms at different times, it might be Lyme, since *Lyme Disease is a multi-system illness, and the symptoms may be transient.*

Tell the school nurse, supplying her with notes regarding what you have observed. Indicate in your notes when the symptoms first became apparent.

Guidance counselors and attendance officers should track attendance and lateness patterns. Again, if excessive absences and lateness began *at a discreet point in time* and academic performance declined, it is important to notify the school nurse, so that she can pursue the question of Lyme disease.

What can you do to provide an optimal education for these children?

Since Lyme is such a complex illness, effecting each child differently, there is *no single strategy* that will help every child.

If the disease is caught early and the child is treated comprehensively, the support the child needs is likely to be minimal, as with many other illnesses. She may be on home teaching for a week or two, and may need to make up some classwork or tests when she returns to school. But she will soon be on her feet, often with no residual effects.

The child with *chronic* Lyme is the one who will need the most supports, often involving ancillary professionals, as well as the classroom teachers. To provide those supports, I'd like to suggest a three-stage system.

Stage #1 - Informal Educational Supports

There is much that a classroom teacher can do to provide supports to a child with Lyme disease. Creative strategies, *based on the individual needs of the student*, can create a learning environment in which she feels confident that she can succeed in school. We all talk about how to *motivate* a child. If we meet her needs and structure a school program that considers her cognitive and psychiatric impairments, we *will* motivate her, and in the case of many students, we will also avoid the need for classification.

Over the years, I have seen teachers use a variety of strategies to help students with Lyme. When a teacher sees a student who is easily distracted and has trouble concentrating, she might seat him in front of the class, where there are fewer distractions. She might allow a student with Lyme to take tests before or after school, in order to afford a quiet place for test-taking, and to provide him with extra time. Some teachers and administrators give students the opportunity to take tests in the guidance office, or the infirmary. If his learning problems indicate a need for tests to be read to him, some teachers or aids will read the test to the individual student - *all without formal accommodations.*

On the middle school and high school level, a *marvelous* tool for adolescents with Lyme disease is *hand-scheduling.*

Hand scheduling

The child with sleep disorder problems usually functions best during the second half of the day. Hand scheduling allows for the student with this set of symptoms to

have “specials” and study hall early in the day, with academics later, when he is more alert. For the student who needs naps, study halls and lunch can be scheduled around the time a nap is needed, and he can go to the nurse’s office for part or all of those periods.

Another problem area for students with chronic Lyme is attention and concentration. Although these children do not necessarily meet the diagnostic criteria for ADD or AD/HD, often because they did not have symptoms prior to the age of 7, *the presentation of symptoms in these students is indistinguishable from ADD*. These children often focus better early in the day, and would respond well to academics in the morning. I have seen an incredible change in performance as well as behavior when one student with attentional problems had math moved from 7th to 2nd period, even though he was assigned the same teacher!!

Stage #2 - Section 504 Accommodations

For some students, a formal plan needs to be provided. It may be enough to classify under Section 504 of the Americans with Disabilities Act. In the district in which I practice, 504 has allowed for adjustments to the curriculum for students who have serious psychiatric presentations of Lyme disease. For example, one girl who had developed anorexia nervosa could not tolerate *any* discussion of nutrition. Her 504 plan allowed her to leave the room when nutrition was discussed, in health or science classes, with an independent learning project provided as a substitute. This girl shows us the extreme to which one can have psychiatric symptoms from Lyme.

She, by the way, went from *failing courses, on the verge of dropping out of school, to graduating in the top third of her class, with this accommodation, as well as hand scheduling, and extra time and a quiet place for testing.*

**Stage #3 - Special Education
Number 35**

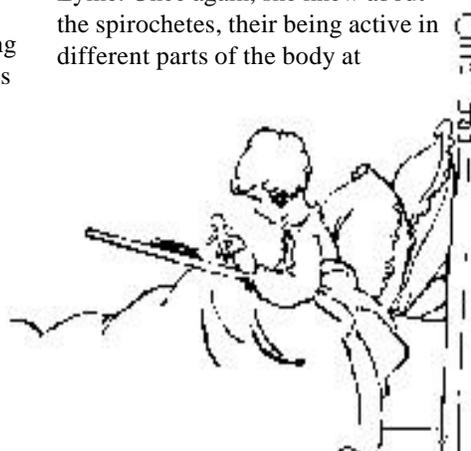
Classification

Despite our best efforts, some students *will* need to be classified under IDEA. A special education meeting will yield an IEP, with plans in place for a child’s curriculum. The IEPs are reviewed periodically, with supports written into the plan.

Please remember - If there is a 504 Plan or an IEP in place, it is very important that the regular ed teachers be made aware of the plan, so that the supports for the student can be maintained. With everyone working together, the child with chronic Lyme can succeed, and the most costly accommodation, out of school placement, can be avoided!!!

Now, I’d like to tell you about Lucy,, a 10-year old girl who came to Family Connections a few months ago with her mother, Alice. Lucy bopped into my office, plopped down on the couch, and started a discussion with me about one of her favorite subjects – cats, noting the pin I was wearing. She was bright and energetic, and delightful to talk with. Aside from discussing her four cats, she told me about the yard full of guinea hens her parents had bought because they eat ticks. From her in-depth discussion about the habits of these hens, and their interaction with the cats, it was certainly evident that she was very sharp and eager to learn, the kind of child who soaks up learning like a sponge.

Then she told me about the four years since she was diagnosed with Lyme. Once again, she knew about the spirochetes, their being active in different parts of the body at



different times, and that when she felt ill, it would pass as the symptoms abated. She was open about the effects of Lyme on her life, and her functioning, the endless medications and doctor’s appointments several hours away. For a child who was so sick for so long, she was coping very well.

Lucy’s symptoms had recently worsened, and she had been on home teaching for 2 weeks. She was bothered by the fact that she had gotten sicker than she *had* been, taking more medication again, with the side effects she had to endure, and not seeing her friends every day. However, since she had a very hard time falling asleep at night and staying asleep, she *was* glad that she didn’t have to get up early for school. *I want to emphasize here that Lucy only needed 2 weeks of homebound instruction. Some Lyme patients are home for months, with symptoms so severe that they cannot go to school!!*

Lucy had been tested by a Lyme-literate neuropsychologist. Her evaluation was typical of many I’ve seen in children with chronic Lyme - superior intelligence, but indicating a wide range of functioning in different areas, one as low as the first percentile, significant problems in mental tracking, attention, concentration and *very poor* short term memory. She was seriously impaired in her ability to learn new material, despite her very high IQ and fabulous vocabulary.

Let’s look at Lucy, a student with chronic Lyme disease, who enters your classroom in the fall. You’ve learned what Lyme can do to the ability to learn, so you are prepared to teach this 4th grade student. Understanding the nature and extent of possible symptoms, you make *no presumptions*. You have reports in hand, from the doctor, and the neuropsychologist who tested her, and these comprehensive reports indicate her deficits, with *specific recommendations* as to her special needs.

You find Lucy to be a very smart

child, but you observe that her IQ may appear to drop 30 points on a given day, and you know *that* to be typical of cognitively impaired students with Lyme. You modify your curriculum accordingly, loading the work on when she has good days. You might call her parents in, and ask for reinforcement at home for some subjects that Lucy seems to have the most difficulty with. She has a separate set of text books at home, so that she doesn't have to count on remembering to transport her books, given the extreme difficulty she has with organization.

You might occasionally request a child study team meeting, to get input from others on what supports might help. Ideally, your school has a teacher who is particularly Lyme-knowledgeable, and has volunteered to serve as a liaison, sitting in on meetings, and suggesting possible supports for students with Lyme. This teacher, *parent* of a child who has Lyme, keeps abreast of information on the effect of Lyme on the education process. She is a therefore a *very* helpful contributor to the team's efforts to find solutions to problems that students with Lyme often present.

The nurse might discuss Lucy's fatigue with her parents and her doctor, and suggest that she have one or two nap breaks a day, when Lucy is very symptomatic. You are delighted to find that she learns more, and retains the information better when those breaks are afforded her. You're also delighted to see that she doesn't fidget as much when she has breaks from the stimulation of your classroom.

You provide Lucy with written class notes when she is unable to take her own. She takes her exams after school, when the room is quiet, and you are able to give her extra time. You may read her a question or two, when she is blocked in her attempt to *read* and *comprehend* the test questions at the same time.

The end of the year comes. Lucy

has had a successful year. With appropriate medical treatment, her Lyme symptoms have diminished, and although she did not achieve as much academically as she would have, had she not been ill, she feels good about herself and her ability to overcome adversity.

Her mother stops by to thank you for the support you have given Lucy. She is planning to go to day camp with some of the new friends she made this year, children who understood that Lucy has this *strange disease* that was causing her to be ill some of the time, thus not always available to play with them. You had helped her through the year socially by bringing Lyme disease to the attention of her classmates, helping *them* to develop compassion for Lucy, *giving these children a wonderful life lesson in empathy.*

Instead of dreading her returning to school next year, Lucy will come in eagerly, knowing that *whatever happens*, she can trust her own ability to learn, and to be a part of the school community. With your support and encouragement, *you have given her that gift.*

As educators, counselors, nurses, you have made a commitment to being a major force in the lives of children. With this subset of children, many of whom have been so ill for so long, you have a *fabulous opportunity* to give them not only the gift of an education, but self-confidence, trust in their world, and the experience of accomplishment!



Depression is a disability

From www.benefitnews.com

A U.S. tax court in North Carolina has ruled that ongoing depression qualifies as a disability exemption under the IRS rules governing early distribution from qualified retirement plans.

IRS levies a 10% penalty against individuals who take retirement distributions before age 59-1/2 unless a statutory exemption applies, such as a disability that renders the employee "unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment [of] indefinite duration."

In the case of Coleman-Stephens v. Commissioner of Internal Revenue, plaintiff Mary Coleman-Stephens stated that she suffered from continuing depression, including being hospitalized twice due to the condition. During that time, she failed to repay a retirement plan loan, and the plan reported the unpaid balance and interest as a taxable distribution. Although she included the distribution on her income taxes, she did not pay the 10% early distribution penalty, asserting her disability.

As she was unable to work during the year the distribution occurred, and had not yet returned to work by the time of trial, the court determined Coleman-Stephens disabled and therefore exempt from the penalty fine.

The decision goes beyond IRS's intended definition of a disability and marks a shift in legal and public opinion of depression as a true and sometimes disabling disease. Although research is scant on how depression affects employers' disability costs, a recent study published in the Journal of the AMA finds depression is a leading cause in lost productivity costs for employers, up to \$44 billion annually.

Opinion

Coinfections, strain variations affect success of treating TBDs

by Lynn Shepler, MD, JD

There is quite a burgeoning literature on *Bartonella*. However, I am weary of this unexamined philosophy of care that monotherapy, devised for use in the context where a person is sick with ONE AGENT, is necessarily going to work in the context of TBD [tick-borne disease] patients who are likely infected with multiple agents and who suffer from varying degrees of immunocompromise.

Monotherapy, we should keep in mind, has been touted in publications in the context of those lucky souls who are infected with a “mono-agent” — ONE agent. So, if all you have is *Bartonella*, chances are that maybe one agent might help get you back on track. However, there are experts who would disagree that monotherapy will work even in those cases once *Bartonella* becomes symptomatic — they believe that you will need TWO AGENTS.

From my review of the literature, there are few papers on the successful use of Cipro, and again, the drugs were not used in the context of Lyme disease patients coinfecting with multiple agents. There is no standard of care for Bartonellosis. Like many of these therapies that Lyme patients receive all the while being told that they will be “cured,” based on what I have read in the literature — and I have read extensively — it seems to me another potentially “suppressive only” regimen.

Bartonella is also NOT just *Bartonella henselae*. One patient told me she just ran out and got tested for *Bartonella*. What SPECIES of *Bartonella*, please? The abstract of Chang et al from the tick study done by the UC Davis group in Santa Clara

County states: “In these infected ticks, molecular analysis showed a VARIETY of *Bartonella* strains, which were closely related to a cattle *Bartonella* strain and to several known human-pathogenic *Bartonella* species and subspecies: *Bartonella henselae*, *B. quintana*, *B. washoensis*, and *B. vinsonii* subsp. *berkhoffii*.”

A negative result on a test for *Bartonella henselae* does not rule out *Bartonella*, just like a negative result on a test for *Babesia microti* does not rule out *Babesia* WA1, and a negative test for HGE does not rule out HME. A negative test on a serology for *Bartonella henselae* and *Bartonella quintana* (the test available through Focus Technologies, Cypress, CA - formerly MRL) also DOES NOT rule out other *Bartonella* species for which testing is not yet available through commercial venues. Ditto for *Babesia* and *Borrelia*.

Theoretically, one could be merely picking up the tail of the whale in finding positive *B. henselae* and/or *quintana* titers, and a person might have even higher titers to a species that has yet to be characterized in terms of its pathology in humans. That is the pattern you can see with all of these pathogens that are cross-reactive—that a person may have a low reactive titer in comparison to the titer to the organism they appear to be truly infected with. So, for example, a low positive titer to *B. henselae* could indicate an infection with *B. quintana* that has not been tested for, or another species which is presently impossible to test for commercially.

One theoretical way to get around

this might be through the use of tests that cross-react with *Bartonella* — such as tests for *Chlamydiae*, *Legionella* or *Coxiella burnetii*. While a species-specific serology test for *Bartonella* is not going to be expected to pick up these new species of *Bartonella*, it might be possible to look for clues using other probes.

This is one of the techniques you will find in old publications when doctors actually ordered tests and didn't feel like there was a gun to their head not to order laboratory tests. In the case studies of people sick with possible TBD, the doctors actually fired off requests for every TBD test under the sun. They weren't loose cannons firing off every possible gun in the diagnostic armamentarium — the doctors were acknowledging the risks posed by the bite, and the impossibility of parsing out nonspecific symptoms.

It astounds me that, with all the frenzy on patents, we have yet to see any genus PCRs or serologies designed to pick up anything other than these tightly defined species. It adds to the expense of testing patients in the context of TBD. We should have genus tests available to use as probes, and THEN test for particular species. Please, are they going to force doctors to test for every possible species in order that scientists and academic institutions make a buck off any and every patent they can devise? I've heard of researchers using their genus probes to “discover” new bugs. How come they've never managed to bring these to the marketplace? Genus tests, now!

As in treating ANY polymicrobial infection, it is imperative that the physician attempt to KNOW what they are treating BEFORE embarking on a treatment plan. Dr. Sherr's poster explaining the emergence of coinfections during treatment is wonderfully edifying. However, lest we have forgotten, the principle that antimicrobial therapy should cover ALL potential pathogens one is treating in a patient is a basic prin-

ciple of ID therapy. All of us have been taught this during our internships.

Since all of these coinfections cause similar non-specific symptoms, the only way to try to get a sense of what is going on in any particular patient is to DO THE TESTING. There is no “sounds like,” “feels like,” “my intuition is that ...” etc. If you read the literature on all of these tick borne infections — borrelia, ehrlichia,

babesia, coxiella, bartonella, *F. tularensis* — and brucella, also (not known to be tick borne) — they ALL have a nonspecific core set of symptoms. All are known to have the potential for causing persistent or relapsing infection. But each organism is very different in terms the standpoint of therapy.

Dr. Shepler comments were posted on the internet group Mental Health and Illness.

diagnosis and treatment, and understanding that by NOT treating it I was risking permanent damage to my eye, it struck me that the downside risk of a month of antibiotics was SO trivial compared to the risk of ignoring the evidence in front of me that I went ahead with treatment.

Some references for you:

Kerkhoff FT, Rothova A, (Univ Hospital, Utrecht, Netherlands) *Bartonella henselae* associated uveitis and HLA-B27 Br.J Ophthalmol 2000;84(10):1125-1129.

Bartonella henselae, a Gram negative rod, was identified as the organism causing cat scratch disease (CSD). Ocular involvement in *B. henselae* infection has been reported to be the cause of Parinaud’s oculo-glandular syndrome, uveitis and neuroretinitis.

The authors have investigated the frequency of HLA-B27 in presumed ocular bartonellosis and have reported the clinical features and laboratory data of these patients.

The page at the following link has 5 abstracts of papers that discuss neuroretinitis due to Bartonella as well as the treatment and outcomes: <http://www.eyecons.com/Caldscat/search.htm>

Article by Joyce Drayton, MD, Assistant Professor, Dept of Internal Medicine Div of Infectious disease, Morehouse School of Medicine: <http://www.emedicine.com/MED/topic304.htm>

From Southeastern Eye Center: <http://www.southeasterneyecenter.com/cases/catscratch.htm>

Massachusetts Eye & Ear Infirmary - scroll down for article about Cat Scratch Disease Neuroretinitis: http://www.uveitis.org/Enhanced/Abstracts/ann_fell_mtg/fel_ARVO1998.htm

Bartonella henselae neuroretinitis in cat scratch disease. Diagnosis, management, and sequelae. Author: Reed JB; Scales DK; Wong MT;

Bartonella can cause serious eye problems

by Jon Strong

The notion that Bartonella is insignificant is outdated, although many physicians don’t seem to be aware of that yet. For several years it was assumed that Cat Scratch Disease was about the worst outcome, and that the infection was self-limiting in all but immuno-suppressed patients. But several papers have been published in the last couple of years documenting Bartonella as a common cause of eye problems, including uveitis, neuroretinitis and optic neuritis. It has been shown that an active Bartonella infection can survive various antibiotic regimens that were previously thought to be “overkill” as well.

Interestingly, most of the recent publications and findings come from the field of ophthalmology. Maybe that’s lucky for us, since those who mock Lyme-literate physicians would happily lump Bartonella in with Borrelia if it were our own LLMD’s who were leading the charge on this issue.

I had a serious and rapidly degenerating ocular problem a few months ago. Examination showed optic disk edema and capillary bleeding/leakage around the optic disk.

After the exam, my ophthalmologist suspected MS or a complication arising from Lyme disease. After an initial exam and an MRI, a neurologist leaned toward MS. However after a more thorough neurological exam and several tests, including a lumbar puncture, it turned out that despite having had antibiotics for quite a while for Lyme disease, I had an active Bartonella infection. A bit of reading illustrated that the antibiotics with which I had been treated for Lyme disease had in the past been shown to be ineffective against Bartonella *in vivo*. With a month of IV antibiotics appropriate for Bartonella, the eye problems disappeared completely. By the way: you can (as my doctors did) test for Bartonella with a PCR an eliminate the possibility of cross reactivity.

There’s enough literature documenting Bartonella and the damage it can do so that it’s worth taking seriously. In my case, I had the option to ignore a rapidly deteriorating problem and assume a) that it would be self-limiting or b) that my Bartonella result was a false positive and do nothing. But having read the literature, having had three doctors in different specialties all concur on the

Lattuada CP Jr; Dolan MJ; Schwab IR; Department of Ophthalmology, Wilford Hall Medical Center, Lackland AFB, Texas, USA. Source: Ophthalmology, 1998 Mar, 105:3, 459-66
 Abstract: <http://organtx.org/dc/comp2.htm> (scroll down for abstract)

Cat-Scratch Disease in Children-Texas, 9/2000-8/2001 (Archives of Dermatology): <http://archderm.ama-assn.org/issues/v138n6/ffull/dnm0602-1.html>

There are numerous articles readily available to anyone who cares to take a bit of time to search for them. The vast majority of those published in the last 3 to 4 years seem to agree that while the symptoms of Bartonella infections may sometimes diminish over time, it's also far more common than previously thought that patients develop chronic infections that may cause severe and permanent damage.

Having been told for 12 years that I couldn't possibly have Lyme disease while I suffered increasingly severe symptoms and what appears to be at least some permanent neurological damage, only to learn that I in fact **did** have it all along has inspired me to lean toward constructive skepticism when doctors disagree on a diagnosis. There's a wealth of information available online that can help you to decide who to believe, and unfortunately, I've learned that many of the physicians that I had formerly assumed knew their stuff had, in fact, failed to keep up with current research and were relying on what they learned in medical school in the 1970's or 80's.

I find it disgraceful that a licensed physician can, based on scant evidence, make a pronouncement ruling out a possible diagnosis when there is an established body of literature demonstrating that such a diagnosis is plausible — and that ignoring the possibility may risk severe negative outcomes for the patient.

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Endorsement of Inadequate Treatment for Lyme Disease

by Raphael B. Stricker, MD and Steven E. Phillips, MD

In the recent "Update on Infectious Diseases", the *Annals of Internal Medicine* has republished, without critical evaluation or rebuttal, the results of two controversial articles on the treatment of Lyme disease by Nadelman et al. and Klempner et al. (1). The first article endorses a questionable prophylactic regimen for acute *Borrelia burgdorferi* infection, while the second article undercuts effective therapy for chronic Lyme disease.

Nadelman et al. endorsed a single dose of doxycycline for the prevention of Lyme disease following a tickbite. Since the primary endpoint of the study, an erythema migrans rash, may be absent in up to 50% of patients who develop Lyme disease (2), the results of the prophylactic trial are highly questionable because roughly half of the patients at risk were not evaluable under the treatment protocol. Furthermore, the single-dose antibiotic regimen threatens to add to the growing risk of tetracycline resistance (3), and this risk is not outweighed by the possible benefit of treatment given the wide margin of error of the study results (95% confidence interval of 25-98%). Compounding the insensitive endpoint and perilous treatment protocol of the study, the six-week evaluation period was far too short to assess the development of later-stage Lyme disease due to persistent infection with resistant microorganisms.

Klempner et al. demonstrated that an inadequate antibiotic regimen was no better than placebo for the treatment of chronic Lyme disease. Of significance, the study found that roughly two-thirds (64%) of patients with chronic Lyme disease had persistent symptoms after standard

treatment for the disease. This alarming observation underscores the inadequate "standard of care" for Lyme disease in our country, and it emphasizes that **this "standard" is completely out of touch with the clinical reality of Lyme symptomatology for many patients** (4) [*emphasis added - ed.*]. The persistence of neurocognitive symptoms also raised technical questions about the study's problematic screening and randomization techniques (5).

In this setting, a combination of intravenous ceftriaxone for one month followed by low-dose oral doxycycline for two months cannot be considered additive or adequate therapy for chronic Lyme disease. If patients are sick enough to merit intravenous antibiotic treatment, clinical experience supports the use of longer intravenous regimens in these cases (2,6-8). Conversely, if patients fail to respond to one month of intravenous therapy, adding a dose of doxycycline that does not penetrate the central nervous system will not benefit these patients with neurocognitive symptoms (2,6,8). Thus the treatment protocol was doomed to failure because of its poor design, and it is misleading to characterize the study's ill-conceived antibiotic regimen as "long-term treatment". Furthermore, the conclusion that subjects were no longer infected with *B. burgdorferi* based on plasma and cerebrospinal fluid testing was spurious, since persistent infection can be demonstrated by tissue biopsy in seronegative animals and humans with chronic Lyme disease despite "appropriate" antibiotic therapy (9-11). Finally, the authors failed to consider coinfections with *Babesia*, *Ehrlichia* and *Bartonella* species in their

patients, and these tickborne coinfections may have contributed to patient morbidity when left undiagnosed and untreated (4).

Coming on the heels of an excellent discussion of the complexity of Lyme disease diagnosis and treatment (4), it is disappointing that the *Annals* has now chosen to disseminate flawed treatment information about a controversial illness without any warning to your readers.

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The authors are members of ILADS (International Lyme and Associated Diseases Society).

stamps the first doctor's position and the case is settled - as far as several aspects of health insurance. Namely, a higher pedigree authorized the denial of diagnosis and treatment, and secondly, there is less malpractice risk than failing to seek consultation.

Some patients are satisfied. It took only ten minutes and the doctor already had the answer before the patient walked or was wheeled in.

Others are not. These patients are seeking a second opinion meeting a standard of care about the disease that concerns them. They realize that it is not the duty of the consultant to set the standard of care (as above) but rather to interpret that standard for a particular illness for the patient - in this case, tick borne diseases.

Interpreting this standard of care requires utilizing the experience of caring for many patients and what has worked for them individually, being up to date in medical literature review, attending conferences, following the patient often for serial multi-visits or reviews to discover what of several coinfections are truly pathological and response to treatment, discussing alternative testing methods while disclosing the limits and flaws of each, and revealing issues where there is significant disagreement among the medical profession. It is never simply checking a flash card of guidelines and interpreting them as having regulatory power. If it were, there would be no need for a second opinion.

In those instances in which the patient, after consultation, wishes to pursue a course used by others than the consultant, the consultant certainly can withdraw but at the same time offers information about where and how to secure the treatment the patient wishes.

Patients and their advocates leave the consultant's second opinion with no question about which one of the two types they have been given. And which one they should demand.

Dr. Smith is a member of ILADS.

Second opinions and the Standard of Care

Patients should avoid "actuarial" second opinion

by Harold Smith, MD

Often a patient learns about tick borne diseases and may or may not have an initial laboratory test result supportive of tick borne disease as a cause of illness. When the same patient presents appropriate concern to a primary physician, that physician will frequently decline treatment based on clinical assessment alone, not order further testing, or will try to reassure the patient that there is no cause for concern about tick borne diseases. Unsatisfied, the patient is

often referred to a specialist such as one with post-graduate training in infectious disease or neurology for a second opinion.

It is very important for the patient to realize that there may be two types of second opinion and to be prepared to secure the one that is most beneficial to her/him, the patient.

The first type can be termed an "actuarial" second opinion. In this setting, the consultant just rubber

Patient Story

Christopher's Story

by Pat and Lem Kinnick

A cheerful, yellow "smiley face" balloon tied to a bag of brightly colored gumballs spelled "Welcome to class". The relief apparent on the face of its 8-year-old recipient was clearly evident. After months of physical, cognitive, and behavioral difficulties that had put his life on hold, finally a teacher was greeting Christopher with open arms and an

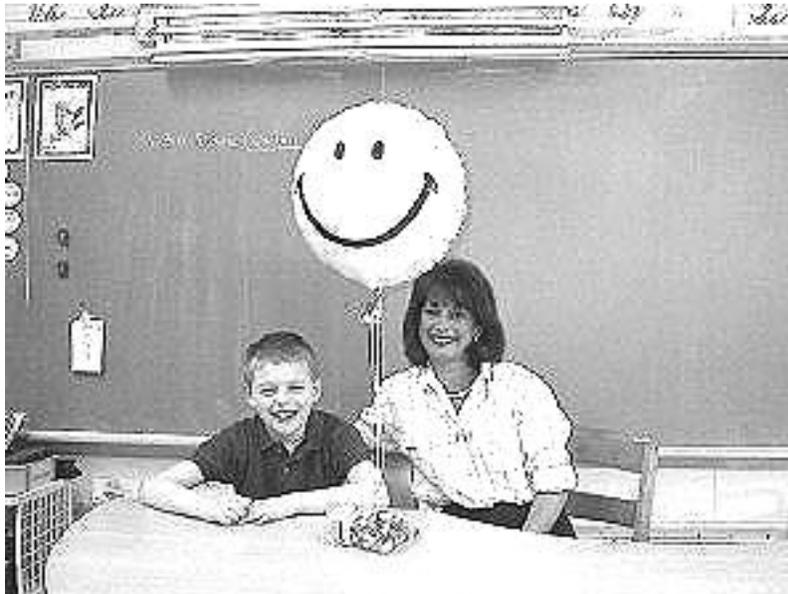
Lyme disease is on the rise and is prevalent in our local tri-state area. Although it hasn't received a lot of media attention lately, it is now found in at least forty-nine states and eighty countries. Lyme disease is thought to be our nation's fastest growing health problem and has become a very expensive thorn in our American insurance industry's side. Misinfor-

hope that it helps to increase awareness of the great need for accurate public education and continuing medical research. It's important that people realize what a huge toll this disease can take, if not diagnosed and treated in a timely and effective manner.

Christopher had always been a very healthy child and rarely needed to visit the doctor. He is also an intelligent child who earned mostly "A's" last year in first grade. Chris visited his pediatrician early in the course of his disease due to our concern about a suspected tick bite and a two-inch red, circular rash surrounding the bite area. A small

black "dot" about the size of a poppy seed was reported to the doctor to have been seen by us in the center of the bite area (but was unable to be obtained for closer examination). Although it was early winter, the weather had been unusually mild and our wooded northern Westchester County (NY) town shelters many ticks within its borders. The physician

Chris with his teacher, Mrs. Marti Rifkin (Teacher for Rockland County BOCES at the New City Elementary School)



understanding smile.

For more than eight months no one had realized that Chris's increasing distractibility, hyperactivity, anxiety and irritability had a physical basis. Instead of being a "bad kid," he was ill with an infectious disease that was seriously affecting his brain and central nervous system. This illness was probably contracted during an afternoon backyard romp with his friends or on a field trip to a local apple orchard. The culprit? A minuscule tick, as small as the period at the end of this sentence, that carries the bacteria known to be the cause of Lyme disease.

mation and debate regarding its symptoms and treatment abound in the public sector and medical community alike. It is a multi-systemic disease that can affect your eyes, heart, joints, nervous system and brain. With 300 known varieties of Lyme bacteria in existence, the disease can affect people in different ways. The popular belief that Lyme disease "only" produces fatigue and painful joint inflammation is an incorrect myth. If incorrectly diagnosed and treatment is delayed, Lyme disease can ultimately result in permanent disability. We would like to tell you one child's story in the

however, dismissed the rash as "not typical" and too small to be considered a sign of Lyme disease. In less than a month Chris returned to his doctor with a second red circular rash on the sole of his foot. This was followed a few weeks later by our phone call to the office nurse regarding a fever and red circular rash around his mouth. Despite all of this, Lyme disease was not considered and/or tested for. Unfortunately for one 8-year-old boy, valuable medical treatment time was being wasted.

As time went on, Chris's illness progressed and increased in severity. We met with his pediatrician to

discuss the dramatic changes in his school behavior as well as physical health that had been occurring for the past several months – all since the initial suspected tick bite and rash. His parochial school teacher reported that he was becoming very distractible and spilling his lunch frequently. He developed low frustration tolerance and even had a temper tantrum in school, something that had never happened before and was very unusual for him. Still, testing for Lyme disease wasn't considered. Instead, Chris's parochial school principal decided it was in his best interest to be kept home from school alone (without benefit of any school provided instruction) for the entire month of March while a parent-financed psychological/educational evaluation could be conducted. In addition, Chris's pediatrician referred him to a local neurologist who (after a 10 minute office examination, a parent interview, and a review of his school report) attributed (incorrectly) his **rapidly** increasing distractibility and hyperactivity as worsening ADHD. The neurologist prescribed a trial of a stimulant drug commonly prescribed for attentional difficulties. Chris then transferred from his parochial school to our small local public school in the mistaken belief that the educational resources enjoyed by the well financed district would result in a program that would better meet his needs. This very quickly proved to be farthest from the truth.

Soon Chris was enduring severe side effects while taking the stimulant medication. These side effects included greatly increased anxiety and paranoid fears. These fears were first observed in the classroom by public school staff (i.e. Chris expressed fear that he was being poisoned by the school hand soap and lead pencils) and were recorded in a pupil log, but were only communicated to us two and a half months later! Even though the public school staff had been informed that he was on a drug trial and were all well trained professionals, this vital

information remained "in house." If these obviously severe symptoms had only been reported to us at the time, Chris would not have been given additional doses of a drug that was causing him such great distress. Within a short time, Chris's drug induced fears lead to a tantrum that included chair swinging to "protect" himself from the people he feared. This incident earned Chris a one-day suspension from school and absolutely no consideration from school professionals that his new medication might have played a role in the severity of the tantrum. Throughout all of this, Chris's Lyme disease

"My brain hurts when I have to think."

Christopher, age 8

remained undetected and continued to worsen.

This is by no means the end of the story. Undiagnosed and untreated Lyme disease continued to seriously affect Chris's life. Like the domino theory, one thing after another continued to lead to yet more misery. The one-day suspension was "informally" lengthened, at public school staff request, to almost an entire month's removal from school. For this extended period, Chris sat at home without any instruction provided by the school district. He missed an important portion of his education; despite the fact education law prohibits this. Chris's behavior was viewed by public school staff (who had only known him for three days) as completely emotionally based, and the services of a consulting psychiatrist to the school were recommended.

Psychiatrist threatens Chris

On Chris's first visit to the psychiatrist he was too uncomfortable to discuss his behavior with

someone new (and we now understand that Chris couldn't have possibly understood the cause of his newly deteriorating behavior) and he thus became frightened when the psychiatrist told him that he risked ending up in a residential hospital treatment program if he didn't improve. This same psychiatrist determined that Chris had an "unconscious agenda" to exhibit difficult behavior and communicated this theory with the school psychologist. Does the story improve at this point? Not by a long shot.

The "Go Back" plan

After a month spent in virtual isolation at home, Chris was invited to return to school for a second try. By now it was May and Chris's undiagnosed Lyme disease had continued to worsen over time. Doctors incorrectly attributed all new symptoms to stress induced anxiety. We were told that public school staff, in conjunction with the consulting psychiatrist, had formulated a "Go back" plan designed to successfully ease Chris back into school. Its goal was to help make Chris's school experience a positive one. However, like so much else, it left much to be desired. Except for provision of a shortened day of only two hours (more instructional time lost) there were no educational modifications or behavioral plans/supports put in place to attempt to help Chris.

The worsening effects of the Lyme bacteria in Chris's brain and central nervous system resulted in his having trouble thinking, concentrating, and processing information. He was over-whelmed, worked very slowly and frequently said he couldn't do the work. Chris explained to one doctor, "My brain hurts when I have to think". In addition, Chris was now exhibiting neurological symptoms that included obsessive/compulsive behaviors, motor tics (i.e. touching others), facial grimaces, increasingly more severe hyperactivity and making odd noises. All of this, plus the physical problem of increas-

ing fatigue and very frequent urination, was perceived by public school staff as deliberate misbehavior and avoidance of work. How difficult it must have been for a seriously ill second grade child to cope with constant criticism for worsening behaviors he couldn't control, let alone understand. Can you imagine the negative effect this had on his self-esteem and self-confidence?

As many people could have predicted, this "Go back plan" didn't work out under the existing circumstances. In no time at all, Chris was once again sitting alone at home without instruction. This time we were smarter and insisted that home tutoring be provided by the district, as is required by law. All in all, Chris received a total of only 16 hours of home instruction (out of a four month period) by the end of the school year.

Parents told not to worry about Lyme

How was Chris's Lyme disease finally diagnosed? I'm sure you are probably assuming that his physicians ultimately realized (as they

should have) that something was physically amiss and decided to investigate. It is a sad commentary that **it was only at our insistence that a Lyme test was finally performed.** After so many months we still remembered the initial suspected tick bite and red circular rash. It seemed odd to us that Chris had never been well since that time. The first test (a Lyme titer or ELISA) returned positive. A follow up titer was also positive, as well as a positive Lyme screen. For some unknown reason, these last two positive results were not even reported to us at the time (and were only discovered when we asked for photo copies of the lab results). A fourth test (Western Blot) was declared negative because only 4 antibody bands (instead of the required 5) were positive. Despite the first three positive test results and all of Chris's worsening clinical symptoms the physician declared that Lyme disease was ruled out. We were told not to worry about Lyme disease any more. The psychiatrist even contributed his erroneous belief that "even if Chris has Lyme disease it

doesn't affect behavior at all".

Fortunately the story did not end here. We had a well-respected Lyme specialist review his case. This doctor recognized correctly that Chris was suffering from probable Lyme disease and arranged for Chris to be seen by several noted Lyme specialists. He didn't understand how a child who had exhibited such classic symptoms of Lyme disease and who resided in a Lyme endemic area had gone undetected for so long. After much testing and evaluation, Chris was diagnosed with chronic Lyme disease as well as several other tick borne illnesses. It is now known that ticks frequently carry more than one type of bacteria and co-infection is becoming more and more common.

After so many months with untreated Lyme disease, Chris was exhibiting increasingly more serious problems. By late spring he had days where it was difficult for him to walk a straight line, had trouble performing simple fine motor tasks, exhibited short term memory difficulties and dyslexic type reading problems, was so distractible that he was unable to complete a simple worksheet in the quiet of his home without constant adult help, and had several mild seizure-like episodes. Chris's Lyme disease was multi-systemic and included brain and central nervous system involvement.

The improvement seen after antibiotic treatment was initiated was nothing short of miraculous! It took approximately three weeks for improvement to begin to be noticed, and the healing has slowly continued since. At this point Chris has received intensive antibiotic treatment for more than three months and he appears so much healthier. Symptoms still continue to fluctuate (a peculiar characteristic of this disease) but are milder and less frequent. This fluctuation indicates the continuing presence of active Lyme bacteria in Chris's body and the future course of the disease remains to be seen. Many Lyme disease specialists do not speak



Chris with Dr. Charles Ray Jones, a pediatric Lyme expert in New Haven, Connecticut. Dr. Jones recognized that Chris was suffering from several tick-borne infections.

of a cure under these circumstances, but rather their goal is to achieve cessation of symptoms without relapse. Chris's pediatric Lyme disease specialist holds a more optimistic view and is hopeful that a cure will eventually be achieved. Much still remains to be learned by the medical community regarding diagnosis and treatment.

What are the consequences to date (bear in mind that his struggle still continues) that Chris's Lyme disease has incurred? Early diagnosis and proper early treatment could have avoided:

- Over \$24,000 (and climbing!) in expenses including doctor visits, medications, medical testing, neuropsychological testing, attorney fees (to protect Chris's educational rights), psychological evaluations, loss of parent wages due to unpaid leave of absence from work, travel expenses to medical appointments, psychotherapy, etc.

- The discomfort, stress and anxiety for Chris incurred by on-going medical procedures (frequent blood tests, MRI, EEG, EKG, Cat Scan, Brain Spect Scan), numerous doctor visits, intensive antibiotic treatment, and various educational/cognitive evaluations.

- The loss of valuable educational instruction time (March – June) and peer socialization with classmates, so necessary for healthy development.

- The humiliation and resulting damage to Chris's self esteem and self confidence by being repeatedly criticized and disciplined by school authority figures for disease-related behaviors and for behaviors caused by a severe drug reaction.

- Damage to physical health, emotional well-being, and cognitive functioning. Only time will tell if this damage is temporary or permanent.

- The uncertainty and anxiety for us of not knowing when (or even if) a permanent cure will be achieved.

Unfortunately, Chris's public

school district proved to be very uneducated about Lyme disease and its various possible effects on learning and behavior. Even when numerous medical reports were submitted to the local CSE, their conclusions were virtually ignored. Despite the fact that Chris was finally diagnosed with an infectious illness that was being successfully treated with antibiotics, the CSE pushed to have him placed in a highly segregated class for severely emotionally disturbed/acting out children. Most sadly of all, this was done **after** Chris had begun to respond so well to treatment. Why? Because no one in the district took the time to observe him **after** antibiotic treatment had begun to alleviate symptoms. The public school psychologist observed and tested Chris in May at the height of his illness – prior to treatment, and based his recommendations on this time period. When Chris's doctors submitted their observations of his improvement to the district in July, it made no difference. Wouldn't you

Charles Ray Jones Video

Dr. Jones was featured in an article in the Lyme Times #32, which may be viewed on the LDRC website at www.lymetimes.org. He is the 2001 recipient of the LDRC Distinguished Physician Award.

A one hour documentary of Jones which has played on community television stations throughout Connecticut, may be purchased (\$35 plus shipping) by contacting Dolly Curtis Interviews at 35 Flat Rock Road, Easton CT 06612, Telephone 203-372-4511, or dollycurtistv@aol.com.

Curtis's website is www.dollycurtisinterviews.com. The video includes a 1/2 hour interview with Jones and 1/2 hour of Jones examining and talking with 5 different children of various ages.

think professional educators and psychologists in a Lyme endemic area should know better? Unfortunately for many children, they don't. It was necessary for us to be proactive, do our own research, and locate an appropriate, supportive class for Chris. With wise legal counsel (the services of an educational lawyer proved to be very helpful) we were able to assist our school district to finally make an appropriate class placement for Chris.

In our Lyme disease endemic area it is a terrible shame that **any** child should have to suffer so severely from a disease that could have been successfully treated in an earlier stage. It is a shame that public awareness of this disease is limited and misinformation abounds. If only the initial circular rash and probable tick bite had been properly investigated and treated by Chris's primary physician; if only the consulting neurologist had asked if Chris had visited his pediatrician for anything unusual in the past year; if only the consulting psychiatrist, principal and school psychologist had not been quite so quick to dismiss consideration of possible physical causes for Chris's newly developing behavioral difficulties; if only members of the medical community would stop arguing amongst themselves about Lyme disease and begin to work together to better help their patients; if only children like Chris wouldn't ever have to tell their parents again that "being eight years old hasn't been fun at all". We can only pray that when Chris turns the ripe old age of nine, he'll do so with a smile. Childhood shouldn't have to be this difficult, and hopefully, increased public awareness of Lyme disease will eventually improve the situation for all of our children.

Christopher Kinnick lives with his parents in North Salem, N.Y.

Feature

The Treatment

A short story

by Roxana Robinson

Here is what I do each morning. As soon as I wake up, barefoot and still in my nightgown, as though I were on the way to my lover, I go downstairs to the darkened kitchen. I'm alone in the house: my husband leaves early, my daughter is away at college. I don't bother to turn on the lights. I go straight to the refrigerator and open the door to its icy glare. From the refrigerator I take a chilled golden globe, the size of a small orange. It's made of firm and springy plastic, and it's solid, with some heft. The pearly outer sheathing is translucent, obscuring the glowing interior and giving it a muffled shimmer. I set the globe, with its neat coil of attached tubing, on the kitchen counter. For the next three hours it will lie there, slowly warming, so that when the fluid inside enters my vein, it will be not cold and torpid but swift and potent. What's inside the radiant globe is Rocephin, a powerful antibiotic, which will cure me.

When you are not ill, when you are well, you think about yourself in a particular way. You take being well for granted: that is who you are. You are someone who does not have to think about her body. Not having to think about your body is a luxury, but since you have always had it, you aren't aware that it's a luxury. When you think about sick people, you think of them as different from you, set apart in some unspecified way: they are Other. They are beyond a mysterious divide. They are branded somehow, in a way you don't consider much. Even if you do consider it, you can't get very far. Why are other people sick? Why are you not? There are no reasons; there is no logic. Things are

the way they are. In some interior, subliminal place you believe that you deserve your health. The person you are, it seems, deserves to be healthy, just as the person you are seems to deserve two legs, a nose. I had two legs, a nose, my health

Ten days ago the line was introduced into my vein. I lay on a narrow examining table at the doctor's office, waiting while the nurse assembled her instruments. She was pleasant and perky, rather glamorous, with long blonde hair and gleaming red fingernails. I lay perfectly still. I was prepared for everything, anything; nothing she did would distress me. This was the initiation ceremony, the start of the healing. It was frightening, but I welcomed it, whatever terror it held. I was embracing the source of my fear. The treatment would be my salvation.

The nurse pulled up my sleeve and exposed the white skin on the inside of my left elbow, the sacrificial site. She cleaned it and laid it down, bare, beside the row of instruments. She took up a length of tubing, like a long, transparent snake. Casually she measured this against me from elbow to shoulder, across under my collarbone, and then down to just above my heart. Here the mouth of the snake would dangle for six weeks.

When the nurse was ready to begin, she paused and looked up at my face. "You're going to feel a pinch," she warned.

I nodded. I knew that "pinch" was code for pain. The nurse looked back down, and I turned my head away. I stared at the square white tiles in the ceiling while she worked, piercing my

skin, invading my body. I could feel her movements. I didn't look.

"I hate when it spurts," I heard her say crossly. "Now it's all over the rug."

I said nothing. I didn't turn to look. No part of the treatment would trouble me; this is what would save me. I stared at the cross-hatching on the tiles while she slid the snake into my vein and sent it up the length of my upper arm, through the widening veins across the top of my chest, and down to the great thunderous vessel directly above my poor heart. I said nothing. This would save me.

Taking pills three times a day is meaningless. Anyone can do it; people do it all the time. The act has no implications. You are simply correcting something, an aberration. Having a plastic tube inserted into your bloodstream, dangling over your heart, is different. It is a violation of your deepest recesses. It moves you into a darker, more dangerous place. It means you are ill, and helpless.

After three months the oral antibiotics had stopped working, and I went back to my doctor. We sat in his office, which is pleasantly cluttered in a domestic way. It has a bright hooked rug on the floor, a tall standing bookshelf, and a big ficus tree with glossy leaves in front of the window. Dr. Kennicott has no desk; he sits in a brown-plaid wing chair. When he wants to write a prescription, he sets a polished wooden board across his lap.

Dr. Kennicott is a quiet man with a kindly manner, slightly bohemian. He has mournful brown eyes and shaggy graying hair and sideburns. He wears a white lab coat, khaki pants, and black-leather running shoes. He sat in the wing chair, and I sat in a smaller chair across from him.

"My neck is stiff again," I said. "I can't turn my head any further than this." I had more to report: the symptoms were back. As I talked, Dr. Kennicott frowned sympathetically, his sad eyes attentive. His elbows

were set on the arms of the chair, his fingers steepled just under his chin. When I finished, he nodded slowly. "That often happens," he announced.

This puzzled and disappointed me: then why had we used that treatment? I'd never before been to a doctor who prescribed something that he knew often didn't work. I'd never been to a doctor who didn't just fix what was wrong

"Then what do we do now?" I asked.

Dr. Kennicott pushed out his lips thoughtfully. "I'd suggest moving on to intravenous antibiotics."

"No," I said at once.

I knew about intravenous – he'd mentioned it before. I didn't want it. It was too serious, too alarming. I told him it wasn't justified: I wasn't that ill. I was basically healthy, I told him. Other people have this disease and are treated for it and recover completely. That happened to my daughter: she was treated for it at once, and now she seems fine. I am basically fine, I told him

The doctor said nothing while I explained this. He said nothing when I stopped. He sat in the wing chair, his hands steepled under his chin. He watched me quietly, waiting for me to understand. Finally I stopped and looked at him, alarm dawning

To understand that you are seriously ill is to cross over into a different country. You are apart from other people now. Something separates you from them, something you cannot change. The realization is like a fall from a great height. You are silenced. You have no recourse. You cannot help yourself. Your body has failed you, and you are helpless. You must change your expectations of all things. You must put yourself in the hands of the healers. They may fail.

When I understood this, I fell silent. I was in a new place. Things were not as I had thought; arguing with the doctor was useless.

This disease, like syphilis, is

carried by spirochetes. We have reason to think that the spirochetes have been in my bloodstream for a decade, for who knows how long. Now, apparently, these spirochetes have set up their malign outposts all through my body. They're in my nervous system, my muscles, the connective tissue inside my joints, my spinal cord. They have stiffened my neck and my shoulders. They have turned my muscles leaden and my limbs resistant, so that when I move, I feel as if I were struggling against an invisible network of tightening bonds. The spirochetes may even have infiltrated the tender, private whorls inside my cranial basin. This idea is so frightening, though, that I don't allow myself to think about it. I don't permit myself to slide into that well of terror. I can't afford to.

The treatment frightens me too, but I can't afford that fear either. I've given myself up to this, like a postulant giving up her soul to God. I'm allying myself with this larger power. The treatment will be my salvation. I can't afford to believe otherwise.

This morning, when the moment for the infusion arrives, I go back to the kitchen from my study. I'm dressed now, in jeans and a sweater. I work at home, getting my doctorate in early childhood development. I've finished the coursework and am writing my dissertation, which means that I don't have to explain to anyone why I now spend every morning at home, unavailable to the world, engaged in a private and fearsome activity.

At the sink I wash my hands with a liquid anti-microbial soap, a surgical scrub. It has a thin, acrid smell, and afterward my skin feels raw. This is proper; this is part of the ritual. I am preparing myself for the secret chamber. My movements now are precise. From my big box of medical supplies, from my zip-locked plastic bags, I take three blunt-nosed syringes. The two white-capped ones hold saline solution, which will be injected before and after the

Rocephin, to clean the tubing. The yellow-capped syringe holds heparin, a mild anti-coagulant. This goes in last, so that the blood idling in the tubing between treatments will not form clots. I lay all these things out beside the globe. The instruments are ready.

I pull up the sweater on my left arm. Clapsed along the inside of my elbow is a white elastic fishnet sleeve that holds the apparatus tight against my skin. I slide this off, letting a translucent line of tubing uncoil downward into the air. One end of this is taped flat to my skin in a serpentine loop before it disappears into my flesh. The other end, interrupted by a small, transparent junction box, ends in a blue valve. This is called a Clave, and it is shaped like the head of a lizard, narrowing and blunt-nosed. I open a foil packet holding an antiseptic swab, and its sharp alcohol odor blooms in the air, powerful and sobering. With a little bad luck any germ I carry at this moment will be transported directly to my heart

Carefully I swab the surface of the Clave. Holding it aloft, sterile, with one hand, I unscrew a white-capped syringe with the other. I screw the threaded nose of the syringe into the Clave. On the line of tubing is a triangular cock, and I slide the tubing free of it. The line into my vein is now open.

I press down on the plunger. The loaded syringe holds two and a half milliliters of saline solution. I watch the solution creep down the coil to where the tube vanishes under the surface of my skin, and the liquid enters my body. I can feel its cold arrival in my vein. I press the plunger slowly down until I reach the flattened air bubble at the bottom of the shaft. I unscrew the syringe and set it down. Still holding the Clave in the air, I unscrew the small cap on the Rocephin line and set its transparent nose into the opening of the Clave. Like the syringe, it screws neatly in. This connection feels smooth and

satisfying, and I am gratified by it, as though such technical perfection means that the treatment will work in just this beautifully engineered way.

I sit down and lean back. Now I'm connected. The valves are open, the liquid has begun its journey into my body. The golden globe is pressurized; for the next forty minutes it will slowly contract, forcing the Rocephin steadily into my bloodstream.

I close my eyes. My part in this is like prayer: I concentrate on what is taking place inside me; I visualize it. I see the golden tide beginning its silent warrior's surge, past the heart and through the wide channels of the great arteries, the smaller ones of the arterioles, moving deep into the interior, into the narrow waterways of the capillaries. I see the golden tide moving into a still lagoon. Calm water on pale sand. The movement is visible, a low, relentless surge. Along the irregular shore a ripple breaks in a narrow line of foam. I hear a sighing hiss, a small, seething commotion: the spirochetes, the tiny corkscrews of the disease, are sizzling in a frenzy of death. I hear them thrashing; I see the surface of the water along the shore boil and churn as they jitter. They twist and sputter as it hits them. They are dying, dying in droves, dying by the millions, at the touch of the smooth golden surge.

During my first week of the treatment I had the predicted reactions: high fever; chills and headaches; brief, wild, stabbing pains in all my joints. I'm told that all of this results from the spirochetes' dying off. I believe this is true. The infusions are Asian hordes sweeping across the wide plains, overwhelming our enemy. I lay in bed, sick with fever, feebly triumphant.

Now the fever has stopped, and I'm better but not well. I know I am ill. I feel as if I were walking carefully on some unreliable surface, not knowing what movement might cause a sudden terrifying crack and plunge. Yesterday I took the dogs out for a walk through the woods, down to the winter-dark

pond and past it, up the hillside beyond. The woods are brown and mysterious now; the trees creak ponderously in the wind, and their gray filigree tops sway silently. The narrow path was soft underfoot. Walking along it, climbing the steep slope of the hill, I suddenly felt the delicate, tangling grope of the snake inside my chest, a dry, grappling sensation just above my heart. When it happened, my heart began to pound, panicky, shrinking from this alien presence. I had nowhere to go for help. I was the one who gave permission for this. My brain believes it's good; my body fears it. I stood still, on the soft path. I tried to calm my heart. Above me the tops of the trees moved slowly, swaying against the gray sky.

On a Saturday my husband, Mark, comes into the kitchen when I'm getting ready to infuse. He's been out in the village doing errands, and now he stands just inside the door, setting down packages. I know he sees my equipment on the kitchen counter, but he keeps his eyes away from it, as though it were a naked body.

"I couldn't find the coffee you like," he says, unzipping his parka. His voice seems loud and artificial.

"That's all right," I say. "They have it at Sgaglio's. I'll get it tomorrow."

"I got everything else," he says. His eyes now fix on mine, faintly accusing, as though I've contaminated the kitchen.

"Thanks," I say, conciliatory.

He ducks back out into the mudroom, to hang up his coat. When he comes back in, he shuts the heavy kitchen door hard.

"You're welcome," he says. Still without looking at my syringes, his dark gaze fixed on mine until it shifts to the door, he heads for his study. Mark is a philosophy professor, and his mind moves either in great wheeling arcs or in little tiny circles, depending on your point of view. I hear him sit down in his study. Alone

in the kitchen, I turn back to my instruments, but now the sight of them fills me with dread. They look diabolical, like something from a horror movie.

When they are ready, I tell myself that Mark was just uncomfortable, not horrified. Or he was abstracted, as he often is. I call in to him in his study, my voice playful. "I'm about to shoot up. Want to watch?" If he'll be part of this, it will be less frightening; it will seem more normal. But he doesn't want to watch.

"No thanks," he calls from his study. His voice is not playful, and after a moment I hear his door close quietly. I know he finds all this repugnant — and why shouldn't he? Why should he have to share it with me?

He's not the only one. My friend Sarah came over one morning, and when she saw my syringes in their bags on the counter, she jumped nervously behind me. "I don't want to look at them," she explained.

I begin to wonder if I should wear a bell, to warn normal people of my approach. I feel frightened and isolated. I can see I am alone here.

Last night, in bed, when Mark was ready to go to sleep, he closed his Kierkegaard and set it on his bedside table next to the clock. "That's it for me," he said. He took off his glasses and rubbed fiercely at the bridge of his nose, which glistened. He folded his glasses, set them on top of his book, and turned off the light. When he rolled over on his side, toward me, I was waiting for him.

"Put your arms around me," I said, and my husband did this at once, gathering me wholly against him. My face pressed close to his chest. Surrounded by his comfort, I said, "Tell me I'm going to get well." I needed to hear the words.

I felt Mark's hand on the back of my head, stroking my hair. "You're going to get well," he said.

"Say it again," I said, pressing my face against his chest.

Tonight I'm alone. Mark is away at a conference, but a visiting nurse, Ginger, is coming. It's her second visit. She came early on to change the bandages around the tube after it was first put in. Now she's going to change the tube. I'm uneasy about this, because I don't know what it means. Will she pull out the whole long snake that has burrowed its way so deep inside me? Drag it out from its secret nest above my heart? I'm frightened to have it in there, but I'm also frightened to have it moved.

Still, I'm looking forward to seeing Ginger. I know I've done well, and I'm proud of myself. I'm looking forward to her praise: I'm a good patient. The pains are mostly gone, and both their arrival and their departure are proof of my prowess. The opening where the line enters my skin is pale and healthy, not inflamed. Each morning I have performed the infusion successfully, sending the golden tide deep into my interior. Each day, screwing the tiny threads into the Clave, unlocking the entrance to my veins, plugging myself into the heavy golden globe, I feel the Rocephin rush silently into my bloodstream and I feel charged with victory. I feel the spirochetes failing against this magnificent onslaught, overwhelmed, undone. I know we'll be victorious, and my nurse knows it too. She is the agent of my healing. Her presence plays a part. It will make this real. She'll infuse me with hope and conviction.

Around eight o'clock Ginger arrives. She opens the back door and bustles cheerfully into the kitchen. "Hi there," she says, boisterous and good-natured. The dogs sniff her, wagging their tails. "Good dog," she says in a croon, leaning unctuously over them and patting their heads too hard, "good dog." Ginger is in her early thirties and thickset, with bushy brown hair in a wild, shoulder-length aura. She's wearing a knitted wool dress, a heavy sweater, and dark, clunky shoes. She's powerful and clumsy, like a shaggy little bull.

Ginger sets down her bag and takes off her padded jacket, already talking. "I just came from an auction in Poughkeepsie," she says. "It was fun."

"Great," I say. "Did you get anything?"

"A rocker," she says emphatically, delighted I've asked. "A porch rocker. It's real old and funky. I really love it."

"Great," I say again.

I don't care what she bought, but I'm so pleased to see her that she could read aloud from the telephone book. I listen happily as she gabs, watching her take out a big plastic packet, sealed and sterile, full of small, intricate objects in their own antiseptic packets. She spreads them on the kitchen table, and I sit down. Outside, the darkness is thickening, and we lean together under the hanging lamp. I lay my arm on the table and roll up my sleeve. Ginger takes off her sweater and tosses back her heavy mass of hair. She is large at that table, breathy, fleshy, bulky. I wish her hair were in a bun. I wish she were lean and smooth, clipped and austere, in a white uniform.

"So, how have you been?" she asks.

"Fine," I say with pride. "Some aches and pains in my joints, but that doesn't bother me."

Ginger nods. "My patients who have this love feeling achy," she says, as though this is an endearingly foolish trait. "They think it means they're getting better."

I smile with her; I know they're right.

Ginger opens her sterile packets, ripping back adhesive strips, putting on thin gloves. I am nervous about this procedure, the hidden snake, fearful of what she is about to do. She yanks off the bandage holding the plastic shunt flat against my arm, to where it enters my skin. As her hands near the opening, I turn rigid. She stops. "Where does it hurt?" she

asks.

"It doesn't," I say. "I'm just wary." In fact I am terrified.

"You think I'm going to pull the adhesive back against the tube," she says indulgently. "We're taught as rookies always to pull with the tube. You pull against it" – she makes a sudden ripping gesture, as though she is about to jerk the unprotected tube from where it snakes into my skin – "and you'd pull the shunt right out of your arm. Like, that is not therapeutic."

I say nothing, trying to calm my heartbeat. My whole system is running on alarm. My heart is pounding. That dangerous gesture, the mimicking of violence, has shocked me. She now begins to do delicate things to the tube. I don't want to watch, and to distract myself I look at her face.

"Do you do this a lot?" I ask.

She told me last time how grateful her patients are, and I want to hear stories of her successes. I want to hear how this disease is vanquished, how good she is at her work, how powerful and inexorable this treatment is. I am greedy for these stories. I want to count myself among this healing crowd.

Ginger looks up. "Oh, yes," she says. "I do chemotherapy all day long."

I frown; this isn't a word I want to hear. This is not a group I want to belong to. "No," I say. "I mean do you do this – treatment for my disease _ often?"

"Oh, yes," Ginger says again. She bends over the tube. Her heavy hair falls over her shoulder, hanging in a thicket above the instruments. "In fact I have one patient who lives right near you. He's been on intravenous treatment for two years."

"Two years?" I say. I've been told mine will last six weeks

"Yes," she says, shaking her head. "He's in terrible shape. He's

had your disease for years, and it wasn't treated right away. He's nearly paralyzed. He's trying oxygen-chamber treatments now. Nothing really seems to help him."

I don't speak. I wish she weren't bending so close to my arm, which now lies bare and vulnerable beneath her fleshy face. The transparent tube curves down beneath my skin and disappears. The whole region of my arm twitches with alarm, with the extremity of its exposure. If she just jostles the tube accidentally now, the possibilities of pain will be horrifying. I cannot permit myself to think of the possibilities: infection, the lethal transmission of things directly to my heart, my poor vulnerable heart, its chambers directly under the snake's dangling toxic head. I feel that everything is dangerous now, that our passage together through this process has become perilous. Each step is crucial.

Ginger shakes her head again. "This is really a terrible disease," she says.

I cannot bear to hear what she is saying. I say rudely, "Don't you have any better stories?" My arm, in her hands, feels bare and frightened.

She looks up. "About this disease? No. If it isn't treated right away, it's really terrible. You see, it mutates in your system." I stare at her, appalled, willing her to stop telling me these things. She looks earnestly at me, her huge, bristling hair surrounding her face. "What happens is that the spirochetes, if they aren't treated right away, change form, so that the treatment can never catch up with the disease. Each time the doctor tries something new, the form is different. The disease goes deeper and deeper into your system. This man has it in his spinal cord, and it's gone into his brain; he has neurological symptoms. Now he's going to doctors who have it themselves, to see how they're treating their own diseases."

I stare down at my arm, mesmerized with horror. As she talks, against

my will I am picturing the spirochetes in my own system, spiraling deeper and deeper, burrowing their way into my spinal fluid, sliding unstopably into the crevices of my brain. Each word she speaks makes this real, inevitable, incontrovertible.

All my feelings of triumph, of power, of victory, are ebbing, cascading toward ruin. She is destroying everything I have accomplished. I hate the words she is saying. I hate what she is doing to me. I want to rip the tubing out of my arm. I want to tear out everything she has touched and throw it aside and order her from my house. She is casting a spell. She is cursing my body. She is destroying the health and vigor of my flesh. She is shattering my hope. She is declaring the futility of everything I am struggling to achieve. She is showing me a future of misery and despair. She is deriding my belief in the golden tide. I hate her more than I could have imagined possible.

Looking down at my arm, I say in a strained voice, "I don't think you should talk this way to your patients."

Alarmed, she looks up. "What does your doctor tell you?"

"He doesn't talk to me like this," I say, my voice choking. "And you should never talk like this to a patient."

"I'm sorry," Ginger says. She is clearly unsettled. "I'm a very sensitive person. I wouldn't have upset you if I had known."

"I've had this disease for ten years, and it hasn't been treated," I say. I am struggling. I am desperate to keep from crying. "I don't want to hear about this."

Shaken, Ginger bends over the tubing again. She is not changing the long snake, I discover. She is replacing only the outer section of it, the part that goes from the Clave to the junction, but I now hate having her touch me. She is contaminating me; her touch is dangerous, poison to my

body. Her touch is lethal to me. I imagine ripping everything out of my arm, flinging the transparent coils away from me onto the floor.

She works for a few seconds in silence, and then starts up again. "Last time I came," she says carefully, "we talked about your daughter, remember? Who has this too, right? And was treated for it?"

How can she not have understood me? Does she imagine I want to hear this about my daughter? "I said I don't want to talk about this," I say.

I am now swollen, huge with wrath and despair and grief. I am outraged that she would choose to use her power over me in this way, that she would come to me disguised as a healer, and reveal herself instead as a black demon, an agent of doom and anguish. I want her to get out of my kitchen, out of my house, off my property. I want to sic the dogs on her. I sit in raging silence while she finishes. She pads heavily back and forth, cleaning up, throwing things away. Her head is down, her face averted. I think she's crying. I don't care.

I want only to control my tears, to keep from breaking down in her presence, to achieve merely that. And in that one small thing I am victorious.

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Time for Lyme

continued from page 1

Deborah Siciliano and LDA president Patricia Smith presented the inaugural "Time for Lyme Outstanding Service Award" to United States Senator Christopher J. Dodd (D-CT) for his advocacy of national Lyme disease legislation. In accepting the award, Senator Dodd recognized the important work of GLDTF in promoting Lyme disease education and research. He also announced that he would be re-introducing a Senate bill that would provide funding for better prevention and research.

The Honorable Richard Blumenthal, Connecticut's Attorney General and Dr. Brian Fallon, Associate Professor of Clinical Psychiatry at Columbia University College of Physicians and Surgeons and director of its Lyme disease research program, also participated in the event. Connecticut Governor John G. Rowland served as the Honorary Chair. Well-known designer and

L-R standing: LDA president Pat Smith, Dr. Brian Fallon, director of the Columbia University Lyme Disease Research Center, Senator Dodd, Conn. Attorney General Richard Blumenthal, and Dr. Anthony Iton from the Stamford, Conn. Dept. of Health. L-R seated: Diane Blanchard and Debbie Siciliano.



Connecticut Senator Christopher Dodd, *left*, honored at the Time for Lyme benefit for his advocacy of national Lyme disease legislation, recognized the work of Greenwich Lyme Disease Task Force in promoting Lyme disease education and research. With him, *L-R*, are GLDTF co-presidents Diane Blanchard, Debbie Siciliano, and LDA president Pat Smith (behind podium).

event co-chair William Bainbridge Steel turned the Hyatt Regency ballroom into a fabulous disco club. Co-chairs Julia Knox, Cindy Rinfret

and their hardworking committee put together the spectacular silent and live auctions, cocktail reception and gourmet dinner, entertainment by Denev Terrio and Motion and disco dancing to Yellow Brick Road. Kendra Farn, WNBC News Correspondent and Noah Finz, WTNH Sports Director, were the Masters of Ceremonies.

Greenwich Capital Markets, Inc. and UBS Warburg were the principal sponsors of the gala. Day, Berry & Howard, LLC, Greenwich Hospital, Grey Goose Vodka, LadyBugDesigns, Tiffany & Co. of Greenwich, U.S. Trust Company of Connecticut, and William Bainbridge Steele Floral Design were also returning sponsors and underwriters.

GLDTF was founded five years ago by Blanchard, Siciliano, Fran Herzog and others whose families were affected by the ravages of undiagnosed Lyme disease. Herzog currently serves as GLDTF treasurer. Their goal was to find answers through research, to educate the public as well as health care professionals, and to advocate for legisla-

tion that addresses such issues as funding, reporting and insurance coverage. The organization is an affiliate of the Lyme Disease Association, their partner in all educational, research and political efforts.

Its fundraising efforts – primarily through the Time for Lyme events — are geared to help create the Columbia University Lyme Disease Research Center, the nation’s first endowed research center focusing on late-stage Lyme disease. To that end, the organization has already raised almost \$1.5 million toward the \$3 million required to open the Center.

Lyme Disease and other tick-borne illness are complex bacterial infections, and infection rates are

growing at epidemic levels with children and adolescents at greatest risk of contracting the disease. New York State reports the highest number of Lyme disease cases nationally, however Connecticut has the highest infection rate per capita. When diagnosed early and treated appropriately, Lyme disease can be a curable illness. If the disease is misdiagnosed, diagnosed late, or treated inappropriately, it often leads to chronic health problems that are multi-systemic and can affect the nervous, cardiac, gastrointestinal and musculoskeletal systems.

For further information about GLDTF or Lyme disease, please call 203-969-1333.

network, announced that it has changed its name to Time For Lyme, Inc. The move is designed to address the expansion of the not-for-profit group’s efforts toward eradicating Lyme disease beyond its Greenwich roots. The board of directors selected Time for Lyme – the trademarked name of the organization’s popular annual gala fundraiser – because of its established brand identity. They have also used the Time for Lyme name in conjunction with educational seminars, a video and the first walk-a-thon to raise funds for Lyme disease research. Time for Lyme, Inc. remains an affiliate of the Lyme Disease Association, Inc., a national organization.

Since it began in 1998 as a grassroots effort to support local families struggling with undiagnosed or late diagnosed Lyme disease, Time for Lyme has become involved in numerous activities beyond its original mission. It has produced and disseminated educational materials – including a video based on a local seminar it presented – that are now being used around the nation. In addition, it is partnering with the LDA to raise funds for and to endow the Lyme Disease Research Center at Columbia University in New York City. It has also worked at both the state and federal levels to advocate for legislation related to Lyme disease issues, including insurance coverage, reporting of cases and government funding for research.

“A ‘task force’ exists for a limited time and purpose,” said Time for Lyme co-president Diane Blanchard. “Although we wish our work to find a cure was already completed, the reality is that it will continue into the foreseeable future. So we need a name that reflects our long-term goals. Until we have a cure it is indeed Time for Lyme.”

In announcing the name change, Blanchard and the organization’s co-president Deborah Siciliano thanked the local Greenwich community for its ongoing support, which, they said,



L-R Back row: GLDTF board member Lauren Brooks; GLDTF co-president Deborah Siciliano; Time for Lyme co-chair William Bainbridge Steele; GLDTF co-president Diane Blanchard; GLDTF board member Dana McAvity. Front row: GLDTF board members Barbara Edwards, Fran herzog, Janet Vaccaro, Julia Knox. Ms. Knox is also Time for Lyme co-chair.

Greenwich Task Force changes name to “Time for Lyme”

by Ellie Becker and Melissa Diamond

GREENWICH, Conn. - The Greenwich Lyme Disease Task Force, Number 35

Inc. (GLDTF), a Lyme disease research, education and advocacy

has been so instrumental in Time for Lyme's accomplishments to date. They also restated the organization's commitment to continuing their efforts in the community, where Lyme disease rates are among the highest in the country.

Lyme Disease and other tick-borne illness are complex bacterial infections whose infection rates are

The name change reflects the organization's expanded scope and builds on established brand identity of the annual fundraising gala.

growing at epidemic levels, with children and adolescents at greatest risk of contracting the disease. Undiagnosed, Lyme disease can have devastating effects on health. Thousands of Americans are currently suffering from Lyme disease-related arthritis, heart problems, neuro-psychiatric/cognitive disabilities, and other serious maladies.

"Because, unfortunately, we in Connecticut and New York have the greatest experience with Lyme disease, we have a great deal of knowledge and information to share with other parts of the country where Lyme disease is spreading," said Deborah Siciliano. "We've found that there's a real need for the educational materials we've developed and we're glad that we can share these with others so that they don't have to reinvent the wheel. And, of course, the Lyme Disease Research Center at Columbia University will benefit people everywhere."

Time for Lyme has already raised more than \$1.5 million, most of which has gone toward the Research Center, which will be the first endowed

research facility in the nation dedicated to undiagnosed or late diagnosed Lyme disease and other tick-borne illness. In its efforts, Time for Lyme has attracted broad support from health care professionals, corporations, foundations, educators, and individuals, and government officials, including Senator Chris Dodd of Connecticut. At its recent Time for Lyme gala event, the organization honored Senator Dodd for his introduction of Lyme disease

legislation in the United States Senate. (*See story on page 1*)

Time for Lyme, Inc. is a not-for-profit Lyme disease research, education and advocacy network headquartered in Greenwich, Connecticut. The organization is an affiliate of the Lyme Disease Association with which it partners its educational, research and political efforts. For further information about Time for Lyme or Lyme disease, call 203-969-1333.

Rhode Island bill

from page 1

2004, so that its impact may be assessed and evaluated by the legislature to determine further action. Joseph S. Larisa Jr., a consultant and former chief of staff for Gov. Lincoln C. Almond, said patients whose policies are renewed next summer will be eligible for a full year of treatment, into 2005. Larisa, who is also Lisa Larisa's brother, helped organize last year's Lyme disease commission. He said he isn't discouraged by the temporary nature of the bill.

LDARIC co-chair Lisa Larisa, present at the late night senate vote, was elated over the passage. She was opposed to limiting treatment duration. The sunset provision was the only change acceptable to LDARIC. Critics of a similar bill in Connecticut several years ago say treatment limitations discriminate unfairly against the sickest patients

"Anything less than what was passed would not have benefited Lyme patients," Ms. Larisa said.

She thanked the House and Senate, and in particular, Representative Raymond E. Gallison Jr., D-Bristol and Senator Michael J. Damiani, D-East Providence, for their sponsorship of the bills.

"We are grateful," said Ms. Larisa, "to Rep. Gallison for initiating the

House bill after constituent input, and for his efforts in achieving unanimous passage. Senator Damiani kept the ball rolling with his monumental efforts to pass an intact bill which strongly protects patients' rights."

LDARIC co-chair Julie Merolla, who provided compelling testimony before a RI Senate committee hearing on the bill, was jubilant. Her son is severely afflicted with Lyme disease and has had difficulty obtaining treatment reimbursement.

"This is a victory for Lyme patients, especially our children," she stated. "They are sick and struggling with this disease, and now maybe they will have one less thing to worry about and can concentrate on getting well."

New Chapter of LDA

LDARIC is a newly formed Chapter of the national Lyme Disease Association (LDA), a New Jersey based non-profit which raises money for research and education. Larisa said they worked with the LDA on the bills that passed last year in Rhode Island and decided they shared common goals.

"We liked the way the LDA freely gave us advice and assisted us in bringing in doctors researchers to testify at the hearings last year," she

said. "Their only goal was to help Lyme patients. They are all-volunteer, like us. By joining them, we will be able to help patients not only in Rhode Island but across the country."

"This law is a jumping off point," says LDA president Pat Smith, who also provided committee testimony. "We are working nationwide with our affiliates and chapters to educate state and federal officials to the problems associated with Lyme disease, so that patients are not only able to receive treatment reimbursements, but also that physicians are able to freely diagnose and treat as physicians are trained to do." She was alluding to the successful passage last year in RI of the Lyme Disease Diagnosis Treatment Act, which permits physicians to treat without interference by the medical licensing board, a situation facing doctors in many areas of the country. "The Rhode Island legislature has been able to see the long range picture here and realize that ignoring patients is not going to solve the problem. They are dealing with it head on," said Ms. Smith. "It is a patient bill, not a vested interest bill."

According to an article in the Providence Journal, Blue Cross & Blue Shield received between 30 and 40 requests for intravenous treatment of Lyme disease last year, in most cases from 4 to 6 weeks. Blue Cross has balked at paying for the care beyond the standard period in nearly all cases. Through January, the company denied extending the care in all but one of 16 cases. Last August, the health insurance agency had agreed to cover intravenous antibiotic treatment in a letter stating:

"Neither Blue Cross, nor the independent reviewer, shall contest, reverse or deny coverage based upon a physician's order of long-term antibiotic therapy solely on the grounds that such treatment may be characterized as unproven, experimental or investigational in nature."

The agreement was revoked in

January 2003, after the state Health Department found the health insurance company's "process was not complying with the agreement," said Robert J. Marshall Jr., spokesman for the Health Department.

The LDARIC thanks all the Rhode Island support groups and citizens for participating in the effort to pass this bill. It also thanks all others, including Internet groups, who supported the massive effort.

2003 Rhode Island Lyme bill

H6136 Substitute A, "an act relating to health and safety—Lyme disease diagnosis and treatment" provides for mandatory coverage for certain Lyme disease treatments by insurance companies which hold service plan contracts in the state of RI on January 1, 2004 and thereafter. Coverage includes diagnostic testing and long-term treatment of chronic Lyme disease deemed to be medically necessary and ordered by a physician after making a thorough evaluation of the patient. Treatment shall not be denied based solely on it being characterized as unproven experimental or investigational in nature. (treatment and parameters defined in the prior Lyme disease legislation passed in 2002, see www.LymeDiseaseAssociation.org).

Victory

from page 1

affecting 23 million people, the Second Circuit Court of Appeals, the federal court governing New York, Connecticut and Vermont, has finally provided justice by changing an unfair law that even Congress has not been able to modify.

"The abuses of managed care have been legal because of a loophole in the ERISA law," said Robert Bransfield, a New Jersey psychiatrist. "Finally the ERISA barrier has been pierced, and managed care can now be held accountable."

David Trueman, an attorney who fights managed care and HMO abuses, successfully convinced the Court to close the ERISA loophole that has blocked individuals from suing their HMOs. In what is a major victory for consumers that will have wide-ranging effects on patients, doctors, and health care plans, the Court ruled that patients' claims against HMOs for alleged wrongdoing in making medical necessity precertification decisions should be

permitted to be pursued under state medical malpractice law. This opens the door for personal injury and punitive damages awards for harmed patients.

This decision came in a \$200 million dollar wrongful death suit on behalf of Bonnie Cicio and her deceased husband, Carmine Cicio, who suffered from myeloma, against Vytra and its medical director, Dr. Brent Spears. The claim alleged that the defendants failed to provide the care Mr. Cicio's physician recommended and delayed two months in approving any treatment at all, resulting in Mr. Cicio's suffering and death.

Mrs. Cicio had originally filed the case in state court but Vytra removed it to federal court where the company successfully used the ERISA loophole to have the case dismissed. Mrs. Cicio appealed to the Second Circuit Court of Appeals, with supporting briefs filed by the American Medical Association, the Medical Society of

the State of New York, and the American College of Legal Medicine. As a result of the appeals court ruling, David Trueman and co-counsel, Joel Ziegler, a seasoned medical malpractice attorney, will now be able to assist Mrs. Cicio in proceeding against the company and its medical director. Trueman expects other federal courts to follow suit.

In a dissenting opinion, one justice wrote: "In the end, stretching to avoid preemption in order to allow state actions for consequential damages in cases like this one, in

which the wrongful coverage decision was medically based, will help a few deserving people, like Mrs. Cicio. It will, however, leave unaided all those who suffer identical consequential damages as a result of non-medically based wrongful coverage decisions....caused by the Supreme Court's denial of consequential damages under ERISA..."

The story appears on the February 18, 2003 front page of The New York Times (<http://www.nytimes.com/2003/02/18/health/18HEAL.html>).

Need help?

David Trueman's website - www.truemanlaw.com - is devoted to helping consumers understand managed care, how to get the care you need, abuses that occur, and laws and cases that protect consumers. To contact David Trueman, write to 18 East 50th Street, 7th Floor, New York, NY; call (212) 758-0993; or (516) 742-1460; or email <truemanlaw@erols.com>

More LDA News

NY Times Bestselling Author Amy Tan supports new LymeAid4Kids Fund

Children without insurance will benefit

Jackson, NJ - The Lyme Disease Association (LDA) has announced the creation of LymeAid4Kids, a fund administered through the LDA and designed to be used by families with no insurance who need to have their children properly evaluated for possible Lyme disease.

Internationally acclaimed author Amy Tan, whose books **The Joy Luck Club**, **The Kitchen God's Wife**, and **The Hundred Secret Senses** have appeared on the New York Times Bestseller List, will support the fund through the proceeds from the speaking tour for her new book **The Opposite of Fate: A Book of Musings**, which reveals the author's own bout with Lyme disease in the final chapter.

"We consider the creation of this formal fund – the first of its kind for Lyme disease – a beginning," said LDA president Pat Smith. "We hope that others will follow Ms. Tan's lead

with generous donations to the fund."

Lyme, the most prevalent vector-borne disease in this country, often strikes children, who may lose years of school and their childhood due to its debilitating effects. Risky behavior may be as simple as petting the dog, playing outside, and even having a live Christmas tree. It is estimated that 10-15% of those who are diagnosed with Lyme go on to develop chronic disease, which may lodge in the central nervous system. Early diagnosis and appropriate treatment may prevent the development of chronic disease, one main reason for creation of this fund. The fund will be administered by the LDA through individual treating physicians nationwide who agree to participate, and will provide up to \$1,000 per child for evaluation, including the visit, testing, and perhaps beginning treatment.

"As the fund grows, the amount per child could increase to provide further services," says Ms. Smith, whose own daughter missed four years of school due to chronic Lyme disease. "Right now, we need to address getting children properly diagnosed as early as possible."

The LDA has funded research projects coast to coast and with its Connecticut affiliate, Time for Lyme, is partnering with Columbia University to open an endowed chronic Lyme disease research center at Columbia, the first of its kind in the world. Studies from Columbia have highlighted cognitive deficits that cause children to develop learning disabilities, which fluctuate with the disease. One Columbia study funded by LDA showed a 22-point increase in IQ after a child was treated for Lyme disease.

Details of the LymeAid4Kids fund will be available for physicians and families on the LDA website by the end of this year. Tax deductible donations earmarked for the fund can be made payable to: Lyme Disease Association, Inc. and sent to: LDA P.O. Box 1438 Jackson, NJ 08527. Please note LymeAid4Kids on your check memo or letter.

To view the LDA website, go to www.LymeDiseaseAssociation.org.

Regional News

Tick season in Kansas and Missouri is year-round concern

A review of the K-State Research & Extension website (www.oznet.KSU.edu) and statements by entomologists in Kansas and Missouri indicate that our most common tick species, the American dog tick, the Lone Star tick, and the black-legged tick can be active all year but are most active from April through September. It must be remembered that due to their life cycle, the tiny nymphs are active in spring, summer, and fall and the adult ticks are active all year. Both can carry disease. Weather has a strong impact on tick activity and during mild winters, ticks can be active, and the most active tick season can start earlier. When the population of host animals increases, one should also expect an increase in the tick population.

The bottom line is: in Kansas and Missouri, one should always be vigilant about doing tick checks on their person and their pets after any outdoor activity such as hunting, camping, golfing, gardening, hiking,

or just playing. Any flu-like symptoms or rash following outdoor activities should be viewed as a cause to see your physician promptly and to seek treatment.

Yard and Outdoor Control In Kansas & Missouri

Spraying pesticide chemical for ticks can be very effective and safe when products are applied **exactly as the manufacturer's label specifies**. Under spraying reduces effectiveness. Over-spraying can create hazardous or toxic conditions for both humans and pets. Over spraying *does not increase* chemical effectiveness against pests. Always use rubber gloves, wear long sleeved shirt and pants, wear eye splash protection (goggles), and an air filter mask when spraying pesticide chemicals for chemical safety. A hand pump pressure sprayer (Hudson type) can be very useful for liquid home application. Some products are applied with the yard fertilizer for easy application. Spraying would typically

start about **March 15 with chemicals reapplied, as the manufacturer's label recommends, until about October 15**. There are different products for use in different locations such as: indoor, yard, field, shaded, and non-shady locations. See the manufacturers' recommendations for specific applications. Below are some products that are currently available in 2003.

ORTHO: Bug-b-Gone series. Products in liquid for spray and granules for dry application.

GREEN LIGHT: Conquest series. Products in liquid for spray and granules for dry application.

Other liquids: TEMPO SC-ULTRA, CONQUER, Suspend SC

Tick Removal

A Tick's mouthparts have reverse harpoon-like barbs, designed to penetrate and attach to the skin. They secrete a cement-like substance that helps them adhere firmly to the host. When you find that a tick has bitten you or a pet, it is very important to remove it as safely and completely as possible.

The attached brochures have clear instructions for removing ticks with pointed tweezers. The following instructions are for use with the **Pro-Tick Remedy (PTR)** that is being provided with this informational handbook.

The PTR is a compressed tweezers that captures ticks by their embedded mouthparts through a forward motion. The key feature of the PTR is the precision V slot that accomplishes the capture of the tick without squeezing or touching its body.

Hold the PTR lightly between the thumb and forefinger. Make sure the V slot is clear. Part any hair or fur near the tick to ensure a clear view. Soft fleshy skin may require stretching the skin at the tick's location to make positioning of the PTR under the tick possible. Position the PTR so the tick's mouthpart (the attachment point of the tick) is aligned within the

LDA upgrades brochures

LDAs upgraded version of both ABCs and LymeR Primer can now be found on the LDA website, LymeDiseaseAssociation.org. Doctors interested in free brochures for their offices please email requests to [<macavitypl@hotmail.com>](mailto:macavitypl@hotmail.com) with name and full mailing address. PO Boxes are not acceptable for delivery of more than a few hundred pamphlets.

Also on the site under "events" is the summary of the LDA meeting with the military in DC along with pictures of Drs Burrascano, Liegner, and Fallon presenting to officials.

Pictures are also available from the joint LDA/GLDTF Time for Lyme Manhattan fundraiser (more to be added at a later time) and from our Lyme Association of Greater Kansas City affiliate presenting materials to school nurses in Kansas.

wide front portion of the V slot.

Slide the PTR gently forward under the tick, while nudging/lifting the tick's body up onto the PTR fingers so that the tick will be perpendicular to the slot. Once the tick is correctly positioned, apply slight upward pressure by lifting the PTR sufficiently to pucker the skin. Hold this puckered skin position steady until the tick releases.

Tick Kits

Tick removal kits are available for \$3 plus \$1.25 shipping and handling, from the Lyme Association of Greater Kansas City. Each kit has a vial containing a tick removal tool, small ziplock bag to save the tick, alcohol wipes, and a tick identification card. Send your check to:

Kathy White
LA/GKC - PO Box 25853,

Overland Park KS 66225

Tick Identification

Ticks can be taken to the Johnson County Extension office for identification. They cannot test for diseases but can identify the ticks for you. Take them to:

Ryan Higbie, County Extension Agent
Agriculture Research & Extension
13488 S. Arapaho Drive
Olathe, KS 66062
Tel. (913) 764-6300

It is more important to get immediate treatment for tick bites than to have the tick tested for disease.

This article was prepared by the Lyme Association of Greater Kansas City as part of their educational packet for schools.

carrying Lyme disease are more prevalent in Santa Cruz County than in five geographically similar California counties. The study is cause for concern for local health officials.

"It got our attention," said county Disease Control Manager Fritzi Nelson. "It's time for people to get more educated."

Mariann Williamson said she wishes she had seen warning signs posted at DeLaveaga City Park the public recreation area by her home where her son was bitten and that doctors had taken her concerns more seriously after the first bite in 2001.

Nelson said the ticks that most commonly transmit the disease in California the Western black-legged tick can infect humans when they are in their nymphal stage, when they are quite small. People who have been bitten might assume the tick is a mosquito bite or a blemish, especially if the tick is on a part of the body that is difficult to see, such as the shoulder or back. Robert Williamson said his family removes ticks nearly every time they go walking in DeLaveaga City Park, and public recreation areas may be the very places where ticks congregate, according to the Journal of Medical Entomology.

Researchers from the Department of Biological Sciences at San Jose State collected ticks from DeLaveaga City Park, Big Basin, Castle Rock, Nisene Marks, Wilder and Henry Cowell state parks, and New Brighton and Sunset state beaches over a two-year period for the journal study. Comparing the rate of ticks carrying the Lyme disease pathogen to rates in five other California counties with similar climate and geography, the researchers found Santa Cruz County had a notably higher prevalence of ticks carrying Lyme disease 6 percent of ticks in Santa Cruz County had the Lyme disease pathogen compared to an average of 2 percent in the other counties posing a potential risk in public recreation areas. According to the report, many areas of the county provide a more suitable habitat for

Doctor fails to recognize Lyme disease in Santa Cruz area

by Robyn Moormeisterr, Sentinel staff writer

During a June visit to the family doctor, Robert and Mariann Williamson's 5-year-old son, Thomas, told his parents not to worry his headaches, swollen lymph nodes and the constant pain in the back of his neck was normal. And in fact, two doctors had told the Williamsons their son was experiencing growing pains. But the couple learned earlier this month what they had long suspected – the boy had Lyme disease.

Thomas had suffered at least four tick bites over a two-year period, but doctors had said a blood test for the disease was unneeded because of its rarity in Santa Cruz County. Now they blame themselves and their doctors for not catching it earlier.

"It seems to be this misconception in Santa Cruz that we don't have Lyme disease," Mariann Williamson said. "Doctors aren't aggressively

testing and they don't feel like there is a reason to test."

But a new study in the Journal of Medical Entomology says ticks

California is unique

Tick season in California starts with the fall rainy season. Adult ticks may be found all winter long when the cold is not too severe. With local variation, adult tick infection rate in the state ranges from about 1 to 6 percent.

Nymphal ticks make their appearance in the spring, and have a HIGHER infection rate than the adults, unlike anywhere else in the US. This is because nymphs' preferred host is the western fence lizard, and a protein in the lizard blood effectively disinfects any ticks feeding on it.

ticks than other areas specifically the damp, foggy mountains and foothills of Santa Cruz County. Nelson said the study makes sense ticks love the shade and moisture of Santa Cruz County's redwood canopies.

The protection of state and city parks, the SJSU study said, may also provide optimal habitats for tick hosts, such as deer and rodents. Nelson said the only way to keep the disease in check is to encourage health providers to report occurrences and educate the public on prevention methods with material posted in public recreation areas.

Thomas Williamson continues to wake up in the middle of the night with muscle and bone aches that only seem to get worse. But he's lived with them so long, Mariann Williamson said, that he still thinks it's normal.

Condensed from an article in Santa Cruz Sentinel, Santa Cruz, CA, August 16, 2003 Contact Robyn Moormeister at rmoormeister@santa-cruz.com.

Research

VECTOR-BORNE DISEASES, SURVEILLANCE, PREVENTION

Detection of *Borrelia burgdorferi*, *Ehrlichia chaffeensis*, and *Anaplasma phagocytophilum* in Ticks (Acari: Ixodidae) from a Coastal Region of California
Kevin Holden,¹ John T Boothby, Sulekha Anand, Robert F. Massung²
Department of Biological Sciences, San Jose State University, San Jose, CA 95192

J. Med. Entomol. 40(4):534-539 (2003)

ABSTRACT A study was conducted in Santa Cruz County to estimate the prevalence and distribution of the agents of Lyme disease, human granulocytic (HGE), and human monocytic (HME) ehrlichiosis in 1,187 adult ixodid ticks collected from eight public-use recreation areas over a 2-yr period. *Borrelia burgdorferi* the causative agent of Lyme disease, was detected by a polymerase chain reaction (PCR) in 44 of 776 (5.67%) *Ixodes pacificus* ticks and in 3 of 58 (5.17%) *Dermacentor variabilis* ticks. *Anaplasma phagocytophilum* the causative agent of HGE, was detected by PCR in 48 (6.19%) *I. pacificus* ticks and 5 (8.62%) *D. variabilis* ticks. *Ehrlichia chaffeensis* the causative agent of HME, was detected by nested PCR in just 1 (0.64%) *I. pacificus* ticks and four (6.9%) *D. variabilis* ticks. Interestingly, eight (1.03%) *I. pacificus* ticks were co-infected with *B. burgdorferi* and *A. phagocytophilum* and just one (0.12%) tick was co-infected with *B. burgdorferi* and *E. chaffeensis*. Less than 1% of 353 *Dermacentor occidentalis* ticks showed evidence of infection with any of the agents tested. To our knowledge, this is the first reported identification of *A. phagocytophilum* and *E. chaffeensis* in *D. occidentalis* ticks from California. This study represents the first extensive survey of Lyme and the ehrlichial diseases across multiple areas of Santa Cruz County, and suggests that prevalence of *B. burgdorferi* in Santa Cruz County may be higher than other areas of the state.

Lyme disease a risk in Monterey County, California

A tick which bit a Monterey woman June 15 was carrying Lyme disease, according to a scientist who tested it, prompting him to warn Peninsula residents about the potentially devastating illness many mistakenly believe doesn't even exist here.

Nick Harris, Ph.D., who runs a Palo Alto laboratory specializing in the study of tick-borne illnesses, used DNA testing to study 21 hard-bodied black-legged ticks collected from parts of the Peninsula. Only one—the one that bit the woman—tested positive, and she has not developed symptoms, but Harris is certain the results were reliable.

"DNA testing is a very accurate way to look at ticks," he said.

Monterey County Health Department
Number 35

ment physician Linda Velasquez believes only 20 percent of Lyme cases end up being reported. Harris said many patients are misdiagnosed as chronic fatigue syndrome, multiple sclerosis or fibromyalgia, a musculoskeletal pain and fatigue disorder.

Three cases were reported in 2002. After one woman began experiencing stiffness and swelling in her joints, a Pebble Beach Health & Wellness Center doctor prescribed steroids to relieve her symptoms. They worked, but later she was tested for Lyme and the test was positive. Steroids are contraindicated in Lyme disease, a bacterial infection

From an article by Tamara Grippi at <http://www.carmelpinecone.com/030718-1>

California could be epicenter of West Nile in 2004

The West Coast likely will be hit hard by West Nile virus in 2004, and California is "the next likely place for large numbers of human cases," Dr. Lyle Petersen, acting director of vector-borne diseases for the CDC, said. Speaking at the University of California-Berkeley, Petersen predicted that the Imperial Valley in Southern California likely will be most affected by the potential outbreak (New York Post, 10/3). He based his predictions on the fact that California is home to a large population of mosquitoes and that the virus has been detected in both mosquitoes and chickens this year.

From the San Jose Mercury News, 10/3

Lyme and other TBDs are underrecognized in far west

by Lucia Hui

In California, of reported cases in 2000, 2001 and 2002, only 30% of the patients had a recognized tick bite – **This means 70% of the patients would not seek proper medical treatment until the recognized symptoms occurred {Erythema Migrans (EM), Bell’s palsy, or swollen joints} weeks, months or years after becoming infected.**

References: VBDS Annual Report 2000 (pg. 20), 2001 (pg. 15) 2002 (in print)

From 1991 to 2002, Lyme disease accounted for 97% of the vector-borne diseases cases reported in California.

References: VBDS Annual Reports; Hui, et al. 1999 (Summary of Reported St. Louis Encephalitis and Western Equine Encephalitis Virus Activity in CA from 1969 – 1997)

Grossly underreported

VBDS Annual Report, 2000 – of 87 cases for which race was reported, 80 (92%) were white

VBDS Annual Report, 2001 – of 90 cases for which race was reported, 81 (90%) were white

VBDS Annual Report, 2002 – of 88 cases for which race was reported, 84 (95%) were white

- The US Census Bureau reported less than 60% of population in CA were white in 2000 – the reported Lyme cases in California were not a true representation of the population

- EM rash would not be a recognized symptom in patients with a dark complexion

- Reported cases: Patients with higher education, higher socioeconomic status, better medical insurance coverage, and internet access were the ones aggressively seeking medical treatments

- Patients infected on the job such as contractors, gardeners, field workers for PG&E, and Pacific Bell were not fully informed by their employers and most likely would not receive prompt treatment. The delayed treatment can be difficult and costly. Many patients may become permanently disabled as a result.

According to the CDC, diagnosis and treatment of Lyme disease should be based primarily on clinical symptoms. Serologic tests (ELISA, PCR or Western Blot) are only useful to support the clinical diagnosis. In the entire state, there are fewer than 20 Lyme literate physicians who know how to treat Lyme patients. Studies have shown that fewer than 30% of EM patients had positive ELISA

seroconversions. Unfortunately, most physicians still use ELISA test as the sole tool and criterion to diagnose. This means the majority of the Lyme patients will not receive proper antibiotics during the time when the infection can be cured and therefore can progress to late chronic Lyme disease requiring complex long-term antibiotic treatment.

Misconception - no Lyme disease in Southern California

Lyme disease bacteria (*Borrelia burgdorferi*) and *Borrelia* spp. have been identified from Western Black Legged Ticks (*Ixodes pacificus*) in 41 of California’s 58 counties, including San Luis Obispo, Kern, Santa Barbara, Los Angeles, San Bernardino, Riverside, and Orange and San Diego counties. There were 200 confirmed Lyme disease cases reported to DHS from Southern California from 1992 to 2001. Thirteen percent (13%) of the total reported cases (1561) in California during the 10 years period were from Southern California (see the table below).

Other tick-borne diseases ~ coinfection

Twelve human cases of HGE and HME were reported to DHS from Humboldt, Marin, and Santa Cruz counties since the first case was identified in 1994.

Eight human cases of Babesiosis have been reported to DHS from Alameda, Fresno, Marin, Mono, Monterey, San Bernardino, and Sonoma counties since 1968.

Pathogens of human granulocytic ehrlichiosis (HGE) and monocytic

Reported Cases of Lyme Disease in Southern California

| County | 1992 | 1993 | 1994 | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | Total |
|-----------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|------------|
| Imperial | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 1 |
| Kern | 4 | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 0 | 18 |
| Los Angeles | 9 | 3 | 2 | 5 | 2 | 6 | 3 | 7 | 2 | 9 | 48 |
| Orange | 6 | 3 | 0 | 0 | 0 | 0 | 1 | 2 | 3 | 0 | 15 |
| Riverside | 4 | 3 | 2 | 0 | 1 | 0 | 0 | 0 | 3 | 2 | 15 |
| San Bernardino | 7 | 1 | 3 | 1 | 0 | 0 | 0 | 1 | 1 | 0 | 14 |
| San Diego | 5 | 4 | 7 | 6 | 5 | 4 | 0 | 16 | 9 | 3 | 59 |
| San Luis Obispo | 2 | 1 | 1 | 0 | 1 | 0 | 1 | 1 | 1 | 0 | 8 |
| Santa Barbara | 2 | 1 | 0 | 3 | 1 | 1 | 3 | 0 | 0 | 1 | 12 |
| Ventura | 2 | 1 | 0 | 0 | 0 | 0 | 2 | 1 | 2 | 2 | 10 |
| Total | 41 | 19 | 17 | 16 | 11 | 14 | 12 | 30 | 23 | 17 | 200 |

ehrlichiosis (HME) were identified from Western Black Legged Tick (*I. pacificus*) in Alameda, El Dorado, Humboldt, Napa, Orange, Sacramento, Santa Cruz, Sonoma, and Yolo counties; and molecular evidence of *Bartonella* spp. was also identified by PCR from Santa Clara County.

Most physicians do not recognize that these new emerging infectious diseases exist in California. In those patients with coinfection, non-Lyme

tick-borne diseases often remain untested and undiagnosed. The untreated silent infections of babesiosis and ehrlichiosis may persist for months to years, generally resulting in more intense illness and prolonged convalescence than from Lyme infection alone.

Lucia Hui is a Senior Public health biologist with the California Dept. of Health Services.

“Ticked-Off About Lyme Disease” Walk in Midwest

by Maureen Johnson

To begin with the weather for the walk was ideal. Approximately 80 Lyme victims and family members were on hand. The walk received an incredible amount of help from the mayor, local and county law enforcement, in addition to having tremendous help from the local Boy Scout troop, not only at the school but along the route as well.

One of the goals set for the first walk was to raise \$10,000 and that goal was reached. Five people received prizes for highest amount of money brought in, and a total of fifteen others received thank you gifts from the makers of REPEL.

I would like to thank everyone in the Lyme Community for all the support they gave to this event. I would also like to thank Renee Thaler, Midwest Task Coordinator with the Lyme Disease Foundation, and Jeanette Wheat, Northern Illinois Lyme Resource Group, for all the assistance and support they provided during the past year.

In total we received four Proclamations declaring May 2003 Lyme Disease Awareness Month from the Governors of Wisconsin and Illinois and Mayor of New Lenox; an Illinois House Resolution, which mentioned the Walk in New Lenox on May 17, 2003.

There will be another walk next year, the tentative date will be the middle of May as it was this year, same time and same place.

Contact the author at PO Box 544, New Lenox, IL 60451 or email:johnson.maureen@att.net.

New information and support network starts in Oregon

by Theresa Denham

Oregon Lyme Disease Network officially opened their doors July of 2003. They are based in Bend, Oregon, but serve the state as a whole.

Lyme disease, once considered a rare and easily treated ailment, is actually a complex infectious disease which can progress to a chronic state and seriously affect even the most healthy individuals and their pets. The discovery of multiple strains of *Borrelia spirochetes* (over 300 to date), coupled with the fact that at least three different forms of spirochetes have been documented (spirochetal, spheroplast, and cystic form), is merely the underlying foundation of the comprehensive infectious soup currently referred to as ‘Lyme disease.’ Our Network works closely with doctors and scientists to provide current research and treatment data in Lyme, Babesia, Erlichia, Relapsing Fever and other tick borne illnesses.

The purpose of the Oregon Lyme Disease Network is to educate and assist Oregon residents in understanding tick borne illnesses, and to assist in locating doctors who are versed in treating the full complexities of the diseases. Our organization also is responsible for disseminating current resources and research to

local doctors having difficulty with interpretation of tests, making a clinical diagnosis and supplying effective treatment regimens for tick borne-illness. We achieve this by networking our local doctors with research scientists and specialty doctors who have been treating tick-borne infections successfully for a number of years, and supplying published scientific journal materials specific to tick-borne illnesses..

Pamphlets on tick illness, prevention and cure are available at no charge. Videos will be available in the near future, and can be purchased at cost. We will be happy to arrange school education for students, teachers and counselors as requested. Tick-borne illness testing kits are available through the Network at no charge (however the labs do charge a fee for running the tests).

You may contact the Oregon Lyme Disease Network by telephone at 541-312-3081.

If you ♥ the Lyme Times, please support us by joining today! Mail in form on page 63.

Connecticut drops lab reporting as case numbers rise

Connecticut has dropped its requirement for laboratory reporting of Lyme disease, a practice instituted in 1998 and paid for by the federal Centers for Disease Control and Prevention while studying a Lyme disease vaccine. The state will revert to a passive reporting system by doctors. But according to several sources, doctors account for only 20 percent of all reported cases. They are concerned that a drop in numbers will have far-reaching effects.

“Doctors don’t bother (reporting it) because there’s too much red tape,” said Karen Gaudian, one of the founders of the new Ridgefield Lyme Disease Task Force. In 2002, she said, the state counted 323 Lyme disease in the town of Ridgefield. Of those, 278 came from lab reports and 45 from doctors. Likewise, said Maggie Shaw of the Newtown Task Force, Newtown had 606 cases reported to the state in 2001 and 2002. Of those, labs reported 584 and doctors reported 22.

Connecticut counted 4,631 cases of Lyme last year – a nearly 30 percent increase over the 3,597 reported in 2001. Statewide, about 136 out of 100,000 people were infected in 2002 – a new record high – according to Kirby Stafford, chief scientist with the department of forestry and horticulture for the state’s Agricultural Experiment Station, and the highest per capita rate of Lyme disease in the United States.

Diane Blanchard co-president of Time For Lyme Inc. (formerly the Greenwich Lyme Disease Task Force) said her organization has contacted state health officials, local and state legislators as well as state Attorney General Richard Blumenthal in an effort to get the policy reversed. Blumenthal has written three letters to the state DPH since April expressing his concern about the new reporting

guidelines.

Some health officials worry that changes in state reporting methods will affect research and funding. “It could potentially influence research and resources, Lyme disease prevention and surveillance,” Stafford said. But Dr. Matthew Cartter, epidemiology program coordinator for the state Department of Public Health, said the state is still doing intensive surveillance. “For those of us in the field,” says Cartter, “it’s nice to move our focus from the counting of cases to the prevention of Lyme.” He acknowledged that not gathering the lab reports “may lead to a reduction” in

the number of reported state cases. “But there are plenty of cases to count,” Cartter said. “We have one of the best surveillance programs in the country.” The state has three model programs that feature both prevention and surveillance.

Blanchard said the new reporting methods allow people to believe the disease is less prevalent. “Cases are rising, but because the state no longer requires labs to report the disease, we are seeing a gross underestimation of the numbers and it’s really going to falsely deflate the actual number of cases being identified,” she said.

Douglas Serafin, director of the Greenwich Department of Health Laboratory, said 43 percent of 730 ticks dropped off have tested positive this year.

Connecticut group spreads ‘truth’ about Lyme Disease

In June, the Greater Hartford (CT)Lyme Disease Support and Action Group tried to enlighten area citizens by setting up an information table at the local farmers’ market.

“There’s been quite a bit of interest,” said Marjorie Tietjen, a support group member, according to an article in the Middletown Press. “The Public Health Department is not educating the doctors about the true facts of Lyme Disease,” she said. “Many people are suffering from misdiagnoses.”

Some have been diagnosed with

The Greater Hartford (CT)Lyme Disease Support and Action Group on the third Wednesday of every month in the Farmington/Unionville Community Center located at 321 New Britain Avenue, Unionville, Connecticut.

having chronic fatigue syndrome, multiple sclerosis, lupus and Lou Gehrig’s Disease, among others, while they actually have Lyme Disease, Tietjen said. “They are only being given symptomatic treatment while the disease is eating away at the body,” she said.

Tietjen was initially diagnosed with chronic fatigue syndrome, and her Lyme Disease went untreated for eight years, she said. About 90 percent of those who stopped by either had Lyme Disease or knew someone who had it, said Haddam resident Anne Schwing, a support group member.

While the support group was disseminating information, they were seeking signatures for a petition to the attorney general to request a new hearing about Lyme Disease. According to group members, more than 100 signatures were gathered on the petition.

New foundation educates and helps North Carolinians

by Beth Jordan, DVM

I am a small animal veterinarian. I was living a fairly picturesque life until I fell ill in the Spring of 1999. Then all hell broke loose. I went from doctor to doctor in an effort to find out why I felt so incredibly bad every day. In my heart I knew I had con-



Veterinarian Beth Jordan started the North Carolina Lyme Disease Foundation after contracting the disease herself.

tracted a tick-borne illness, but convincing a doctor to believe I had contracted Lyme Disease in North Carolina was a losing battle.

So I found the name of someone that had been suffering for years with this illness and she gave me a referral to a doctor up North. This doctor was Doctor Kenneth Leigner and he knew right away what was wrong with me and it only took him a few months to prove it. Of course, he started me on treatment immediately and he probably saved my brain because of his immediate efforts.

Little did I know at the time this was just the beginning of a very long journey. I am still not totally well today; however, I feel leaps and bounds better than I did then. I work full time as a Doctor of Veterinary Medicine and I have a wonderful life partner of 12 years and 3 beautiful dogs and 6 cute kitties. So my life is very full and so far very blessed.

Of course there are days when I still ask myself why did this happen to me? My life was going so well. I was so happy with everything in my

life. I did not have a lot of money or a lot of possessions. These are things I never cared about. I knew material wealth was just something that eventually fades away. So why did this happen to me?

As I started to feel better I realized I had to do something with all I had learned. I was not willing to sit still in silence while so many others were suffering. I thought that if I had the experience with the medical profession that I had, what in the world was happening to all the other people in my state? Surely as careful as I was if I contracted this disease so many others must be suffering the same fate with probably worse outcomes.

So I approached the major news paper in the triangle area and convinced a news reporter to do a story about my experience. The reporter did a great job and things really started happening fast. I started getting calls, visits and referrals to talk to people that had had a similar experience with no resolution to their situation.

After a while I got a call from my boss asking me to talk to a lady from his church. Her name was Fonda

Notch and little did I know that she would be an important part of the big puzzle.

Fonda and I got together at her house and talked about her illness. It did indeed sound as if she had Lyme Disease so she traveled up North for healthcare. During this period we formed a friendship and gradually started talking more and more. I suggested we form a support group and she agreed this would be a good idea. We had our first meeting in June of 2002. I decided to invite a doctor one of us was seeing in Huntersville, N.C. to speak at our meeting.

The meeting was a great success and I decided to take things even further. I thought we should become a non-profit because it would give us more credibility and increase what we could do to help people. So, the North Carolina Lyme Disease Foundation, Inc. was born in September of 2002. Fonda and I did all the work to get this going and it has been more than worth it. We now have a board and members and a website. So we have come quite a long way.

The NCLDF works to increase Lyme awareness in the state. We have brochures to educate the public about the threat of Lyme and other tick-borne disorders. We run a hotline from our own personal homes in order to talk with people that believe they

North Carolina Clinic treats Lyme

The Jemsek Clinic is a center for the practice of Internal Medicine and Infectious Disease located just 15 minutes north of Uptown Charlotte in Huntersville, NC.

According to their website, the healthcare professionals at Jemsek believe it is time for a change, a time to go back to the art of medicine where the physician really listens to what you have to say about your health rather than spend our time tied up in red tape.

Clinic founder and director Dr. Jemsek and his colleagues at Jemsek Clinic treat Lyme and associated tick-borne diseases.

Information about the clinic, these diseases and their management can be found at <http://www.jemsekclinic.com>.

may have been infected with lyme disease. We are able to provide names of Lyme-literate medical professionals who can help them. We also answer countless emails and questions about Lyme disease.

We have meetings every 6 weeks or so where we usually have a speaker that can further educate people in this state about Lyme disease. We ran a booth at the Dixie Deer Classic to help educate hunters, and outdoors people about the threats of Lyme. This is usually a family event so we were able to educate many people.

Fonda and I have spoken with countless numbers of people about

this mysterious illness and we have probably saved a few from our fate. Our LLMD in this state Dr. Joseph Jemsek has been a wonderful support to our group as well as a very good doctor making every effort to try and heal us from this illness and to improve the quality of our lives. We are still new, but you will see very big things from the North Carolina Lyme Disease Foundation. Our website can be found at <http://www.nclyme.org>. It is updated monthly with our meeting times. We are here in North Carolina and we are not going away!

Dr. Beth Jordan can be contacted at vetrelief@earthlink.net or phone 919-496-7390.

another of Mather's projects - dissecting an adult tick the size of a sesame seed to analyze its salivary glands.

"Thomas N. Mather peers into the microscope, a pair of small tweezers in his right hand, a metal pin mounted on a short wooden handle in his left. His patient, a tick, squirms a bit as it lies on its back, so he holds it still with the small implement. Then Mather reaches for an everyday razor blade, neatly slicing the creature down the middle. Slowly, he peels back each side, exposing scores of tiny translucent orbs, knotted together by delicate white threads. He calls them "clear grape clusters." The clusters are a black-legged tick's salivary glands."

A tick's salivary glands contain about 500 complex molecules, including clotting inhibitors, anti-inflammatories and numbing agents.

With a share of a \$2.5-million NIH grant, Mather, his team at URI and NIH researchers hope they can make a vaccine that will prevent tick-borne illnesses in humans.

His research on tick saliva is in its eighth year. It's painstaking work, including a year spent extracting microscopic droplets of saliva. A muscle-relaxant liquid is first dropped on the tick, making it open its mouth and drool. Then thin, tiny glass tubes inserted into their mouths collect the saliva.

Each tick yields two to three microliters of this saliva. A microliter is a pinpoint of liquid. One hundred microliters is a small drop.

In a year, Mather's department managed to collect the yield from 2,400 female ticks.

The complete article may be found at http://www.projo.com/news/content/projo_20030615_lyme15.44ceb.html

For more information, email tmather@uri.edu

Rhode Island expert receives grant to create Tick Index

Thomas N. Mather, an entomologist who runs the Center for Vector Borne Illness at the University of Rhode Island, has received a \$100,000 federal grant to create a tick-risk index for the Internet, similar to sun damage warnings targeted for beachgoers in the summer.

According to an article in The Providence Journal (8/14) Rhode Islanders, particularly those who live or visit areas with the highest rate of tick-borne illnesses in the nation — South County, Block Island and Prudence Island — could then take precautions depending on that day's tick report.

Mather hopes to find more funding as well, particularly for another venture he's starting next spring. Research associates from the center will travel to half a dozen neighborhoods in Narragansett, Charlestown and South Kingstown that have a high concentration of black legged or deer ticks, tiny creatures that can carry serious illnesses: Lyme disease, babesiosis and ehrlichiosis. They will advise

residents how they can reduce the number of ticks in their yards by clearing old brush and dead leaves, spraying the perimeter of their properties and installing devices that kill ticks on field mice.

A June 15 article in the same Providence newspaper described

Bowen Lab director receives Award

In March, Congressman Tom Delay announced that Dr. Jo Ann Whitaker is the recipient of the 2003 National Leadership Award. She has also been made Chairman for the National Business Advisory Committee for Small Business. On May 20th Dr. Whitaker was the honored guest of President Bush at a special recognition dinner in Washington DC. Dr. Whitaker is President of Bowen Research Lab in Palm Harbor Florida and the research developer of the Bowen Test for Lyme Disease.

News Briefs

by **Candy Sandford**

N.E. Region – Recent study in seven northeastern states found a correlation of early summer Lyme disease incidence with the June moisture index in the region. The correlations may reflect enhanced nymph tick survival in wetter conditions.

An **Alabama** man hospitalized for an unknown virus died of Rocky Mountain Spotted Fever.

In Yolo-Sacramento counties in **California**, 21% of tick pools test positive for *Borrelia burgdorferi* in 2002, up from 2% (9 of 431) positive in cumulative testing from 1985-2001.

Connecticut health officials are no longer requiring laboratories to report confirmation of Lyme disease cases, although physicians are still required to report them. See story on page 40.

A clinic will open in Norwalk specializing in counseling for Lyme victims. Margo Friedman will address issues that impact chronic illness, including family problems, school issues, and workplace difficulties.

A task force to educate residents of Ridgefield about the seriousness of Lyme disease has been formed. Their goal is to get the word out that while the state of Connecticut may “not care about tracking the disease” anymore (no longer requiring reporting of the disease), their city does take it seriously.

Health Extenders Lyme Disease Treatment Center in Norwalk is the first primary care facility in the nation that offers comprehensive care for Lyme disease. The center offers the diverse help that many patients with the severe effects of Lyme disease need, including diet advice, physical therapy and chiropractic care. Dr. Amiram Katz is the center’s medical director - [tel. (203) 853-1919].

Lyme Walk-A-Thon in **Illinois** on May 19 netted \$10,000. The brainchild

of the wife of a Lyme victim, Maureen Johnson, and sponsored by the Lyme Disease Foundation, the walk was a big success for a first time venture. More than 90 people participated in the four mile walk. (*see page 39*)

Five **Indiana** biology professors received a \$1.88 million grant from the National Science Foundation and National Institutes of Health to fund the research on how harmless and disease-causing bacteria interact inside ticks. They are collecting samples of hundreds of ticks from 40 to 50 sites, mostly in central and southern Indiana. They then grind up individual ticks and sequence the genetic material. So far they have found a total of 10 to 15 different bacteria that live in their tick samples, some of which cause disease and others that live harmlessly in the ticks.

Coyotes, now common in **Indiana**, thrive in urban and rural areas. They are scavengers but primarily feed on mice, which could carry ticks infected with Lyme disease into homes. People don’t have to worry about trying to regulate the population by killing them because predators are self-regulating by nature. The birth rate is regulated by the food sources available. If you eradicate the coyote, there will be an increase in Lyme disease, according to Laura M. Nirenberg of the Wildlife Orphanage.

Scott Taylor, an Ames, **Iowa**, veterinarian says he suffered for years because physicians didn’t realize he had Lyme disease. Taylor and others in the Iowa Lyme Disease Association say state and national experts have wrongly concluded the disease can only be carried by deer ticks, which are rare in most of **Iowa**. Members of the group travel to Missouri to be treated. The 2002 total for **Iowa** was 42 and cases tend to be clustered in the northeast part of the state.

In **Massachusetts** the number of reported Lyme cases expected to surge again in the Concord area, after doubling last year, while Urbana

County, **Maryland**, is reporting a surge in the number of Lyme Disease carrying ticks.

Massachusetts State Rep. Michael J. Rodrigues of Westport has introduced legislation that would require insurance companies doing business in Massachusetts to pay for the diagnosis and treatment of Lyme disease. The bill would place all decisions concerning an appropriate treatment plan in the hands of physicians and medical providers. A similar debate played out in **Rhode Island** last year. The legislature there ultimately passed and the governor signed a bill that requires insurance companies to pay for treatment. The bill has won the backing of the Lyme Disease Coalition of **Massachusetts** and its director, John Coughlan.

The state is investigating 73 probable or suspected ehrlichiosis cases in Berkshire County. For 2002, **Massachusetts** had five probable or suspected cases in the Berkshires, compared with 113 statewide. By comparison, there were 69 confirmed Lyme disease cases in 2002 in the Berkshires, with 1,789 statewide. Before the late 1990s people thought that tick-borne illnesses were confined to the Cape and Islands, Cape Ann and the Connecticut River valley.

Ticks infected with the microbe that causes Lyme disease, never recorded in **Michigan** before, have been found in unexpectedly large numbers in a survey of Allegan, Berrien, Cass, St. Joseph and Van Buren counties.

Lyme disease totals soared in **Minnesota** – an increase of 88% from 2000 to 2001. Added to the concern over Lyme is the increase in cases of HGE (human granulocytic ehrlichiosis) – cases reported have risen by 61% in one year.

Epidemiologists are studying a new tick-borne disease carried by wood ticks. In the last few years, 5 to 10 cases a year have appeared primarily in pockets along the Yellowstone River in central **Montana**.

People have developed a red bull's-eye rash around a tick bite followed by weeks of fatigue and a fever. The disease appears to be related to Lyme Disease, but victims do not appear to be as severely affected. To find out more, **Montana** officials recently began running ads asking that people who find embedded wood ticks to save them in a plastic bags and take them to a designated lab.

Hunterdon County, **New Jersey**, has reported a decline in reported Lyme disease cases for the third year in a row, although they feel this may be partially attributed to drier conditions. They also attribute the decrease to increased public awareness and education.

Two grants totaling \$224,670 for Lyme disease prevention and research will be used to fund ecology projects and prevention programs that will eventually benefit **New Jersey** residents. Freehold Township Committee members placed the grants in the municipal budget at a recent meeting. The Lyme disease prevention grant was for \$132,150 and a 2003 Lyme disease ecology research grant was for \$92,520.

Mid-Hudson area, Columbia County, **New York**, is facing surge of deer ticks and Lyme Disease cases. Columbia has the highest per capita rate of the disease in the nation. Reported cases of Lyme disease in 2002 jumped 36 percent to 5,476 cases in upstate **New York**, again leading the nation. New York City had another 59 cases.

Dutchess County, NY, with 1,722 cases, is in the third and final year of a \$900,000 CDC-funded effort to reduce the tick population and educate the public about tick-borne illness. However, a centerpiece of that program—using tick-killing deer-feeding stations—has been held up by the process to get a government permit.

The Hudson Valley Lyme Disease Committee and its community advisory board has created a tick-

borne disease video lending library. Among the video volumes available for borrowing: monthly expert lecture series hosted by the committee; medical and scientific conferences; a Sesame Street video "Facts for Kids," in both English and Spanish; two general information videos titled "What You Need to Know about Lyme Disease" and "Many Faces of Lyme Disease." To borrow a tape from the new tick-borne disease lending library, call Jeanette Hughes at (845) 471-5952. A refundable \$5

Donations needed

Orens Legal Defense Fund

c/o Asher Fensterheim, Esq.
555 White Plains Road
Tarrytown NY 10591

Please make checks payable to Asher Fensterheim, Esq., and write "Orens Legal Defense" in the memo section of your check.

deposit will be charged.

The **New York** Legislature also has approved \$7,275.00 for signs about Lyme disease warning visitors to parks, schools, playgrounds and other public outdoor areas in Dutchess County.

With 197 cases of ehrlichiosis in 2002, **New York** state also had 27 percent of the nation's 729 reported cases.

Dr. Perry Orens' appeal to overturn the 1999 decision of the OPMC to revoke his license has been rejected. He plans to appeal to a higher court. Funds are needed (*see box at right*).

Oklahoma ranks among the highest reported cases of Rocky Mountain Spotted Fever. The primary tick involved in the contraction of the disease is the American dog tick.

An increase in reported cases of 39% in **Wisconsin** may be blamed on moister conditions.

Advocates work behind the scenes on two NY bills

by Ellen Lubarsky

The Office of Professional Medical Conduct (OPMC) Reform Bill (S.5221) has twice passed the NY Assembly, but has not gotten out of committee in the Senate. The bill would revamp the OPMC so as to give physicians due process in protecting themselves from unjust prosecution.

Grassroots lobbyists have already done an excellent job of educating legislators about the Lyme controversy and OPMC injustice toward Lyme-treating doctors. To totally revamp the legislation regulating the OPMC, legislators (particularly Senator Hannon, chairman of the Health Committee) need to be convinced that the current OPMC legislation is inherently unjust to ALL physicians, i.e., that the system is

broke and needs fixing. Otherwise, senators can argue that it is not necessary to revise an entire government department to protect just one group.

Much work is currently going on behind the scenes to try to get enough support for the bill so that it could be put on the calendar to be voted on in the fall. Lawyers, assembly advocates for the bill and Foundation for Alternative and Innovative Medicine lobbyist Monica Miller are working to get the important points through to the significant senators. A progress report should be available by the end of November.

Nettie Mayersohn's bill

During this session, Assembly-woman Nettie Mayersohn introduced

a bill similar to the bill passed in Rhode Island and to the 2002 NY assembly resolution urging the OPMC to “cease and desist” from targeting Lyme doctors. She is now talking with a specific senator whom she would like to see introduce her bill into the Senate during the next session beginning in January. At that point, grass roots efforts to get this bill passed will be started.

“Attention focused on the OPMC has at least seemed to slow down their attempts to strip our doctors of their licenses,” said Ellen Lubarsky, a leading patient advocate. “The OPMC is currently investigating more than one Lyme doctor, but this seems more like a slow water torture than an

aggressive attempt to take their licenses away. We are optimistic that OPMC reform can pass soon enough to protect these physicians.”

If you are a New York resident and not yet signed up to the group of activists in NYS, please email your name, address and phone number to NYLyme@yahoo.com

For information about the OPMC bill, please see www.healthlobby.com

For information about OPMC history and Mayersohn’s bill, please see www.lymeinfo.net.

To get the action alerts along with timely news about Lyme disease issues, send an email to Lymeinfo-subscribe@yahoogroups.com.

The relative new Medical Board as a whole and their Committee on Non-Conventional Medicine has been positive in seeking to have their policies and regulations become fair and effective. They will be very open to hearing positive input in support of the proposed amendment. Under the law when considering this amendment they can not hear any information about discipline concerning a physician.

To read the current Business and Profession Code 2234 go to <http://www.leginfo.ca.gov/calaw.html>, click on first box, and then on search, on that page scroll down to 2234.

A vote of support from the Medical Board is a major step in the process of having this amendment added to the Senate Business & Professions omnibus bill and becoming law in January of 2004.

Please support our efforts by sending a letter to the Medical Board of California at 1426 Howe Avenue, Suite 54, Sacramento, CA 95825-3236 or FAX (916) 263-2387. You may simply state that you endorse the proposed amendment 2234.1. We will also need support from California Medical Association (CMA) and the Center for Interest Law. The CMA legal team is reviewing the amendment. I expect they and the Center for Public Interest Law will not oppose the amendment.

This set of amendments if added to the bill will shift California to a Medical Freedom state. Omnibus committee bills are used to clean up language in the codes and must be non-controversial in nature. These bills pass the legislature with full support and always obtain the governor’s signature.

Frank Cuny is Executive Director of California Citizens for Health Freedom. To contact him email - frank@citizenshealth.org, or telephone (530) 534-9758. This alert will be posted on the CCHF web site at www.citizenshealth.org. The LDRC is supporting this amendment.

California group sponsors bill for medical freedom

by **Frank Cuny**

California Medical Board will vote on a proposed amendment to the Business & Professions Code in their Nov. 6-7 meeting at Sheraton Suites, 701 A Street, San Diego, CA 92101 - (619) 696-9800.

Our research on physicians who have been disciplined for practicing safe and effective alternative medicine revealed that they were almost always charged under section 2234 of the Business & Professions Code. Our proposed amendment of the code will recognize that physicians who offer safe and effective alternative/ non-conventional/ complementary medicine can not be disciplined on the bases that the treatment they provide is not within the “standard of practice”.

The proposed amendment (2234.1) to section 2234 of the California Business and Professions Code was developed in meetings between Ron Joseph, Executive Director of the Medical Board, Donna Russell, my administrative assistant, myself, and

other key staff. It has the support of the Chair of the Boards’ Committee on Non-Conventional Medicine. This amendment will allow California physicians to practice safe and effective alternative/non-conventional medicine legally.

Draft of proposed change

2234.1 (a) A licensee shall not be subject to discipline pursuant to subdivision (b), (c), or (d) of section 2234 solely on the basis that the licensee’s treatment or advice rendered to a patient is complementary, alternative or non-conventional if that treatment or advice is given after written informed consent and a good-faith prior examination and medical indication therefore, and does not cause death or serious bodily injury to the patient.

Ask the Expert

How is Rifampin used to treat tick-borne disease?

by Jerry Simons, PA

There has been a great deal of excitement over the last few months about the antibiotic called Rifampin (brand names Rifadin; Rimactane). It is in a class of antitubercular antibiotics- i.e., those originally employed just to treat TB. Later it was shown to be effective against germs that cause meningitis, and later staph germs.

Although this medicine has been out for quite a long time, it was only this year that rifampin became a “newregular” antibiotic for chronic, resistant TBDs. It seems most effective for Bartonella, HGE/HME, Mycoplasma and Lyme. We use this medicine not as first line, but for our patients that continue to be symptomatic despite all of our other interventions.

Rifampin is a new antibiotic for most patients- i.e., the TBD and Lyme germs have not yet encountered Rifampin, so one can imagine the types and intensity of Jarisch Herxheimer reactions we are seeing! Of interest, many patients who have not experienced a Herxheimer, or those who experience them only to IV medications, are experiencing them now. Many patients are feeling better after this Herxheimer than they ever did before it— many patients request to stay on the medication due to the positive effects they are experiencing.

As mentioned, Rifampin targets the lung and neurologic system, so many patients with chronic pulmonary and neurologic complaints are especially feeling better.

Rifamin needs to be taken on an empty stomach (we usually use 300mg twice a day, starting off once a day at first).

The top three side effects include

headache, muscle, and joint pain. These side effects usually start sooner than the first Herxheimer. Also, Rifamin soaks into body tissues very well, and this may change the color of your urine, sweat, even tears brown-orange glow (it makes for great conversation at Thanksgiving parties)!

Patients with TB take Rifampin up to 3 years. So we have not seen patients experience difficulty in getting more than what their prescription plan usually deems “necessary” for antibiotics.

I always think its funny that TB patients are treated for years with antibiotics, and no insurance company or doctor ever argues!

Anyway, in this population (TB patients on long term rifampin) there have been a few cases of abnormal liver and blood counts, so we do routine labs regularly.

Rifamin also interacts with oral contraceptives and coumadin. Rifampin is not allowed in pregnancy! We have found that Rifampin

Ask the Expert is a new feature in the Lyme Times. If you have a question of general interest you would like our Expert to answer, please send it by mail to the Editor or email to info@lymedisease.org with “Ask the Expert” in the subject line.

combined with an intracellular antibiotic (i.e., Biaxin XL) provides much more positive results than rifampin alone. So you may often hear of the combination called “R&B.” It s not the music, but the two antibiotics in combination. Naturally, lots of yeast protection is required!

More and more patients are taking gabapentin (Neurontin). It is great for chronic peripheral neurologic pain, and has only a tiny list of medications that it interacts with. The usual daily dose can be advanced to over 2,000mg per day! It may take this high a dose to achieve symptom resolution, and it may take several weeks for it to kick in. But remember, that 1 in 4 patients may have dizziness and/or malaise. I think that is a high number, and Lyme patients usually are more sensitive to medications as well.

Its often a tough call between being pain free vs. exhausted. Talk about it at your next visit.

Lastly, many of you with chronic peripheral neurologic disease follow the research in MS. It seems that many of these patients have a TBD!!

There has been a re-interest in the “Swank Diet.” This is a low fat plant-based diet. He has found that high fat diets actually cause the blood cells to become sticky, and circulation decreases (makes sense). He feels that this diet, in chronic form, may result in the perivascular lesions seen in MS. He wrote an amazing article in THE LANCET in 1990, which describes this in much more detail. Dr Swank documents patient improvement, or cessation of disease progression with his diet. I think it will be a winner! All of our ALS and MS patients are going on this diet.

Have a great, low-fat, high protein Thanksgiving (well, maybe one SMALL piece of pie...)

Physician Assistant Jerry Simons works with Joseph Burrascano, MD, in Southampton, New York. This column appeared in an internet Lyme Information newsletter that has been discontinued.

Patient Support

Free and/or cheap medications are available

and you don't have to be destitute

The research-based pharmaceutical industry has had a long-standing tradition of providing prescription medicines free of charge to physicians whose patients might not otherwise have access to necessary medicines. According to an article in *Z-Magazine*, all of the top 30 pharmaceutical companies make prescriptions available free, and these programs are horribly underutilized. PhRMA, an industry trade group, says that 2.8 million prescriptions nationwide (not including samples) valued at about \$500 million were given away in 1998.

Of the patient population most dependent on medications – those older than 65 – 31% lack coverage for prescription drugs. Seniors who have coverage typically use 21 prescriptions a year. A drug just for one chronic condition can cost between \$500 and \$3,000 a year if bought in the U.S.

A great place for information about drug manufacturer's "Patient Assistance Programs" is the website at www.NeedyMeds.com. It lists

specific drugs available through manufacturers' programs as well as most of the different programs that exist.

For example: for a patient denied coverage (ineligible for coverage) for Rocephin, Roche Labs will send an application to the prescribing doctor's office—the doctor fills out the form (which includes the prescription and DEA #) and returns it. Generally, within 3 to 4 weeks, the patient will start to receive the medication. In the case of Rocephin, Roche will provide a 3-month supply for each form submitted by the physician.

NeedyMeds was founded by Libby Overly, MEd, MSW and Richard J Sagall, MD, in 1997. Ms. Overly, a home health social worker in Alabama at the time, had a written database on patient assistance programs to help her patients obtain the medicines they needed but couldn't afford.

Dr. Sagall, then a family physician in Bangor, Maine, was looking for a worthwhile net-based project. He

knew Ms. Overly from projects they worked together on when she lived in Bangor. She told him about her database and the result was NeedyMeds.

The website was started on November 24, 1997. From the start, it was decided that the information would always be available at no cost on the web. It continues to grow with new information, links, and more are added to the website.

In response to requests for printed versions of the data, they began selling the NeedyMeds Manual. It contains the information on the website for those who find it easier to use a printed version rather than accessing the website.

In January, 2002, NeedyMeds became a non-profit Pennsylvania corporation. With this change in status they plan to expand the services they offer. Their goal is to become the best source of information on patient assistance programs and other programs that help people obtain health supplies and equipment.

The PhRMA Directory

To make it easier for physicians to identify the growing number of programs available for needy patients, member companies of the Pharmaceutical Research and Manufacturers of America (PhRMA) created this directory. It lists company programs that provide drugs to physicians whose patients could not otherwise afford them. The programs are listed alphabetically by company. Under the entry for each program is information about how to make a request for assistance, what prescription medicines are covered, and basic eligibility criteria. For additional copies of this directory, people can call 800-762-4636 or check the PhRMA website at <http://www.phrma.org>.

To qualify, applicants must show they have no coverage for outpatient prescription drugs; that their income must be low enough that paying for medicine would pose a hardship; and that they do not qualify for Medicaid.

Websites for drug and science information

Drugfacts.com bills itself as the Net's premium source of unbiased drug, herbal, patient and disease management data. A huge compendium of news, tools and backgrounders.

<http://www.drugfacts.com/DrugFacts/>

Get smarter about the use of prescription drugs. "MEDLINEplus" publishes an online guide to more than 9,000 prescription and over-the-counter medications. You'll find out about proper use, precautions and possible side effects.

<http://www.nlm.nih.gov/medlineplus/druginformation.html>

The largest scientific dictionary ever compiled in the English language makes the jump to cyberspace. The "Academic Press Dictionary of Science and Technology" lets you search more than 130,000 terms defined in 130 fields of science. <http://www.harcourt.com/dictionary/>

Thanks to Julie in SW Florida for these resources.

In reality the doctor writes a two-sentence letter to the pharmaceutical company without any other documentation. Patient-advocacy groups say they have seen families with incomes of \$50,000 or more get free prescriptions.

Most companies supply three months at a time on a case-by-case basis. The corporate drug programs are underutilized. Z-Magazine writer Dorothy Guellec sees this as political, not philanthropic.

“They want to keep it a secret,” she writes. “They do it so they can tell Congress, ‘We give away medicine for free,’ but then, they don’t tell anybody about it and make it very hard for people to apply.”

The non-profit organization Medicine Program can help to simplify the process in some cases. Dan Hogg of the Medicine Program said, “We just serve as the patient’s advocate.” For \$5, refundable if you do not qualify for the free drugs, this non-profit organization will help with the paperwork and get them to the right pharmaceutical company. The Medicine Program’s website is www.themedicineprogram.com

Free Rocephin from Roche

The drug of choice for neurological or late stage Lyme disease is often ceftriaxone, otherwise known as Rocephin. Rocephin is prohibitively expensive for some people, sometimes up to \$200.00 a day. If you need Rocephin but you cannot afford it, Roche Pharmaceuticals has made free Rocephin not only possible, but very simple.

1. Call Roche Pharmaceuticals in Nutley, New Jersey at (973) 235-5000. Call and ask about their patient assistance program. Tell them how extremely serious your situation is and ask if the forms can be processed ASAP. Ask them to send you a “Needy Meds Application.”

2. Upon receipt, fill out the form with your doctor. The form consists of only a few lines and should take no longer than 5 minutes tops. No files or

papers must be sent- ONLY this simple form. Your doctor should send it off.

3. Usually, from the time the form is sent to arrival of the drug at your Doctor’s office will take 3 weeks. The usual shipment is of 3 months of Rocephin. You may refill at will with the same simple form.

IV supplies can be gotten cheaply if you comparison shop. A Visiting Nurse is essential for a week in the beginning to teach a family member (or self, if able) to do dressing changes, infusions and sterile procedures.

Prescriptions at cost

Drugstore owner Joseph DeCuir is honoring the memory of his daughter by reaching out to help all those with a chronic illness in the United States. DeCuir, who lost his beautiful 19-year old daughter to leukemia will sell you drugs at cost plus shipping (UPS) and handling (credit card or money order only – no personal checks). No matter what your financial situation is, if you have no insurance for medicines, you can get your prescription drugs at cost. You may fax your prescription from any licensed physician to Joseph DeCuir, 323-461-3600, or mail your prescription to:

Consumer’s Discount Drug
6542 Hollywood Blvd.
Hollywood, CA 90028

The telephone number for the store is 323-461-3606 or toll-free 888-272-9834 to call and price your prescription.

Do price comparisons

CostCo (www.costco.com) maintains a very low profit margin on its prescription drugs, selling at just above cost. Check this store and other discounts outlets in your area before you buy.

Thanks to Jon Strong, Sue Massie, Barbara Barsocchini, Dorothy Guellec of Z-Magazine, and Gail Kansky of the National CFIDS Foundation for the information contained in this article.

Health Care Helpline for HMO and insurance denials

US Senator Mark Dayton is willing to try and help people who can’t get the care they need. Last year he set up a tollfree Health Care Helpline for patients who have been refused treatment by their HMOs and believe they should not have been denied. Although Senate rules do not allow members to use their office funds for public service announcements, Dayton paid \$3500 from his own pocket for public service announcements which ask:

“What can you do when you need medical care but your HMO or insurance company says no? Call toll-free, 866-296-4319. If you have already received treatment and your HMO or insurer refuses to pay, Senator Dayton’s Health Care Help Line can provide assistance.”

At a Washington press conference Senator Dayton said, “I am not asking the insurance companies to do anything for patients than that which is already called for in their contracts. It’s unfortunate that it takes a call from a US Senator to elicit a response.”

Three staff members will manage the cases, sitting down with insurers to determine a resolution in each instance.

MPPA contacted his office a week ago, and staff then reported that well over 300 calls had come in. Lee Beecher, MD, President Minnesota Physician-Patient Alliance MPPA 6600 Excelsior Boulevard, Suite 121 Saint Louis Park, MN 55426-4746 www.physician-patient.org leebeecheer@aol.com Phone: 952/935-7116 FAX: 952-935-0687

The use of Cefotaxime in treating CNS Lyme disease

by Carolyn Cramoy, M. S.

The following paper was prepared to support an external appeal for a Lyme patient who was refused coverage because the insurance company stated that the dosage administered was greater than that recommended by IDSA guidelines and therefore was not medically appropriate or necessary. The writer, Carolyn Cramoy, M. S. is not a medical doctor or pharmacologist and the information and opinions expressed should not be interpreted as medical advice. Rather, this is a review of the scientific literature pertaining to the case in question and the treating physicians' decision to use antibiotic levels greater than those recommended by the IDSA for the initial treatment of uncomplicated Lyme disease. References are provided.

Antibiotics are accepted as mandatory in active Lyme disease treatment. However, the ideal antibiotics, their dosage, route of administration and duration of therapy have not been established. Treatment failures occur with all regimens tested to date (1, 2). There is no IV antibiotic that currently has FDA approval for the treatment of Lyme disease. Ceftin is the only oral antibiotic so approved and that approval is only for the treatment of early Lyme disease. Persistent infection has been proven repeatedly through the culturing of live *Borrelia burgdorferi* (*Bb*) from the blood or tissue of previously antibiotic-treated patients, as well as by DNA detection by PCR. Because there is no gold standard test, the final diagnosis of and treatment decisions for persistent Lyme infection remain with the experienced

clinician directly involved in the treatment of the patient. When the Lyme bacteria have established themselves in the central nervous system, effective treatment becomes an urgent and complex challenge.

Guidance on appropriate treatment of difficult-to-treat, antibiotic-responsive, neurologic Lyme disease can be gleaned from the extensive medical literature available on Lyme disease and other spirochetal illnesses, as well as that available on other bacterial infections of the central nervous system. Bacterial eradication from the cerebrospinal fluid (CSF) is the definition of bacteriologic cure or response in meningitis (3). The same definition can be valuable in Lyme disease but must be taken a step further and demand eradication of both spirochetal and cystic forms of the bacteria

from intra- and extracellular spaces within the body as well.

Successful treatment of a central nervous system (CNS) infection is dependent on adequate CSF penetration by the chosen antibiotic, with the goal of achieving greater than minimum bactericidal concentration (MBC) levels for as long as necessary to assure destruction of the bacteria in question (4).

Much research and clinical experience supports the need for sustained high levels of CSF concentration in treating Lyme disease.

Though early reports claimed that Lyme disease will resolve by itself if left untreated, it has been found that, even over a period of years, the immune system is often unable to clear the infection. *Bb* DNA has been shown to persist in untreated patients for up to 7 years after onset of arthritis (49). In infections where the host defenses contribute minimally to cure, bactericidal drug concentrations must be achieved in the infected tissue (5).

Bb's slow rate of replication, proven access to intracellular and extracellular "privileged sites", immune system evasion tactics, and conversion to cystic forms when exposed to antibiotics or CSF – all add to the challenge of selecting the proper antibiotic, adequate dosage and length of treatment. The large body of evidence proving continuing *Bb* infection in a percentage of patients following antibiotic treatment underscores the need for truly bactericidal results in treating Lyme disease. The ability to eradicate *Bb* infection in an individual patient is likely dependent on bacterial load, infecting strain, bacterial penetration of privileged sites, the ability of antibiotics to penetrate those privileged sites, and the ability of cyst forms to survive exposure to antibiotics (6). The formation of *Bb* cysts *in vitro* upon exposure to antibiotics, which can later revert to active spirochetes when antibiotic levels drop, may help to explain the ob-

Share your success story with us and help others

The LDRC is compiling insurance appeal material as part of its insurance advocacy program. These materials will be made available to the Lyme community to assist people in their efforts to obtain insurance coverage for treatment of tick-borne diseases. Identity information of the doctor and patient will be redacted prior to use to insure privacy.

Please submit letters of appeal or medical necessity or other supporting materials (articles, studies, etc.) that helped you prevail with your insurance claim to the LDRC, PO Box 707, Weaverville, CA 96093.

served need for repeated courses of antibiotics in order to achieve total eradication of the infection (6). The experiences of clinicians in Lyme endemic areas, as well as the work of many researchers support this idea. The presence of these cystic forms in blood of Lyme disease patients has also been demonstrated.

The third generation cephalosporins, cefotaxime and ceftriaxone, members of the beta-lactam group of antibiotics, are recommended for the treatment of Lyme disease because of their efficient penetration into CSF, and because of *Bb*'s *in vitro* sensitivity to both substances. Cefotaxime has been shown to achieve access to the vitreous humor, a proven "hiding place" for the Lyme spirochete (7). Cephalosporins are widely used in clinical situations because they cover a large range of bacteria and they offer a lower frequency of toxicity than other antibiotics (8). According to clinical studies, cefotaxime is one of the safer third generation cephalosporins (9,10,11,12,13,14). The dosage used and length of treatment is dependent on the bacteria involved and the location of the infection.

Ceftriaxone is often recommended for home infusion situations because it can be delivered in a convenient once-a-day dose. However, the advantages of cefotaxime over ceftriaxone are numerous and it should be carefully considered as the firstline of treatment in CNS Lyme disease. Most patients find the small (approx 3"x6"x1"), quiet portable electronic pumps now available for multiple daily dosing or continuous infusion to be only minimally intrusive as they recover and are able to resume activities outside the home. These pumps are generally worn all day in an inconspicuous waist pack. Another option is the non-electronic "Homepump" automatic delivery system if a multiple dose schedule is chosen. These small (approx 3" diameter), silent, pre-filled and calibrated, elastic pumps fit in a waist pack, remain totally sterile and are easily hooked-up no matter where the

patient might be. They are especially popular with teen-agers who don't want their therapy to be noticed by their peers.

Cefotaxime has a lesser degree of protein binding in the serum and therefore a higher potential for concentration in the CNS. Studies have found the percent penetration of cefotaxime and ceftriaxone into the CSF in humans with meningitis to be 27% and 16% respectively (38). Additionally, 95% of cefotaxime elimination is renal, eliminating the

They are especially popular with teen-agers who don't want their therapy to be noticed by their peers.

possibility of liver toxicity and the gall bladder damage so often seen with long-term ceftriaxone use, especially in young women. The major metabolite of cefotaxime, desacetyl-cefotaxime has antibacterial activity at about 1/4 that of cefotaxime and can make significant contributions to the maintenance of bactericidal levels in the CNS. The short half-life of cefotaxime (approx. 1 hour) and desacetyl-cefotaxime (approx. 1.5 hours) makes maintenance of high levels in the CNS practical without the likelihood of undesirable accumulation (39).

Beta-lactam antibiotics work by preventing the proper formation of the bacterial cell wall during cell division. Therefore, they are only bactericidal when cells are actively dividing. *Borrelia burgdorferi* has a very slow reproduction rate of 7 to 22 hours.

Beta-lactam antibiotic effectiveness against bacteria is dependent on the presence of adequate drug levels through multiple cell divisions. While

increases in the concentration of these drugs above a certain point have little effect on kill rate, the constant maintenance of adequate concentrations over the entire treatment time is extremely important in achieving eradication of the infecting bacteria (15). When *Bb* was incubated for 5 days in Pen G, severe cytolysis of the bacteria only occurred at levels 75% to 300% above the MBC. Allowing levels to cycle below optimum will allow for regrowth of the bacteria, as there is either no, or short, post antibiotic effect (PAE) for most beta-lactams both *in vivo* and *in vitro* (16, 15). Research has shown that the CSF levels need to exceed the minimum bactericidal concentration (MBC) by 10 to 30-fold to obtain maximum bactericidal activity in experimental models of meningitis. This may be in part due to the slower growth rate of bacteria in CSF than in broth (18). Given *Bb*'s very slow reproduction rate even under ideal conditions, this point is especially important in designing a treatment schedule for persistent CNS Lyme disease.

The minimum inhibitory concentration (MIC) of cefotaxime against *Bb* was shown by Hunfield, et al to be 0.15 mg/L (19). Given that the MBC's for ceftriaxone against *Bb* are usually 2 to 8 times the MIC, it is reasonable to predict that the MBC for cefotaxime is in the range of 0.30-1.2 mg/L and that a therapeutic CSF concentration would be 3 to 12 mg/L. Studies of CSF concentrations of cefotaxime in meningitis indicate that levels vary tremendously from individual to individual, but it is reasonable to expect that effective therapeutic levels can be achieved through high-dose continuous infusion. The median CSF levels and (range) in children given 300 mg/kg/day in 3 divided doses, were 4.7(1.4-12.4), 3.3(<0.5-7.1), 1(<0.5-23.7) and 2.2(<0.5-7.8) at 2, 4, 6 and 8 hours after dose (20). In a discussion of the clinical use of antibiotics, Mills lists a cefotaxime level in CSF (with inflamed meninges) of 0.3-27 mg/L for dosages

of 30-150mg/kg/day, however he offers no details or reference for this information (21).

Experience has shown that both cefotaxime and ceftriaxone given at the IDSA recommended dosage for neurologic Lyme often result in treatment failure, incomplete resolution of symptoms, or subsequent relapse even when given for treatment periods of many months (22, 23, 24, 25, 26). It has been shown that retreatment increases the number of patients cured (27, 28).

Though lower than traditional doses of cefotaxime have been found to be effective against organisms outside of the CNS, the necessity of increasing the dose in the treatment of meningitis and endocarditis has been shown (29,30). Additionally, a higher dose may be necessary for resistant bacteria, and in treating immunocompromised patients (29). Studies of the immune competency of Lyme disease patients have shown a reduction of killer T-cell activity, and the actual invasion and killing of human B and T lymphocytes by *Bb* (31). Additionally, *Bb*'s ability to elude the immune system by various methods, in fact, compromises the patient's immune system with reference to its ability to find, identify and eliminate those specific bacteria.

The manufacturer of Claforan (cefotaxime), Hoechst Marion Roussel Pharmaceuticals, Inc., states that 12 gm/day in adults, or 200 mg/kg/day in children, is the recommended dosage for treatment of serious infections. However, in clinical settings, it is now fairly common for dosing to be given at 300 mg/kg/day in both adults and children (20, 32, 33, 34). The Canadian Pediatric Society recommends cefotaxime 300mg/kg/day plus vancomycin 60 mg/kg/day for the empirical treatment of suspected bacterial meningitis (34). It is interesting to note that an early study of Lyme treatment used ceftriaxone at a dosage of 4 gm per day, but this dosage was subsequently reduced due to the manufacturer's warnings of

toxicity (35). Given cefotaxime's safety record and the number of documented Lyme disease treatment failures, it is puzzling that it continues to be recommended only in doses equivalent to the reduced ceftriaxone levels.

Pulse therapy with high doses of cefotaxime being given 2 to 4 days per week at a dose of 10 to 12 gm/day has been reported in anecdotal accounts to be effective in some patients. However, this is a confusing finding

There has never been a study that proves that currently recommended short-course (two to four weeks) therapy results in a bacteriologic cure in Lyme disease.

in light of all the research showing the importance of maintaining levels well above the MBC to assure maximum effectiveness of beta-lactam treatment. A possible mechanism of effectiveness would be that gaps in antibiotic exposure help to preserve the spirochete in its cell wall form and thus maintain its vulnerability to the cell wall inhibiting action of the cefotaxime. Without further knowledge of the dynamics of cyst formation in *Bb* only speculation is possible.

When 300 mg/kg/day doses are used, the upper limit of dosing is set at 24 gm/day. The dose for a 120 pound adult would be 16 gm/day. In that same 120 pound adult;

12 gm/day is equivalent to 220 mg/kg/day.

10 gm/day is equivalent to 180 gm/day.

8 gm/day is equivalent to 145 gm/day

6 gm/day is equivalent to 110 gm/day

The experience of clinicians in Lyme endemic areas indicates:

- that long-term antibiotic therapy is sometimes necessary in treating Lyme disease,

- that testing for co-infection with other tick-borne illnesses should be performed

- that in the absence of clear objective evidence of Lyme a thorough differential diagnosis is necessary, including infectious, auto-immune, and neurological conditions with similar clinical presentations, and if indicated, psychological/psychiatric evaluation,

- that complications are possible with oral or parenteral antibiotics and careful monitoring is the best way to assure safety

- that gradual but continuous resolution of minor symptoms may be acceptable after stopping antibiotics,

- that worsening of symptoms after stopping antibiotics likely indicates failure to eradicate the infection and retreatment should be considered

- that the choice of antibiotics used in retreatment should be carefully determined based on the patient's clinical presentation and responses to past therapy

- that multiple retreatments may be necessary and can lead to cure (27, 28, 36, 37).

MIC's and MBC's are useful in guiding clinical decisions on antimicrobial usage, however, it must be recognized that they may or may not be analogous to the clinical situation, and results must be interpreted accordingly. Treatment of most serious (bacterial) infections requires parenteral administration of antimicrobial agents. When toxicity is not a limiting factor, an increase of the dose may result in a sufficient concentration of free drug to be effective (22).

There has never been a study that

proves that currently recommended short-course (two to four weeks) therapy results in a bacteriologic cure in Lyme disease (41). Clinical improvement is the best and most comprehensive guide to the adequacy of therapy, but it often is difficult to monitor objectively, especially in critically ill patients with multisystemic disease. Clinical improvement may be very slow for infections requiring long-term therapy (for example, endocarditis and osteomyelitis) (22). Although agreement among multiple double-blinded, placebo controlled clinical trials would be the gold standard, there are many sources of valid scientific evidence for clinical decision-making. In the absence of well-designed, double-blind studies, the strength of evidence available to clinicians in making treatment decisions for individual patients can be divided into 3 levels:

1. Evidence obtained from at least one properly randomized controlled trial.
2. Evidence from at least one well-designed, clinical trial without randomization, from cohort or case-controlled analytic studies preferably from more than one center, from multiple time series or from dramatic results in uncontrolled experiments.
3. Evidence from opinions of respected authorities on the basis of clinical experience, descriptive studies or reports of expert committees. (19)

The information provided in this paper supports the medical appropriateness of high dose cefotaxime treatment in difficult cases of chronic or relapsing antibiotic responsive Lyme disease.

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Carolyn Cramoy received her M.S. in Human Nutrition from Columbia University and her B.S. in Zoology from San Diego State University. She has been in private practice as a Nutrition Consultant for 25 years. Carolyn is the mother of two young adults who suffered from chronic and relapsing Lyme disease.

Even though both are currently symptom-free, Carolyn has continued to stay active in the Lyme community, offering support and sharing information and insights acquired through the research she did in seeking answers for her children's illnesses over an 8 year period, and through 2 successful external appeals for insurance coverage of IV therapy. To help fund scientific and clinical research into Lyme disease, Carolyn has set up a Lyme Disease Research Fundraiser through her business as a distributor of health, fitness and personal care products. Up to 90% of net profits from sales to Lyme disease sufferers and their families, friends and supporters will be donated to non-profit Lyme disease advocacy groups such as the Lyme Disease Resource Center, specifically to promote Lyme disease research. For details concerning this fundraising project and the products offered, visit Carolyn's website at "www.NutritionAtHome.com/fundraiser.htm".

Research

Limitation of serological testing for Lyme borreliosis: evaluation of ELISA and western blot in comparison with PCR and culture methods.

Tylewska-Wierzbanska S, Chmielewski T.

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The aim of the study was to evaluate a one-step procedure using an ELISA test of high specificity and a two-step procedure using immunoblot as a confirmation test, and to compare the results of serological testing with detection of bacterial DNA and living spirochetes.

Sera, synovial (SF) and cerebrospinal fluids (CSF) were obtained from 90 patients with clinical symp-

toms of Lyme borreliosis. Serum samples were tested with recombinant ELISA and Western blot assay. Citrated blood, cerebrospinal and synovial fluids samples were cultured in cell line and tested by PCR to detect spirochetes.

No correlation was found between levels of specific *B. burgdorferi* antibodies detected with a recombinant antigen ELISA and the number

of protein fractions developed with these antibodies by immunoblot. Moreover, Lyme borreliosis patients who have live spirochetes in body fluids have low or negative levels of borrelial antibodies in their sera. This indicates that an efficient diagnosis of

Lyme borreliosis has to be based on a combination of various techniques such as serology, PCR and culture, not solely on serology.

Wien Klin Wochenschr. 2002 Jul 31;114(13-14):601-5.

geographical overlap between schizophrenia, MS and neuroborreliosis rather emphasises a causal relation that derives from exposure to a flagellar virulence factor at conception and delivery. It is hoped that the pathogenic correlation of spirochaetal virulence to temperature and heat shock proteins (HSP) might encourage a new direction of research in molecular epidemiology. Published: 20 December 2002

International Journal of Health Geographics 2002, 1:5

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Geographical and seasonal correlation of multiple sclerosis to sporadic schizophrenia

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Abstract

Background: Clusters by season and locality reveal a striking epidemiological overlap between sporadic schizophrenia and multiple sclerosis (MS). As the birth excesses of those individuals who later in life develop schizophrenia mirror the seasonal distribution of Ixodid ticks, a meta analysis has been performed between all neuropsychiatric birth excesses including MS and the epidemiology of spirochaetal infectious diseases. **Results:** The prevalence of MS and schizophrenic birth excesses entirely spares the tropical belt where human treponematoses are endemic, whereas in more temperate climates infection rates of *Borrelia garinii* in ticks collected from seabirds match the global geographic distribution of MS. If the seasonal fluctuations of Lyme borreliosis in Europe are taken into account, the birth excesses of MS and those of schizophrenia are nine months apart, reflecting the activity of *Ixodes ricinus* at the time of embryonic implantation and birth. In America, this nine months' shift between MS and schizophrenic births is also reflected by the periodicity of *Borrelia burgdorferi* transmitting *Ixodes pacificus* ticks along the West Coast and the periodicity of *Ixodes scapularis* along the East Coast. With respect to Ixodid tick activity, amongst

the neuropsychiatric birth excesses only amyotrophic lateral sclerosis (ALS) shows a similar seasonal trend. **Conclusion:** It cannot be excluded at present that maternal infection by *Borrelia burgdorferi* poses a risk to the unborn. The seasonal and

Antibiotics join arsenal of treatments for Lyme mimics

Several recent studies have documented the effectiveness of antibiotics in treating neurologic diseases, some of which have long been thought to be autoimmune. Although the mechanism of their action is not yet known, research is suggesting that antibiotics may be a standard treatment approach in the future for diseases that have, up to now, no cure.

Infection with *Borrelia burgdorferi*, the spirochete responsible for Lyme disease, often involves the central nervous system. Later stages of the disease may mimic the clinical symptoms of Multiple Sclerosis (MS), amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease), Alzheimer's disease, Parkinson's disease, and others.

Multiple Sclerosis

No one knows what causes MS. Researchers have suggested it may be triggered by various viral infections, e.g. human herpesvirus 6, rubella, measles, and by *Chlamydia pneumoniae*. From 1909 until the 1950s many researchers considered MS to have a spirochetal origin because of its similarity to other spirochetal diseases.

In a study published in 2001 in the journal *Annals of Neurology*, researchers tested minocycline, one of the tetracycline family of antibiotics, in rats with autoimmune encephalomyelitis, a condition that mimics MS. The treated animals did not develop neurologic dysfunction or had a less severe course than

untreated rats, according to the senior author of the study, a neurology professor at the University of Wisconsin-Madison.

The researchers believe that minocycline primarily inhibits the inflammatory cascade in the central nervous system, particularly the activation of a cell known as a microglial cell. Evidence from other labs has shown that minocycline can protect the nerve cell. The researchers think that a similar therapy could be used in MS patients with early relapsing-remitting disease. The complete article may be found at <http://www.wisc.edu/>.

Amyotrophic lateral sclerosis

A new study shows that combining the supplement creatine and the antibiotic minocycline significantly slows disease progression and prolongs survival in a mouse model of amyotrophic lateral sclerosis (ALS), or Lou Gehrig's disease."

The disease attacks nerve cells that control movement. As these cells degenerate an affected person becomes progressively paralyzed. Most cases appear between the ages of 40 and 70, and death follows an average of four years after symptoms appear. Daily injections of minocycline delayed appearance of the disease and prolonged life. Treated mice lived about 137 days, compared to 126 days for untreated mice.

The researchers don't think the drug's effect has anything to do with its antibiotic ability. Rather, they think that the minocycline reduces production of a protein within nerve cells that can lead to cell death.

Because of the safety record of minocycline, and its ability to penetrate the blood-brain barrier, this drug may be a novel therapy for ALS. The study was published in the journal *Nature* (v417).

Alzheimer's disease

In a 101-patient Canadian study, Alzheimer's patients treated with

antibiotics doxycycline and rifampin for three months had significantly less mental decline than those given dummy pills, said Dr. Mark Loeb, associate professor at McMaster University in Hamilton, Ontario, and the study's lead author. He suggested that the antibiotics may work by interfering with the buildup of plaques around neurons in the brain that are a hallmark of Alzheimer's. It is also possible that the anti-inflammatory effects of the antibiotics are critical.

The trial found that mental scores of those in the placebo group declined by an average of 2.75 points more over six months than those who received the antibiotic, out of a 70-point scale. At 12 months, there was still a difference between the groups, but it was not considered significant

Parkinson's disease

Relapsing motor neuron disease is uncommon, but this is what happened to a 71-year-old woman as she received several courses of antibiotics for symptoms of Parkinson's disease. The patient was placed on ceftriaxone 2 g intravenously daily for 3 weeks. Her condition improved. Two years later the patient presented again with diffuse weakness, hyperreflexia with extensor plantar responses. She was placed on ceftriaxone 2g daily with rapid improvement. On switching to oral antibiotics, she relapsed, becoming unable to ambulate across a room. Reinstitution of intravenous ceftriaxone resulted in marked improvement within 1 week. This patient exhibited a fluctuating course of relapse and remission of motor neuron disease over a 3-year period. Repeat neurophysiologic studies appeared consistent with motor neuron disease. The report appeared in the *Journal of Spirochetal and Tickborne Diseases* 2(3):64, 1995.

Spanish doctors treated an elderly man with Progressive Supranuclear Paralysis (PSP), a disorder of unknown etiology, considered to be the commonest cause of Parkinsonism-plus, one of the symptoms of which is

dementia. The man had positive Lyme tests and his condition improved after treatment with ceftriaxone. (Garcia-Moreno JM et al. *Rev Neurol*. 1997 Dec;25(148):1919-21.)

Dementia

In a letter to *JAMA* (Oct. 24/31, 1986—Vol. 256, No. 1) pathologist Alan MacDonald stated that he had identified spirochetes in serial subculture of autopsy brain tissues from two patients with dementia. "Case 1 was a 74-year old woman with mild dementia of less than one year's duration.... Case 2 was a 69-year-old man who died in a nursing home in Texas after a four-to five-year history of progressive dementia. Parkinsonian symptoms were noted during his last year of life. Neither patient had symptoms of the skin, joint, or cardiac disorders described in *Borrelia* infection. Dr. MacDonald suggested that such patients should be "candidates for intensive parenteral (IV) antimicrobial therapy analogous to the treatment now used for neurosyphilis."

In 1995, Waniek et al. reported a case of fatal neuropsychiatric Lyme disease (LD) that was expressed clinically by progressive frontal lobe dementia and pathologically by severe subcortical degeneration. Antibiotic treatment resulted in transient improvement, but the patient relapsed and died after the antibiotics were discontinued.

Huntington's disease

The antibiotic, minocycline, was shown recently to prolong the lives of mice with a version of Huntington's disease, another neurodegenerative disorder. It is now being tested against Huntington's in people.

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Large cerebral vessel occlusive disease in Lyme neuroborreliosis.

Klingebiel R, Benndorf G, Schmitt M, von Moers A, Lehmann

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We report on a 12-year-old, previously healthy girl with an acute hemiparesis as the predominant clinical manifestation of Lyme neuroborreliosis (LNB). The diagnosis of LNB was based on cerebrospinal fluid (CSF) studies, laboratory findings and the clinical course whereas the patient's history and the

lack of characteristic skin lesions obscured the diagnosis in the beginning. After four weeks of antibiotic and physiotherapeutic treatment, the hemiparetic symptoms had completely resolved. Although evidence of vasculitic and perivascular inflammation in LNB has been described in the literature, large cerebral vessel occlusive disease

represents a rare finding. Appropriate treatment strategies can lead to good clinical rehabilitation, as shown in this case, making the timely diagnosis a crucial issue. We conclude that LNB should be considered in every stroke-like episode of unknown origin in children, even in the absence of a history of a tick bite or typical skin lesions.

Neuropediatrics 2002 Feb;33(1):37-40.

Cannabinoids inhibit neurodegeneration in models of multiple sclerosis

Gareth Pryce, et al.

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Multiple sclerosis is increasingly being recognized as a neurodegenerative disease that is triggered by inflammatory attack of the CNS. As yet there is no satisfactory treatment. Using experimental allergic encephalo myelitis (EAE), an animal model of multiple sclerosis, we demonstrate that the cannabinoid system is neuroprotective during EAE. Mice deficient in the cannabinoid receptor CB1 tolerate inflammatory and excitotoxic insults poorly and develop substantial neurodegeneration following immune attack in EAE. In addition, exogenous CB1 agonists can provide significant neuroprotection from the consequences of inflammatory CNS disease in an experimental allergic uveitis model. Therefore, in addition to symptom management, cannabis may also slow the neurodegenerative processes that ultimately lead to chronic disability in multiple sclerosis and probably other diseases.

Brain, Vol. 126, No. 10, 2191-2202, October 2003

Neuroborreliosis Briefs

F. Tager et al. A Controlled Study of Cognitive Deficits in Children With Chronic Lyme Disease. J Neuropsychiatry Clin Neurosci 13:500-507, November 2001.

Children with Lyme disease had significantly more cognitive and psychiatric disturbances. Cognitive deficits were still found after controlling for anxiety, depression, and fatigue. Lyme disease in children may be accompanied by long-term neuropsychiatric disturbances, resulting in psychosocial and academic impairments.

Hájek et al. Higher Prevalence of Antibodies to Borrelia burgdorferi in Psychiatric

Patients Than in Healthy Subjects. Am J Psychiatry 159:297-301, February 2002. Among matched pairs, 166 (33%) of the psychiatric patients and 94 (19%) of the healthy comparison subjects were seropositive in at least one of the four assays. These findings support the hypothesis that there is an association between *Borrelia burgdorferi* infection and psychiatric morbidity.

Newberg et al. Cerebral metabolic changes associated with Lyme

disease. Nucl Med Commun 2002 Aug;23(8):773-7.

We used [¹⁸F]fluorodeoxyglucose (FDG) PET to determine the metabolic landscape in 23 patients with Lyme disease. Images were evaluated for cortical and subcortical abnormalities by two experienced reviewers blinded to the clinical information. The most striking finding was hypometabolism in the temporal lobes in 17/23 (74%) patients.

Wilke et al. Primarily chronic and cerebrovascular course of Lyme neuroborreliosis: case reports and literature review. Arch Dis Child 2000 Jul;83(1):67-71.

Two patients suffered from a primarily chronic form of neuroborreliosis and displayed only non-specific symptoms. An 11 year old boy presented with long standing symptoms of severe weight loss and chronic headache, while the other patient had pre-existing mental and motor retardation and developed seizures and failure to thrive. Two further children who presented with acute hemiparesis as a result of cerebral ischaemic infarction had a cerebrovascular course of neuroborreliosis.

Book Reviews

A Glimpse into the American Gulag ?.. in Nevada County?

by Gary Quinn

He thought of calling his new book, *A Glimpse into the American Gulag... in Nevada County and Beyond...* However, Penn Valley [California] resident retired Air Force Lt Col David Moyer, Alaska Licensed Clinical Social Worker, Board Certified Diplomate, and former employee at Nevada County Behavioral Health Services, wanted a positive message that would bring hope to psychiatric patients and their families. So he called it *Too Good To Be True? Nutrients Quiet the Unquiet Brain - A Four Generation Bipolar Odyssey*. He also thought of calling it *Nutrients Quiet the Unquiet Mind*, borrowing from the best seller, *The Unquiet Mind*, by Dr. Kay Redfield Jamison. But he says he didn't want to write about mind – or mental for that matter. He wanted the title to reflect his odyssey into biological causes and solutions for what most people call mental illness but he now calls central nervous system disorders. "In my book I try to take the 'mental' out of mental illness."

He says he changed his view about mental illness in the process of researching and writing the book. His great aunt, grandmother, father, and son all exhibited symptoms of what is commonly called bipolar disorder. For his family, existing assessment and treatment paradigms were ineffectual as well as life threatening. After three years of research he came to the conclusion that bipolar disorder is actually a syndrome, not a biologically discreet illness. Rather, it is a manifestation of many different biological disorders, many of which are known, and all too frequently ignored by treating physicians. He

concludes that mental health professionals would serve their patients better by treating the biological conditions that cause the symptoms rather than an illness known as "bipolar disorder." "We need a new typology for CNS disorders that focuses on biologically valid psychological variables applied to diseases and drug effects."

"We mental health professionals have been trained to use terms like schizophrenia and bipolar disorder as if they described actual physical disorders. They don't. These terms are labels, descriptive labels, not physical diagnoses. They describe common manifestation of many different of physical disorders. At the beginning of the last century in the South, the state hospitals were filled with patients who were labeled as schizophrenic. Now we know they had pellagra, a deficiency of an important B vitamin. Patients with syphilis were mistakenly diagnosed as bipolar patients. Why do psychiatric patients today have almost twice the frequency of antibodies to Lyme disease as do non psychiatric patients? How many psychiatric patients are assessed for Lyme disease, let alone treated for it? As a clinical social worker I knew next to nothing about such terms as Lyme disease, stealth virus, tubulin antibodies, glial fibrillary acidic

protein, and heavy metal toxicities, biological factors that play a role in causing bipolar behavior."

"In the absence of adequate biological models for CNS disorders, folks in my profession have come up their own pet theories as to what causes these disorders. For example, there was the double bind theory of schizophrenia put out by the highly respected therapist Virginia Satir and others in the 60's. This theory placed the responsibility for a child's schizophrenia on the so-called schizophrenogenic mother. We need to be finding the problem, not blaming the parents for it. Now the parents of autistic and schizophrenic children may unwittingly play a role by, believe it or not, feeding their children casein and gluten. But parents can't be held responsible when no one warns them about that link. He says Dr. F Curtis Dohan first proposed the idea in the mid 60's and there is now a vast amount of both epidemiological and clinical data to corroborate Dr. Dohan's hypothesis." He says that some of the ideas in his book came from his consulting with Dr. Robert Cade, from the University of Florida, the creator of Gatorade, who, among others, has published extensive research on the link between casein/ gluten and schizophrenia.

In his book he states that our preoccupation with mind over matter

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has replaced our appreciation of the importance of matter over mind, as, for example, those basic building blocks for proper brain functioning such as the proper amounts of vitamins, minerals and amino acids. He says, "Our brains won't work right if they don't have the necessary supplies. No psychotherapy can heal a brain that does not have what it needs to function properly. One doesn't tell an Andrea Yates to just stop thinking homicidal thoughts. You don't tell a person like her to change her mental attitude. You help restore her brain to health."

"So what is this about the American Glulag?" I asked him.

"It exists here in Nevada county as well as California where, last I heard, we have built 21 prisons for every university."

"But what is it?" I repeated.

"It is a place, actually, lots of places where thousands of people are sorted, drugged and warehoused daily. Normally we associate the word "American" with apple pie, the flag, and patriotism. We associate Gulag with imprisonment, victims, the all powerful state, and of course the famous book, *Gulag Archipelago* by Solzhenitsyn. My juxtaposition of those words might seem unfair, even sensational to some, but I think anyone who reads my book will get a realistic glimpse of the American Gulag. One of the reasons I wrote the book is to help those who are in the Gulag get out and those who are out stay out. Unfortunately many of those who care for these people are down on what they are not up on and don't want to get up on what they are down on. Therefore, the myth continues to be perpetuated throughout the mental health community that nutrition has no place in the treatment of the "mentally" ill. Nutritional considerations remain at the fringe instead of the center where they need to be."

"Nutritional and other biological based solutions exist now. If they were utilized more fully, I believe we

would see a substantial reduction in the population of the American Gulag. As leaders in Nevada County plan for an eventual mental health crisis center, I hope they will take into account the extensive research on nutrition and mental health that is already in the medical and scientific literature. We need fewer outposts for

the American Gulag, not more. We need centers that can individually assess each patient and, give them what they need so that their brains will work properly."

You can learn more about Moyer's research and view his website at www.bipolarodyssey.com.

The Journal of a Disappointed Man, by W.N.P. Barbellion, 1889-1919

Reviewed by Lee Lull

I admit it. I see Lyme almost everywhere I look. Like most Lyme patients who have researched scientific articles for a few years and who have heard hundreds of case histories, I have concluded that Lyme disease is underdiagnosed by a factor far beyond anything yet conceived of by mainstream medicine. It is intellectually easy to link infectious etiologies, spirochetal or otherwise, to most of the so-called "auto-immune" illness that are proliferating; proliferating right along with the tick population. I follow Brorson & Brorson's research religiously; their recent small study that finds positive findings of cystic structures (probably of spirochetal origin, judging by positive tests and cultures) in CSF of all 10 Multiple Sclerosis subjects did not surprise me. I don't understand why researchers aren't doing MS studies with long-term aggressive antibiotics...or are they? Most of us have met people "mistakenly" diagnosed with MS who have gone on to get much better with that aggressive treatment approach. And so when I read the following excerpt from a book first published in 1919, you will understand why I wanted to read the whole book. Diagnostic sleuthing was my intent. And of course I conclude he had Lyme disease. But read the book for yourself and draw your own conclu-

sion.

Excerpt from "The Journal of a Disappointed Man" by W.N.P. Barbellion 1889-1919:

January 20, 1917

"I am over 6 feet high and as thin as a skeleton' every bone in my body, even the neck vertebrae, creak at odd intervals when I move. So that I am not only a skeleton but a badly articulated one to boot. If to this is coupled the fact of the creeping paralysis, you have the complete horror. Even as I sit and write, millions of bacteria are gnawing away my precious spinal cord, and if you put your ear to my back the sound of the gnawing I dare say could be heard".

The book has selected journal entries that track Barbellion from the age of 13 up to a few months before his death in December of 1919. Barbellion was the pseudonym for Bruce Frederick Cummings. (Even the initials of his pseudonym have meaning...but I'm not going to tell here) He was an intense, brilliant, ego centric, self-taught naturalist. He combed the countryside of England collecting, observing and dissecting a variety of wildlife in his youth. But he was smitten with a disease that had a waxing and waning nature in his early twenties. He was diagnosed as having multiple sclerosis, and was prescribed strychnine, a common potion of the times. He referred to it as "rat poison", but was compelled to try and exorcise the "daily demon" that plagued him by any means available...driven by desperation, as many of us are, to try potions not always as safe as we would prefer.

His illness affected his ability to think, heart rhythm irregularities occurred, pains came and went, gastrointestinal disturbances occurred and ocular problems so bad that at times he thought he was going blind. Some days he felt pretty good, other days he sort of hibernated and couldn't exert himself and he describes depression. He tried to conceal many of his symptoms. Near the end of his life paralysis was a problem. And as the excerpt above mentions he became rather cadaverous in appearance. So the question remains, did he succumb to Lyme disease or did he really have MS? Or is MS really one manifestation of Lyme disease? Or was it something entirely different? Did the strychnine do him in? If you like medical sleuthing this book will give you a great opportunity to do just that. It also gives one a peek into an interesting, albeit self- preoccupied mind.

If the diagnosis of Lyme disease is truly based upon symptoms and the likelihood of tick exposure, then Barbellion fulfills the diagnostic criteria as far as I can determine.

Barbellion wanted to entitle his journal "The Diary of a Dying Man" and referred to it as "a study in the nude", alluding to his openness in an age just coming out of the Victorian period.

This book can be obtained from Amazon.com...softback, for \$11.95 [or support your local bookstore - Ed.]. Although I had to wait a few weeks for delivery, the wait was worth it.

Lee Lull runs a Lyme Disease Support Group in Marin County, California. She also serves on the Lyme Disease Advisory Committee to the California Department of Health Services.

Copies of the new book are available for \$14.95 + \$5.95 for shipping and can be obtained as follows:

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Desperation Medicine, by Ritchie Shoemaker

by Kathleen Dickson

It's here - the book that gives you the whole story -

- How does Lyme Disease create neurotoxins?
- How does cholestyramine remove neurotoxins?
- What is the Visual Contrast Test (VCS) and How does it work?
- Actos is new - is it safe? What does it do? Will it help you?
- Related diseases - Chronic Fatigue, and many more
- Why fibromyalgia is not a diagnosis

The book is *Desperation Medicine*, written by Ritchie Shoemaker, MD. It includes an explanation of the medical science, the social impact of Lyme Disease, the difficulties with the

medical profession, the lack of understanding by the insurers, and problems with government.

It presents case histories wherein the use of cholestyramine has resulted in dramatic improvements for Lyme Disease as well as Sick Building Syndrome, Chronic Fatigue, and a number of other related neurotoxin illnesses.

Reading this book requires some understanding of Lyme Disease (most Lyme Disease patients have this, often more than some of the doctors they consult!). Covered are the history of cholestyramine use, early test panels, current acceptance, combination with Actos, future needs for education of health care providers.

The author, who himself has had several bouts of Lyme Disease, has presented technical papers to various scientific societies, and discussed neurotoxins at the International Lyme and Associated Diseases Conference. He was awarded Maryland's "Family Doctor of the Year," and is in practice in Maryland.

Finding The Way Home: A Compassionate Approach to Illness, by Gayle Heiss

Based on the author's personal experiences and those of hundreds of people who have attended her weekly support groups, *Finding the Way Home* is a book of thoughtful reflections on living with illness. Gayle Heiss clarifies the life-altering emotional and spiritual shifts that take place in confronting and coming to terms with human vulnerability.

Ms. Heiss places illness, pain, loss, and death in their proper context—as part of the human condition, not as aberrations that beset an unfortunate few. She helps remove the painful stigma that frequently burdens those who are ill in our health/youth obsessed culture. She offers a more wholesome yardstick than physically-based accomplishments or appearance to measure human worth.

Looking at illness from the inside out, Ms. Heiss reveals distinctions which are profoundly important to those who are ill. *Finding the Way Home* explores the difference between disease (a biological condition) and illness (the individual human experience of it); between curing (the alleviation of symptoms) and healing (the healthy integration of all life experience, including illness); and

between pain (physical distress) and suffering (the loss of meaning, connection, and hope in the face of pain).

Grief is the natural and necessary response to loss, and the resilience of the human spirit in transcending grief is part of the healing process. Rather than offer formulaic solutions, Ms. Heiss affirms the need—and the right—of each individual to forge his or her own path.

As witness rather than expert, her humility is refreshing and her reflections honest. Her profound understanding of individual differences and her ability to support each individual's struggle make for an uplifting, even joyful, reading experience.

Ms. Heiss recognizes that being ill and witnessing illness both create distress. Her caring analysis of relationships with loved ones, friends, caregivers, and health care providers conveys not only what happens to people but between them. Accounts of support group discussions give the reader the rare opportunity to hear ill people talk honestly and openly with one another.

Anyone touched by health concerns will want to share *Finding the Way Home* with others. The inner world of illness is portrayed with clarity and compassion. Here is a book for anyone trying to live wisely, no matter the state of his or her health.

How to purchase:

Purchase or order from your local bookstore, or contact the publisher: QED Press, 707-964-9520 or 800-773-7782. \$24.95 case bound.

“*Finding the Way Home* is a thought-provoking and unique perspective on illness as a path towards integrity, a way to grow in wisdom and to learn to love better. An important book for anyone who has been ill or who could become ill.”
—Rachel Naomi Remen, MD, Author, *Kitchen Table Wisdom: Stories That Heal*

Common Sense Pest Control Quarterly, special pathogen issue

Publication on Vector Borne Disease in America: Lyme Disease, West Nile Virus, and Hantavirus

The Bio-Integral Resource Center is a nonprofit, scientific organization dedicated to providing practical information on effective, least-toxic methods for managing pests. BIRC's technical staff reviews the world's scientific literature searching for the most promising methods—physical, biological, cultural, and least-toxic chemical—of pest control. We publish our findings in our two journals, the *IPM Practitioner* and the *Common Sense Pest Control Quarterly*, accessed by public health agencies, libraries, and universities, worldwide.

The Summer 2000 issue of the *Common Sense Pest Control Quarterly* is dedicated to vector borne disease in America: Lyme disease, West Nile encephalitis, and hantavirus.

Lyme disease is the number one, vector borne disease in America. The *Common Sense Pest Control Quarterly* discusses the importance of ecology in the spread of Lyme disease, identifies areas of risk, describes symptoms, outlines advantages and disadvantages of the Lyme disease vaccine, and lets you know how you can protect your pet and discourage ticks in your local environment.

The special pathogen issue of the *Common Sense Pest Control Quarterly* is available from BIRC. The *BIRC Least-Toxic Pest Management Series* includes one booklet on ticks. For more information, or to make an order, please contact the Bio-Integral Resource Center by phone at (510) 524-2567, or by email at birc@igc.org. For more information about our organization, please visit our website at www.birc.org

The LDRC launches National Survey Program — Stand up and be counted — NOW!

Tell me about the program.

The LDRC has launched a survey program to compile the data necessary to support our health care advocacy issues. Survey data is much more useful than anecdotal evidence because it tells the extent of the problem on a broader basis. Many legislators and other public policy officials prefer survey data to illustrate a point. This is your chance to stand up and be counted. Make your voice heard by filling out the survey on the opposite page and mailing it to the address specified.

Do I have to identify myself?

While it is not absolutely required, we strongly recommend that you do so to lend strength to the validity of the study. In order for surveys to be deemed valid for scientific and advocacy use it is necessary to ensure that there are no duplicates. Some surveys request the patient's name or social security number to accomplish this purpose. We request your phone number because it is the least direct unique patient identifier. When we compile the data, we will use this number to insure that there are no duplicates. However, we will not disclose this information to anyone else and we will not call you!!! Nor will your patient identity be included in any reports compiled from the data.

Please copy, fill out, and mail in the form on the opposite page!

Please copy or tear out this page and complete the questions below. Send the completed form to the LDRC, Attn: Surveys, PO Box 707, Weaverville, CA 96093. Thank you!

SURVEY

Impact of CDC Surveillance Definition of Lyme disease

Date: _____

Patient identifier _____

(phone number strongly urged but not required)

1. ELISA:

- a. Have you ever been told that you did not have Lyme disease because of a negative ELISA test result? **Yes** _____ **No** _____
- b. If so, in what year did this occur? _____
- c. Have you ever been denied medical reimbursement by an insurance company because of a negative ELISA test result? **Yes** _____ **No** _____
- d. Have you ever been denied disability coverage by the state or an insurance company because of a negative ELISA test result? **Yes** _____ **No** _____
- e. Have you ever had a physician refuse to perform a Western Blot test for Lyme disease because you tested negative for Lyme disease with an ELISA test? **Yes** _____ **No** _____

2. Western Blot:

- a. Have you ever been told that you did not have Lyme disease because a Western Blot did not evidence at least 5 of the 10 CDC approved IgG bands or 2 of the 5 CDC approved IgM bands*? **Yes** _____ **No** _____
- b. If so, in what year did this occur? _____
- c. Have you ever been denied medical reimbursement by an insurance company because a Western Blot did not evidence at least 5 of the 10 CDC approved IgG bands or 2 of the 5 CDC approved IgM bands*? **Yes** _____ **No** _____
- d. Have you ever been denied disability coverage by the state or an insurance company because a Western Blot did not evidence at 5 of the 10 CDC approved IgG bands or 2 of the 5 CDC approved IgM bands*? **Yes** _____ **No** _____

3. Diagnosis.

- a. In what year were you first diagnosed with Lyme disease? _____
- b. On what basis were you diagnosed with Lyme disease? (Check below)

ELISA _____

Western Blot _____

PCR _____

Clinical Symptoms _____

Spinal tap _____

Other _____

*CDC considers an immunoblot positive for IgM if 2 of 3 bands are present: 24 kDa, 39 kDa, & 41 kDa...and for IgG if 5 of 10 bands are present: 18 kDa, 21 kDa, 28 kDa, 30 kDa, 39 kDa, 41 kDa, 45 kDa, 58 kDa, 66 kDa, & 93 kDa.

LDA Conference Agenda

continued from back page

3:55-4:35 pm The Pituitary Involvement of Lyme Disease, Jacqueline Springer, MD

4:35-5:15 pm General Considerations of Antimicrobial Agents Used in Treatment of Lyme Disease, Mitch Hoggard, RPH

5:15-5:55 pm Borrelia, Bartonella, Mycoplasma & Helicobacter Infections, All Associated with Abdominal Pain, Martin Fried, MD

5:55-6:00 Interactive Discussion

6:00 pm Thanks and conference closing remarks.

6:15-8:15 Reception

An educational and networking event featuring prominent speakers on tick-borne diseases.

Carolyn Barley Briton, MD
Neurologist Associate Professor of Clinical Neurology, Columbia University College of Physicians & Surgeons Former Chair, Neurology/Neurosurgery Section, National Medical Association, New York, New York

Joseph Burrascano, MD Internist
Southampton Hospital: Chairman ad hoc Committee on Lyme Disease, Chairman, Transfusion Committee, Co-chair Medical-Nurse Practice Committee; Board of Directors, International Lyme & Associated Diseases Society, East Hampton, New York.

Sherwood Casjens, PhD, Professor, Division of Cell Biology & Immunology, Department of Pathology, Adjunct Professor, Department of Biology, University of Utah College of Medicine; NIH Committees: Advisor to National Center for Biotechnology Information's Viral RefSeq Genomes Database, Study Section on Regional Centers of Excellence in Biodefense Research; American Academy of Microbiology workshop on Future Directions for Bacterial Genomics, Salt Lake City, Utah

Paul Duray, MD, National Institutes of Health, Department of Pathology, National Cancer Institute, Bethesda, Maryland

Brian A. Fallon, MD, MPH, MEd, Director, Lyme Disease Research Program, New York State Psychiatric Institute; Associate Professor of Clinical Psychiatry, Columbia University, College of Physicians and Surgeons, New York, New York

Paul Fawcett, PhD, Assistant Professor of Pediatrics, Thomas Jefferson University, Philadelphia Pennsylvania; Senior Research Scientist, Head of Immunology Laboratories, Alfred I. DuPont Hospital for Children, Wilmington, Delaware

Martin Fried, MD, Director of Pediatric Gastroenterology and Nutrition, Jersey Shore Medical Center Neptune, New Jersey

Mitch Hoggard, RPH resident, Chico Hyperbaric Center Director, Sacramento Hyperbaric Center Former President/Owner, Northern California

Pharmacy Associates, Inc. Chico, California

Judith Miklossy, MD, Assistant Professor, Medical Faculty, University of Lausanne The University Medical School & Hospital (CHUV) & University of Lausanne (UNIL); Current research at Center for Neurovirology & Cancer Biology of Temple University, Philadelphia Pennsylvania & Columbia University of Vancouver, Canada Lausanne, Switzerland

Kenneth Nealon, PhD University of Southern California Wrigley Professor of Geobiology; Member Space Science Exploration Committee (Congressional Committee); Member, Mars Exploration Science Working Group, NASA; Editorial Board: Geobiology Journal, Applied and Environmental Microbiology, FEMS Microbial Ecology, Geomicrobiology Journal, Symbiosis California

Steven E. Schutzer, MD, Associate Professor of Medicine, University of Medicine and Dentistry & Newark, New Jersey (UMDNJ) Newark, New Jersey

Jacqueline Springer, MD Endocrinologist, Olathe, Kansas

Support the LDRC NOW!

The Lyme Disease Resource Center is a non-profit corporation that seeks to prevent tick-borne diseases, encourage early diagnosis and improve the quality of health care provided to those with tick-borne diseases through education and advocacy. The LDRC compiles and distributes health, insurance and advocacy information to assist the Lyme community at the state and national level. Beginning with this issue, the Lyme Time is launching its national survey program. (See page 60).

The LDRC also serves as the central voice for tick borne disease

issues in California and shares its best practices with the national Lyme community through the Lyme Times, the LDA and state Lyme groups. The LDRC is currently working on a patients education packet, local support group advocacy packet, patient and physician insurance "battle" plans, which will be shared with the broader Lyme community when completed.

iGive giving

Giving is painless when you shop on iGive. iGive will direct a percentage of your purchases to LDRC. All

Continued on next page

Yes! I'd like to join the fight against Lyme disease!

Please begin a one year membership in the **Lyme Disease Resource Center**

- **\$30 - Basic***
- **\$50 - Supporting***
- **\$100 - Sustaining***
- **\$200 - Patron***
- **\$15 - Special Needs***
- **I enclose an additional \$ _____ as a tax-deductible contribution to the LDRC for education and research.**

**All members receive a complimentary subscription to the Lyme Times.*

- Enclosed is my check or money order for total amount of \$ _____.

Please make your check payable to LDRC and mail with this form to LDRC, PO Box 707, Weaverville, CA 96093.

| | |
|----------------|-----------------|
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| _____ | |

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| | |
|----------|--|
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| City | City |
| State | State |
| Zip Code | Zip Code |

Your email address

you have to do is sign up. iGive makes it easy, with over 460 familiar stores (like Barnes & Noble, Lands' End, PETsMART, Dell, Office Depot, QVC.com, and Best Buy) to choose from. Signing up is free.

For more information go to <http://www.iGive.com>.

United Way giving

You can name LDRC when your company collects for United Way. If you don't have a campaign at your company, you can give directly to the

United Way in your community.

Wills and Bequests

Finally, we don't like to think about the demise of our friends, but what better way to celebrate a life than to give to a charity that is helping others to live better and longer? Please remember us in your will.

LDRC is an IRS 501(c)(3) organization and your donation is deductible to the full extent allowed by law.

the **Lyme Times**

Bulk Rates

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

Calendar

ILADS 6th International Conference on Lyme and associated diseases

Hyatt Hotel at Penns Landing
Philadelphia, Pennsylvania

Saturday, November 15
8am to 6 pm
Sunday, November 16
8am to noon

The conference is open to members of ILADS and to non-member health care providers.

Registration Categories
Member (MD, PhD) \$195
Affiliate \$195
Allied Health \$120
Non-Member Professional \$220
Non-Member Allied Health \$145

Please make check payable to ILADS and return with the registration form to:

ILADS
C/O Barbara Buchman
PO Box 341461
Bethesda, MD 20827

The Conference agenda and online registration are available at www.ilads.org.

Hotel and transportation information:

Hyatt Hotel at Penns Landing
201 S. Christopher Columbus Blvd.
Philadelphia, PA 19106
(215) 928-961234

Situated on the Delaware River waterfront in the eastern part of downtown Philadelphia, within walking distance to the historic, shopping, and entertainment areas.

The Hyatt is 8 miles from Philadelphia International Airport, and 28 blocks from the Amtrak station.

Guest Rooms are available at a negotiated group rate of: \$130.00 per

night for single/double occupancy
\$155.00 per night for triple occupancy
\$25.00 additional for an upgrade to a river view or executive room

Hotel reservations can be made online through this secure link or by calling the Hyatt at (800) 233-1234 or (215) 928-1234.

Transportation is available from the airport to the hotel by taxi, or by Lady Liberty shuttle service. The shuttle cost is \$8.00 each way and is available daily from 5 AM until midnight. Once you arrive, go downstairs to the luggage claim area and there will be a sign that says, "Ground Transportation." Pickup one of their phones and dial #27. Lady Liberty will send a shuttle around to pick you up.

LDA/Columbia Conference

Hyatt Hotel at Penns Landing
Philadelphia, Pennsylvania

Friday, November 14

For physicians and other health care providers. The public is also invited to register. For additional information and to register, go to www.lymediseaseassociation.org.

Conference Agenda:

7:30-8:00 am Registration/Breakfast/Exhibits
8:00-8:05 am Welcome, Patricia V. Smith, President, Lyme Disease Association
Introduction of Brian A. Fallon, MD, Morning Session Facilitator
8:05-8:50 am Community Activities as Guides to the Search for Life: Are There Connections with Medical Microbiology? Ken Neilson, PhD
8:50-9:30 am Proteomic Approach to Identify Borrelia Antigens, Steven Schutzer, MD
9:30-10:10 am Natural Genome Rearrangements in *Borrelia Burgdorferi*, Sherwood Casjens, PhD

10:10-10:25 am BREAK
10:25-11:05 am *Borrelia burgdorferi* Persisting in the Brain Can Cause Dementia in Tertiary Lyme Neuroborreliosis, Judit Miklossy, MD
11:05-11:45 am Pathologic Findings in Lyme Disease, Paul Duray, MD
11:45-12:00 am INTERACTIVE DISCUSSION
12:00N-1:00 am LUNCH
Steven E. Schutzer, MD, Afternoon Session Facilitator
1:00-1:40 am Laboratory-based Tests for Lyme Borreliosis, Paul Fawcett, MD
1:40-2:20 pm Leukoencephalopathy or Abnormal White Matter on Brain MRI-Lyme, Multiple Sclerosis, and Other Causes, Carolyn Briton, MD
2:20-3:00 pm Microbes and Mood - Does Lyme Disease Really Cause Psychiatric Problems? Brian Fallon, MD
3:00-3:15BREAk
3:15-3:55 Diagnosis & Treatment: A Retrospective study of Lyme Disease Patient Records, Joseph Burrascano, MD

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the Lyme Times
Lyme Disease Resource Center
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