



FREE

PUBLIC HEALTH ALERT

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Investigating Lyme Disease & Chronic Illnesses in the USA

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Appeal Filed for Dr. Jones Verdict

Biased Panel Member Raises Question of Due Process

by Lorraine Johnson

Dr. Jones filed with the Connecticut Medical Examining Board a Motion for Reconsideration and to Vacate the decision of the December 18 hearing, which had imposed civil penalties and placed Dr. Jones on probation for two years.

The basis for the motion is bias on the part of one of the panel members, Dr. Senechal, who had told the parents of a child diagnosed with chronic Lyme disease during the Jones hearings that there was no such thing as chronic Lyme disease, that the treatment of chronic Lyme disease was a "big racket" and referred to physicians who treat chronic Lyme disease as "quacks" who were "in cahoots" with lab companies.

The motion argues that this profound bias prevented Dr. Senechal from having the necessary impartiality to pro-



vide Dr. Jones a fair trial in a fair tribunal—a fundamental underpinning of due process under the constitution. Due process requires an absence of actual bias in the trial of cases.

Two parents who attended the December 18th hearing stepped forward at its conclusion to express their concerns that a physician with such strong bias had been included on the panel. The parents had learned of Dr. Senechal's bias through personal encounters with him as a physician of their child, who had been diagnosed with chronic Lyme disease. The information came to light at the end of the December 18th hearing, when the two parents, first approached counsel for Dr. Jones. The parents had not met Dr. Jones nor his counsel prior to the conclusion of the December 18th hearing. *pha*

For detailed info on hearing:
http://www.lymesite.com/hearing_1_synopsis_by_sandy_bere.htm

The Faces of Lyme Art Show Preparing to Tour the Country

Artist Linda Marcille Determined to Spread Awareness

by Dawn Irons

A friend loves at all times, and a brother is born for adversity. (Proverbs 17:17)

This proverb rings true to those who know Linda Marcille, a well known artist who lives in central Vermont. The award winning poet, photographer and artist who has sold paintings on silk internationally has taken her talents and put them to use for the cause of raising Lyme disease awareness. This is exactly the kind of friend people suffering the adversities of Lyme disease have needed. Linda is a friend who will put human faces to the stories that have touched many lives and translate those stories to the canvas so people can see *The Faces of Lyme*.

The artist shared, "The Lyme Awareness Art Project (LAAP) was born out of my own struggle with advanced Neurotoxic Lyme disease. I needed to find some way to transcend my own suffering and to give myself a sense of purpose."

Linda began seeking other Lyme patients and their stories in order to start the paintings that will become *The Faces of Lyme* art show. She began requesting patient stories and submissions began pouring in and the inspiration began to flow.

The first submission for the Lyme Awareness Art Project read:



Linda Marcille painting her first submission "Dinosaur Boy" for the Lyme Awareness Art Project.

"I'm not afraid of Lyme disease. I know I can beat it. I'm tough and strong and I can be as mean as a dinosaur. This disease can't slow me down."
 Jeff - age 6 - Middlesex, VT

Linda recounted, "There was a photo of 6 year old Jeff attached to the submission looking as fierce and tough as he possibly could to show how strong he was. I wrote him back and told him

that he was my Super-Hero and that I was going to name him "Dinosaur Boy" and paint him as a super-hero fighting Lyme all over the world. I was very uplifted as this is exactly what I envisioned this project to be about."

The Lyme Awareness Art Project is in full motion! Stories are being submitted and the artwork is being created. This traveling art show will

become a reality through the blood, sweat and tears of Lyme patients all over the country and around the world who share their stories, and through Linda sharing her gift of painting.

If you would like to contribute funds to this project, donations for art supplies are welcome and appreciated. Linda uses specific supplies and suppliers for her materials and monetary donations to help defray her costs will be needed along the way.

As the completed paintings number enough to send *The Faces of Lyme* on the road the LAAP will be looking to book venues for the art shows.

Lyme disease awareness month is in May. If you have an interest in booking the traveling art show in your area please contact Linda Marcille directly for more information.

Linda can also use volunteers who can help her make contacts to various support groups about hosting the *Faces of Lyme* in their area. It will take a collaborative effort to get this show in the public eye.

For more information you can reach Linda Marcille at:

smalldog@tops-tele.com

Or by submitting your story at:
www.crowhousestudio.com

pha

Lyme, Depression, and Suicide



by Robert C. Bransfield, MD

In the late 1970's, I treated a depressed patient who appeared to have more than just depression. Her weight increased from 120 to 360 pounds, she was suicidal, had papilledema, arthritis, cognitive impairments, and anxiety. This patient became disabled, went bankrupt, and had marital problems.

Like many whose symptoms could not be explained, she was referred to a psychiatrist. However, I was never comfortable labeling her condition as just another depression. At the time, I did not consider her illness could be connected to other diagnostic entities, such as neuroborreliosis, erythema migrans disease, erythema chronicum migrans, Bannwarth's syndrome, Garin-Bujadoux syndrome, Montauk knee, or an arthritis outbreak in Connecticut.

With time, the connection between *Borrelia burgdorferi* infections and mental illnesses such as depression became increasingly apparent.

In my database, depression is the most common psychiatric syndrome associated with late stage Lyme disease. Although depression is common in any chronic illness, it is more prevalent with Lyme patients than in most other chronic illnesses. There appears to be multiple causes, including a number of psychological and physical factors.

From a psychological standpoint, many Lyme patients are psychologically overwhelmed by the large multitude of symptoms associated with this disease. Most medical conditions primarily affect only one part of the body, or only

one organ system. As a result, patients singularly afflicted can do activities which allow them to take a vacation from their disease. In contrast, multi-system diseases such as Lyme, depression, chronic Lyme disease can penetrate into multiple aspects of a person's life. It is difficult to escape for periodic recovery. In many cases, this results in a vicious cycle of disappointment, grief, chronic stress, and demoralization.

It should be noted that depression is not only caused by psychological factors. Physical dysfunction can directly cause depression. Endocrine disorders such as hypothyroidism, which cause depression, are sometimes associated with Lyme disease and further strengthen the link between Lyme disease and depression.

The most complex link

development of depression. Dysfunction of other specific pathways may more directly cause depression. The link between encephalopathy and depression has been more thoroughly studied in other illnesses, such as stroke. The neural injury from a stroke causes neural dysfunction that causes depression. Injury to specific brain regions has different statistical correlation with the development of depression. Once depression or other psychiatric syndromes occur with Lyme disease, treating them effectively improves other Lyme disease symptoms as well and prevents the development of more severe consequences, such as suicide.

Suicidal tendencies are common in neuropsychiatric Lyme patients. There have been a number of completed suicides

nesses, such as cancer, cardiac disease, and diabetes.

To better understand the link between Lyme disease and suicide, let's first look at an overview of suicide. Chronic suicide risk is particularly associated with an inability to appreciate the pleasure of life (anhedonia). People tolerate pain without becoming suicidal, but an inability to appreciate the pleasure of life highly correlates with chronic suicidal risk. Of course, there are many other factors that also contribute to chronic risk. For example, one study demonstrated that 50% of patients with low levels of a serotonin metabolite (5HIAA) in the cerebrospinal fluid committed suicide within two years. Apart from factors which contribute to chronic suicidal risk, there are also factors which trigger

most are of an impulsive nature. Both suicidal and homicidal tendencies can be part of a Jarish-Herxheimer reaction.

I cannot emphasize enough the behavioral significance of the Jarish-Herxheimer reaction. As part of this reaction, I have seen and heard numerous patients describe becoming suddenly aggressive without warning.

I can appreciate skepticism regarding this statement. How can this be explained? Like many other symptoms seen in Lyme disease, it challenges our medical capabilities. In view of this observation, I advise that antibiotic doses be increased very gradually when suicidal or homicidal tendencies are part of the illness.

Although I have discussed the significance of depression and suicide associat-

ed with Lyme disease, I would like to emphasize that treatment does help. Combined treatment which addresses both the mental and somatic components of the illness significantly improves the overall prognosis. This is supported by clinical observation and laboratory research showing antidepressant treatment improves immunocompetence.

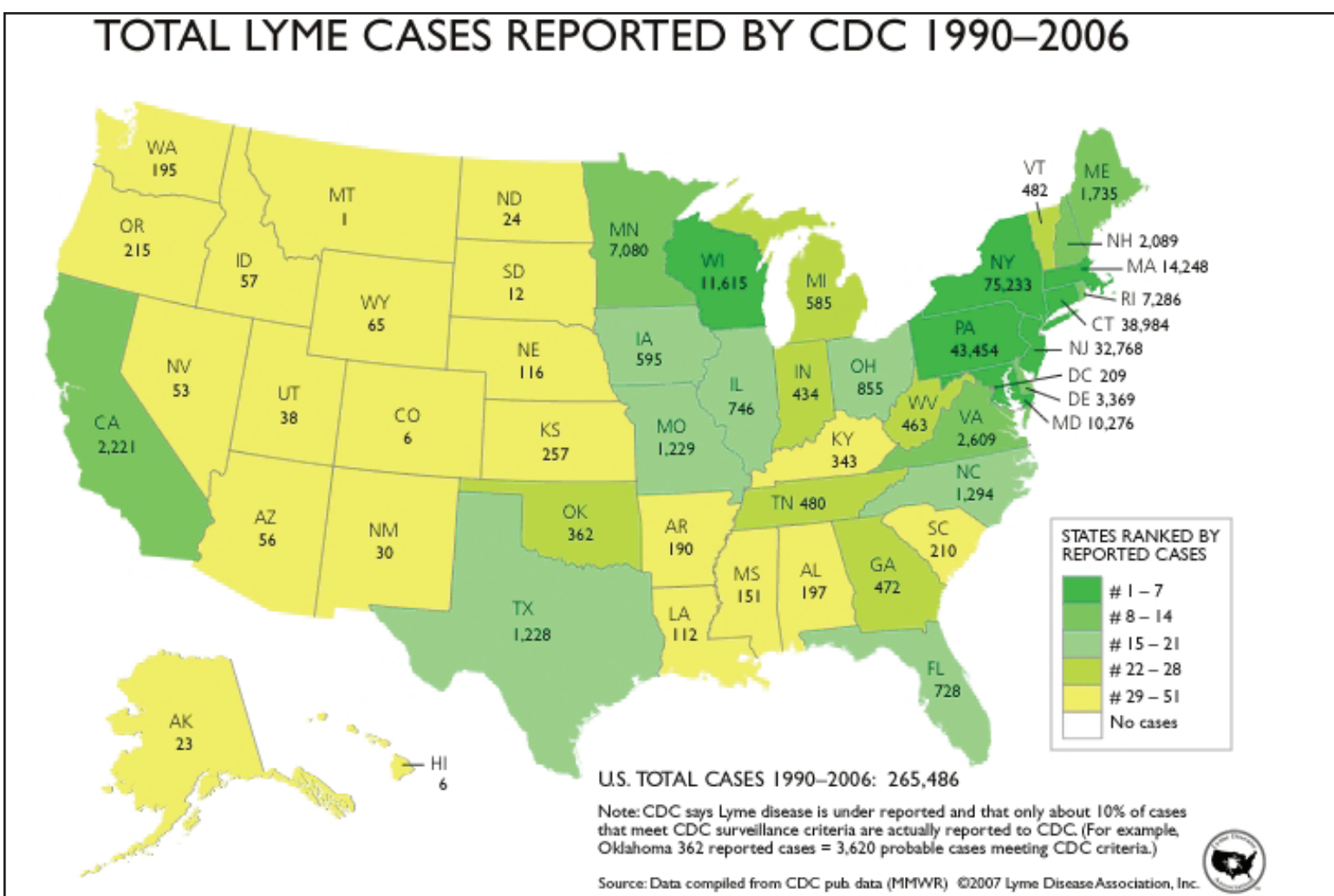
It has been demonstrated in vitro that antidepressants which act on the serotonin 1A receptor (most antidepressants) increase natural killer cell activity. In addition, there are undoubtedly other indirect effects on the immune system through other neural or neuroendocrine and autonomic pathways. To state this more concisely - anti-

depressants can result in antibiotic effects, and antibiotics can have antidepressant effects.

Most depression and suicidal tendencies often respond to treatment. Suicide is a permanent response to a temporary problem. Many people who survive very serious attempts go on to lead productive and gratifying lives.

Suffering can be reduced. The joy of life can be restored. Needless death can be prevented. Don't give up hope. There are answers, solutions, and assistance. There is life after Lyme.

pha



Lyme disease is typically thought of as an "east coast" disease. The latest research has shown that Lyme disease has been reported in every state of the USA. This map shows that over 50% of the US has significant reportings of the disease. The remaining yellow states show a rising problem where once there was thought to be none. With the incidents of neuro-cognitive and psychiatric symptoms related to Lyme disease this is becoming a nationwide threat.

is the association between Lyme disease and central nervous system functioning. Lyme encephalopathy results in the dysfunction of a number of different mental functions. This in turn results in cognitive, emotional, vegetative, and/or neurological pathology. Although all Lyme disease patients demonstrate many similar symptoms, no two patients present with the exact same symptom profile.

Other mental syndromes associated with late stage Lyme disease, such as attention deficit disorder, panic disorder, obsessive-compulsive disorder, etc., may also contribute to the

in Lyme disease patients and one published account of a combined homicide/suicide. Suicide accounts for a significant number of the fatalities associated with Lyme disease. In my database, suicidal tendencies occur in approximately 1/3 of Lyme encephalopathy patients. Homicidal tendencies are less common, and occurred in about 15% of these patients. Most of the Lyme patients displaying homicidal tendencies also showed suicidal tendencies. In contrast, the incident of suicidal tendencies is comparatively lower in individuals suffering from other chronic ill-

an actual attempt, i.e.; a recent loss, acute intoxication, unemployment, recent rejection, or failure.

There is much impairment from Lyme disease which increases suicidal risk factors. However, suicidal tendencies associated with Lyme disease follow a somewhat different pattern than is seen in other suicidal patients. In Lyme patients, suicide is difficult to predict. Attempts are sometimes associated with intrusive, aggressive, horrific images. Some attempts are very determined and serious. Although a few attempts may be planned in advance,

depressants can result in antibiotic effects, and antibiotics can have antidepressant effects.

Most depression and suicidal tendencies often respond to treatment. Suicide is a permanent response to a temporary problem. Many people who survive very serious attempts go on to lead productive and gratifying lives.

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Enforceable Regulations with Penalties Needed For Overseeing Tissue/Cornea Transplant Materials

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PHA seeks to bring information and awareness about these illnesses to the public's attention. We seek to make sure that anyone struggling with these diseases has proper support emotionally, physically, spiritually and medically.

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by Vickie Travis

A few months ago we learned at the KaiserPapers that an attending physician had attempted to obtain the corneas of a deceased patient by directly obtaining permission from the family. He had intentionally bypassed his hospital's contractually obligated and federally mandated organ procurement process.

This caused concern for the family mentioned above as they were aware that the patient had signed an advance directive forbidding any harvesting of organs or tissue/corneas.

Federal regulations state that a federally designated non-profit organization is responsible for coordinating organ donation and transplantation. They are also responsible for determining the viability and safety of the organs or tissues for transplant.[1]

The State of California code states that the attending physician may have no part in this process and that advance directives must be respected.[2, 3]

Unfortunately there is no enforcement capability in existence nor is there any actual punishment for knowingly violating these regulations.

The criteria for cornea transplants are such that there are absolute exclusions - HIV positive, active cancer and systemic infection. The patient had died of a cancer that had spread into her bone marrow. If this harvesting had been allowed it is possible that the patient's dis-

ease would have spread to the recipient. Transmission of donor malignancy to the recipient could be one of the most serious complications of corneal grafting.[4]

We asked for an opinion of a cancer specialist regarding the probable danger of the spread of disease under these circumstances. He did not think that there was much danger because of the lack of blood vessels in corneas. We later provided him the evidence that proved the risk is great enough that the patient should be informed and given the opportunity to make their own decision on using the potentially diseased cornea tissue. Some of the diseases that can be transmitted through cornea transplant are known to often take months or years to develop and there is often no way to track their source.

It seems rather cruel if a child receives a diseased cornea that manifests into a life threatening disease years down the road that he or his parents had no say in the matter, even if the odds were considered low when the transplant was done. If that happens it still has happened, low odds or not and his life is shortened. If a person in their 70's or 80's wishes to take the risk of disease being spread years down the road that is another matter and one in which the risk is more realistic to take. Currently there is little chance of patients having the opportunity to make those types of decisions.

We also did a quick, non-scientific survey to see, in general, how informed people in the medical field and private sector are on this topic. We also contacted the agencies that we were advised were regulating these issues to ask the same questions.

What we found is that no one cares. They do not have the facts and simply do not think that it is either possible to spread disease through the cornea or do not think that the risk is great enough for concern.

There are numerous

studies that show how diseases can spread through cornea transplants. Yet, many people in positions of authority do not recognize or acknowledge the inherent dangers of these tissues when obtaining corneas from bodies recognized as having potentially transferable disease.

We also wondered why any physician or their hospital or medical group would condone such a dangerous practice.

We found that in the United States you may not purchase a tissue or organ for transplant purposes. There is a processing fee however, that is charged by the contracting Organ Procurement Organization. The cornea processing fee costs around \$2,800.00. Synthetic corneas which do not carry the risk of disease run around \$7,000.00.[5]

We noticed that a facility that routinely performs cornea transplants and does harvesting at the same location could save some money by bypassing the Organ Procurement Organization. We also checked with the Organ Procurement Organization that should have been involved in this matter and found that their primary concern was the contract violation. It sounded as if their concern would have been the money they missed out on if the family would have allowed the harvesting of the corneas.

The most common transplanted organ/tissue in the United States is the cornea. In 2005 based on information provided to the U.S. Census Bureau by Organ Procurement Organizations and transplant centers there were 44,329 cornea grafts.[7] According to the National Eye Institute - the cost of the operation itself runs around \$5,000.00.[6]

We also found out that there really is no law protecting anyone, although the Organ Procurement Organizations lead people to believe that there is legal protection.

There is a Federal regulation instructing the Joint

Commission to oversee these issues but at best their recommendation, if they so choose to make one, is that Medicare funding could be withdrawn. The Joint Commission on Accreditation of Health Care Organizations (JCAHO) sets donor standards and requires hospital policies and procedures for organ and tissue procurement. In a perfect world this could be a good system but it is not.

Perhaps this is a case of good intention not having proper follow through. In any event, with what took place with the deceased and her family mentioned in this editorial, good intention is not good enough.

pha

Sources:

1. (US Federal Code : 42CFR482.45 also known as the The Routine Death Notification Legislation re facilities; Sec. 482.45)
2. Health and Safety Code Health 7154(b) (transplant protocol-enlisting organs from patients)
3. California Probate Code 4733(a) (dying patients wishes in their Medical Directive, a legal document) is also supposed to cover these issues. The attending physician may have no part in this process according to regulation.
4. IOVS, April 2006, Vol. 47, No. 4 Experimental Study of the Survival of Metastatic Cancer Cells in Corneal Organ Culture.)
5. Wikipedia - I found so many different upwards costs cited that Wikipedia seemed a moderate and reasonable source to cite:
http://en.wikipedia.org/wiki/Corneal_transplantation#Risks
6. http://www.census.gov/compendia/statab/health_nutrition/.
7. www.nei.nih.gov/news/press-releases/101492.asp



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Virtual Book Burning and the Lyme Disease "Federation"

An opinion piece by PJ Langhoff



"If they give you ruled paper, write the other way." [1]

One method utilized by the German Nazi party during the early part of this century to control civilian thought processes was through literary censorship. In April 1933, the German students association's press and propaganda office declared a nationwide action which included a literary purge or cleansing by fire. The SA (Sturmabteilung, German for "storm department" or "stormtroopers") "brown shirts," so named for their SA uniform, participated in very public book burnings such as those in Munich and Berlin that year. More than a hundred years earlier, the poet Heinrich Heine said, "Where books are burned, human beings are destined to be burned too."

Seventy-five years later (as we enter 2008), we again witness what appears to be a deliberate censorship declaration designed to control the thought processes of the masses, this time in the arena of the Lyme disease-afflicted. But the "books" burned aren't necessarily made of paper, they are also the virtual books, articles, and opinion pieces located in cyberspace, the "new frontier" of medical politics. This includes peer-reviewed articles, published articles in trade journals, newspapers, research data; all the way down to the opinions of advocates, patients and also physician organizations. The end result is the attempted purging of an entire line of thinking about a complex,

endemic illness which has been declared off-limits by this "Federation" to the masses; in favor of a minimized, slow-played, non-endemic, less serious version, (with devastating consequences to thousands).

Enter a small group of powerful Infectious Disease academicians and their supportive, grant-funding government agencies, and medical board associates, whom I will collectively dub here (a pretend) Lyme denialist, stormtrooper posse called the "Federation." Please do not misquote or misunderstand. I am merely poking fun here and not remotely suggesting anyone referenced are Nazis, SA members, extremists, or are of any particular nationality. But I am making a point that in the media, we see a similar kind of censorship being played out in a very political arena, at the hands of a select group of Infectious Disease academicians (some of my pretend "Federation.")

Some Federation members seem to trumpet their position that Lyme patients and their doctors are attention-seeking hypochondriacs who are imagining an illness which doesn't exist. Others are attempting to promote restrictive guidelines for the diagnosis and treatment of an illness that at best, is poorly understood. Meanwhile, the earlier research and materials published by members of this imaginary Federation seems to now conflict with their most recently published "denials" that the illness exists in its most serious, chronic form.

And despite very ill patients and their doctors' attempts to illustrate what the Federation already knows (that Lyme disease is a debilitating illness with a chronic form when improperly treated), the Federation appears to be working diligently in the background to silence anyone who does not agree with its current modus operandi. This includes but is not limited to the recent meeting December 18, 2007 at the Hartford, CT Legislative Office building from 10 a.m to noon. In what can only be described

as another strategic effort on the Federation's part, IDSA member Durland Fish spoke at a forum on Lyme disease "prevention." Incidentally, no Lyme advocacy representatives were invited to attend, though it was admittedly a public event.

At the same location on the same date, but at 1:30 p.m., renowned pediatric Lyme physician Dr. Charles Ray Jones was present for his legislative hearing regarding his licensure and accusations by the CT medical board of "unprofessional conduct." Some accusations included his failure to examine two children before prescribing medications - something that most physicians across the country in all forms of medicine, routinely do. Those who know Dr. Jones and who are familiar with his case, will tell you that is not what happened.

And it is no surprise that his hearing would be strategically targeted by the Federation either. Patients and advocates see it as another attempt by the Federation to silence anyone with an anti-Federation viewpoint. Perhaps since they cannot burn books, they might as well burn reputations. From the viewpoint of this imaginary Federation, perhaps obliterating a beloved Lyme physician who did nothing wrong, by offering their physical presence to go hand-in-hand with false accusations and trumped up charges resulting in "discipline" is a convenient way to "teach" other physicians not to go against the Federation's views. How convenient that a Federation forum would be held at the exact location, and just an hour and a half before the very public crucifixion of a physician servant who has dedicated his life to treating thousands of ill children - someone who is perhaps the most beloved and important Pediatric Lyme specialist in the country.

And the persistence of the ideology of the Federation "members," whom in part drafted and promote restrictive guidelines which seem to define chronic Lyme disease

out of existence, and for which they previously acknowledged existed, is mind-boggling. At present, the IDSA Lyme disease guidelines are under investigation by the CT Attorney General's office for possible anti-trust violations. This has to do with the unilateral formation of the guidelines excluding important peer-reviewed research, and the possibility that their structure and edict will impose restrictions on insurance company benefits and patient treatment options.

And patients and their physicians witness tit-for-tat publications in intermedia arguments defending both sides of the Lyme debate - a staunch Federation position with attempts at censorship, and a re-teaching that Lyme disease is "hard to catch" and "easy to treat"; and the "other side," which includes ill patients and their physicians left with debilitating illness barely acknowledged by the Federation, government, insurance, and many doctors. How has this censorship come about?

Around 1975, academician, Infectious Disease Society of America member and Rheumatologist Dr. Allen Steere and his Yale university associates dubbed a strange illness "Lyme Disease," so named after the town in which the first cluster cases were identified, thanks in part to the persistence of a housewife named Polly Murray. Over the course of a few years, Lyme disease was defined as an illness with various stages, including a chronic form.

In 1980, Steere and associate Malawista wrote that some patients (even when treated soon after an EM rash), developed later manifestations, and some patients with these manifestations never experienced a rash.[2] In 1983, Steere's associate Barbour (et al.) wrote an article describing Lyme as a "multisystem" disorder.[3] In 1984, Steere and Barbour wrote an article revealing knowledge in 1955 that an EM rash could be passed from human to human.[4] The following year Steere and associ-

ate Pachner wrote an article about a triad of neurological symptoms of Lyme disease.[5] The authors discussed the duration of the acute phase of the illness lasting up to 18 months in those not receiving antibiotic therapy. (Those studied were not followed for a more extended time.)

In 1988, Steere associate Pachner wrote an article about Bb in the nervous system calling it the "new great imitator." [6] He outlined similarities between Bb and syphilis, with the ability of both organisms to "stay alive in human tissue for years." He also outlined the stages of LD, including early skin disease and later disease in the brain. He warned "the effective clinician must take special care to consider Lyme disease primarily because of the excellent response to antibiotics early in its course in relationship to some of the diseases it mimics." He labeled Lyme meningitis the second stage of the disease, (including the EM rash). He suggested that most patients have very mild symptoms, and called it "likely that a large percentage of patients go undiagnosed and untreated." He further elaborated that "the frequency of progression to third-stage disease is unknown but may be quite high," inferring this from a large number of patients manifesting Lyme arthritis, many whom bear no other symptoms. Pachner considers serology an important tool, but recognizes the test limitations: "...while the tests are understandably unreliable for identification of patients with ECM..." he explains that antibodies in some patients are not as high as in others, associating a higher prevalence of antibodies in those with more symptoms. He also states that those with only CNS disease, sometimes do not have high titers.[7] This underscores the theory that some Lyme patients can be seronegative but still have Lyme.

In an Italian paper from the same year, the topic of maternal/fetal transmission of

"Book Burning"...cont'd pg 14

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Book Review of David Brownstein M.D.'s Iodine : Why You Need it, Why You Can't Live Without It



Review by Marjorie Tietjen

197 pages, softcover, revised 2nd edition with 2 new chapters, \$15.00

Iodine deficiency has become rampant in our society. Dr. David Brownstein has found through the years, when he has tested his patients for iodine, that over 90% of these patients have been deficient in this trace element. In his book, *Iodine : Why You Need It - Why You Can't Live Without It*, he helps lay people and medical professionals to understand why it is so very important to have adequate levels of iodine, to keep the thyroid gland functioning at optimum levels. The author also explains that not

only is iodine crucial to thyroid health but it is also a necessary factor in keeping the immune system running smoothly.

In the first chapter Dr. Brownstein shares with us the fact that "Iodine contains potent antibacterial, antiparasitic, antiviral and anticancer properties." He also provides a list of conditions which can be treated with iodine supplementation. In recent years there has been an exponential rise in chronic illness involving infectious disease, autoimmune problems and body overloads of toxic chemicals. Could this very discouraging trend be partially due to lack of iodine in the diet? Dr. Brownstein's book is very helpful in addressing this question.

In my experience I have noticed that most Lyme disease sufferers have problems with their thyroid gland. All Lyme patients that I have met, report subnormal body temperatures. They also complain of being cold and very fatigued. It is thought that the Lyme disease pathogen attacks the thyroid which in turn would lower immune system function. However, Dr. Brownstein's book leads one to ask the question: Could a lack of iodine in the diet weaken the thyroid functions that affect immunity,

which would then allow the pathogen to take hold and perhaps also promote chronicity of the disease?

Throughout the book it is stressed repeatedly, that certain chemicals, such as the halides -- bromide, chloride and fluoride, compete with iodine for absorption into the body tissues and glands, including the thyroid gland. If there is a shortage of iodine in the body, these toxic elements will be absorbed in place of the iodine. So, then, not only would many people have an iodine deficiency but as a result they may also have accumulated toxic levels of halides. Dr. Brownstein assures his readers that supplementing with adequate iodine (above the RDA) will help their body to detoxify. He also speaks of how to lessen the detoxification reaction.

The author also covers the subject of iodized salt and how that relates to the issue of the iodine deficiency epidemic. Another important point he discusses is that there are two different forms of this element, iodine and iodide. For more complete improvement in thyroid function, he recommends both forms together in one supplement. The reader will also learn the different reasons as to

why we are not getting the amount of iodine which our bodies apparently need. He thoroughly explains why iodine deficiency is so prevalent in our society. Dr. Brownstein strongly recommends an iodine loading test which was developed by his mentor, Dr. Abraham. This test will guide patients and doctors in the process of determining how much iodine the patient needs. Radioactive iodine is also discussed.

Another important point made was...if one is being treated with thyroid hormone, while the body is deficient in iodine, then the thyroid hormone could exacerbate the iodine deficiency. So, while one may feel better in the short run on thyroid hormones, iodine deficiency may eventually worsen the thyroid condition, despite prescribed hormones. Many times people do well on both the iodine and the thyroid hormones together. However, Dr. Brownstein tells us that about one third of the patients are able to discontinue the thyroid hormone and take only iodine. Also included are iodine dosage guidelines and a question and answer section.

My contention with the conventional medical system is that they intentionally only

develop symptomatic treatments and rarely look for the root cause of disease. There are no profitable economic gains when promoting cures. This is where Dr. Brownstein steps in and makes a very valuable contribution. In this book and others he has written, he probes into the basic origins of disease and shares his research and experiences with us.

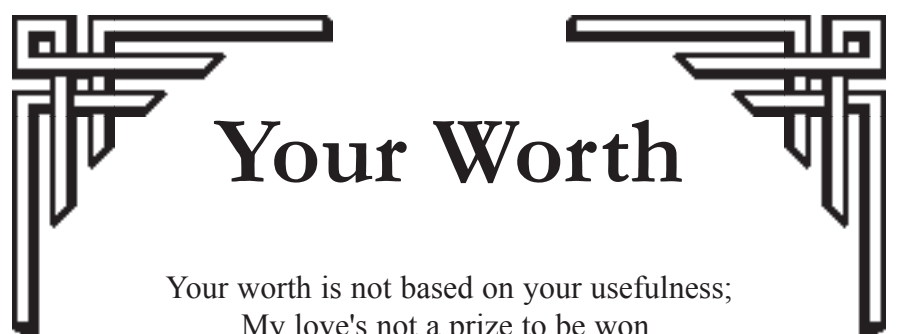
I highly recommend this book to anyone who is concerned about their health. One doesn't need to be sick to find this book interesting and helpful. Everyone who is familiar with the Price-Pottenger Nutrition Foundation, knows that prevention is the optimal goal.

Iodine: Why You Need It, Why You Can't Live Without It, is available from PPNF. See order page. *pha*

Marjorie Tietjen is a freelance investigative journalist with a BS in nutrition. She writes on various topics but has a special interest in public health, education and awareness. Her writings can be found online and in several print publications.

The Faith Factor...

A Poem by Rebecca Sabota



Your Worth

Your worth is not based on your usefulness;
My love's not a prize to be won.
My precious child you'll be,
Throughout eternity;
And my love can never be undone!

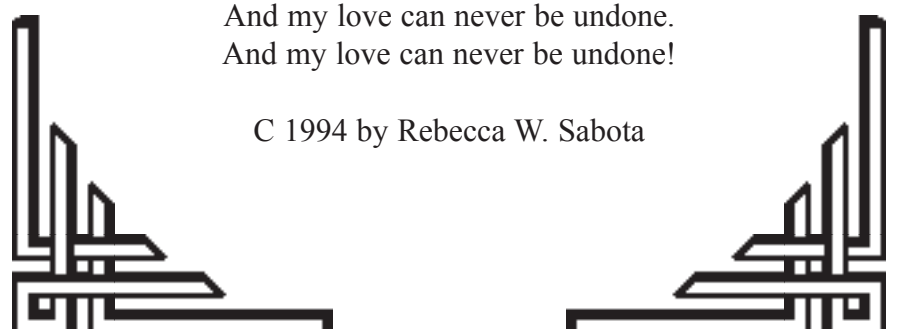
As a helpless babe you came into this world;
Your each and every need was my concern.
I gently held you close to me each day;
Expecting nothing from you in return.
And as you grew and took your first few steps;
A helping had to you I did extend.
And on your face I saw a look of trust;
You knew on me you always could depend.

Your worth is not based on your usefulness;
My love's not a prize to be won.
My precious child you'll be,
Throughout eternity;
And my love can never be undone!

If you're worried that your talents are too few;
Or when you feel discouraged, tired and weak;
Remember I am here to see you through;
Just count on me to give the strength you seek.
And if along life's pathway you should fall,
Though others may be quick to walk on by;
I'll gently pick you up and hold you close;
For on my love you always can rely.

Your worth is not based on your usefulness;
My love's not a prize to be won.
My precious child you'll be,
Throughout eternity;
And my love can never be undone.
And my love can never be undone!

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ILADS Members Dispute Dr. Charles Jones Verdict

Ruling Threatens to Limit Access to Care for Lyme Patients

Official Statement from ILADS

Bethesda, MD –

Members of the International Lyme and Associated Diseases Society (ILADS) believe the recently announced ruling by the Connecticut Medical Examining Board puts current and future Lyme patients at risk.

Dr. Jones is an ILADS member and one of the few pediatric Lyme experts in the United States. Jones has been in practice for 40 years and has been treating Lyme disease since it was first defined. He has treated more than 10,000 children suffering from Lyme, a significant number having trav-

eled from out of state or from other countries.

"Dr. Jones has a stellar record of successfully treating children who are very sick with Lyme disease," said Dr. Daniel Cameron, President of ILADS and chief author of the ILADS treatment guidelines for Lyme disease. "We need more physicians like Dr. Jones who are well educated on the complexities of Lyme and are willing to treat patients to improve their quality of life."

Lyme is a difficult disease to diagnose and can be equally difficult to treat. A significant number of patients do not experience the classic symptoms and currently there is no test sensitive enough to determine an absolute diagno-

sis. As a result, many cases are misdiagnosed leaving many at risk of developing chronic Lyme disease, an extremely debilitating form of the disease.

Additionally, medical evidence regarding the nature of the disease and possible treatment options is insufficient, making it too early to justify a single best practice for the treatment of Lyme disease. ILADS is disturbed that Connecticut Public Health Commissioner Robert Galvin, who has stated that the department would not initiate cases against physicians who treat chronic Lyme disease allowed the case to proceed. Physicians and patients rely on public health officials to stand by their public health policies.

Lyme disease is characterized by the CDC as a clinical diagnosis, reinforcing the importance of physician understanding and experience treating the disease.

"Not all doctors are truly Lyme literate," added Cameron. "Patients, no matter where they live, must be able to access doctors who have established track records in successfully treating the myriad forms of Lyme, and physicians must be able to use their clinical expertise to treat these patients. Otherwise, the epidemic of chronic Lyme disease will continue to accelerate and patients will continue to suffer unnecessarily." *pha*

About ILADS:

ILADS is a nonprofit, international, multidisciplinary medical society, dedicated to the diagnosis and appropriate treatment of Lyme and its associated diseases. ILADS promotes understanding of tick-borne diseases through research and education and strongly supports physicians and other health care professionals dedicated to advancing the standard of care for Lyme and its associated diseases.

For more information contact Pam Kahl: pam.kahl@verbal800.com 503.284.1534

www.ilads.org

UnBreak Your Health

Sue Vogan Interviews Author Alan E. Smith

Alan Smith is a phenomenal person to speak with. He has so much energy and passion that it almost comes through the phone lines and is absorbed instantly by the person on the other end of the phone. His enthusiasm about his new book, "UnBreak Your Health," wasn't because he actually wrote a book - it was because he wrote a terrific book!

The therapies researched and outlined in "UnBreak Your Health" are like holding the catalogue of all the good things in life. You are allowed to choose anything and as much as you like, but it will take a little reading to see what might work best for you. You are responsible for your health and if you want better health, and have gone down the pill path with little or no success, this book should be your next turn.

Please tell me a little about yourself.

I was born in Kansas City but I consider Chicago to be home. I've been married to my wonderful college sweetheart for 23 years. We don't have any kids. My college degree is in broadcast journalism and I spent the first decade after school in radio/TV sales. Most of my working life has been in the field of supermarket promotions but two decades of

travel all over the country and the stress of being in a dying industry caused the health problems -- which led me to where I am today.

Why did you write "UnBreak Your Health?"

"UnBreak Your Health" is the book I wish had been around a few years ago after my disappointing trip to the Mayo Clinic. After running out of medical options I had to turn to complementary and alternative medicine to find solutions to my health problems. The more I learned (and the better I became) the more I wanted to share all of the good news with the world. Everybody kept saying, "Somebody should write a book!" So I did!

I started out with about 60 therapies which was more than anybody else had ever written about before but as I would research one I'd discover something I'd never heard of before, which led to another, so the book has 136 different subjects. It's the big overview, like looking out from the top of the mountain, to see all of the options available to improve your health.

How long did it take you to write the book once you had the idea?

It took nearly a year of researching and writing to put

the book together after I came up with the original idea. It was one of those "good news/bad news" situations. My new PSYCH-K business wasn't keeping me busy so I had plenty of time to work on the book every day.

What makes you an authority to write this book?

My expertise comes from experience. I'm a Baby Boomer too stubborn to take my doctor's advice to simply "learn to live with it," so I set out to find something that would help. In the process of looking for a health solution I found a lot of amazing therapies that I wanted to share with others. I believe there are lots of others out there who're looking for solutions and hopefully "UnBreak Your Health" will save them time.

Since the book, what have reviewers' responses been?

The reviews have been amazing, better than I could've hoped for. Right now I've got seven 5-star reviews on Amazon! It's such a simple book that I wasn't sure it would be well received. People seem to love a book that makes difficult new subjects easy to understand and offer a new world of hope.

Your book is set up in a dis-

tinctive way - health concepts, body, mind, spirit/energy, and insurance. Please briefly describe these sections.

One of the challenging parts of the book was figuring out how to organize all of the different therapies. In the end I arbitrarily decided to categorize each one by its primary intention. In other words, was it designed to change something in the body, in the mind or in the spirit/energy system. Many therapies could be in all three sections so it's really just my opinion.

I organized the book in a way I would like to learn new information. It's been my guiding principle for the whole book - what would I like to see? Figuring I'm the kind of average person who needs the information I tried to create the book I would want to read.

You have something more books need - "user comments." Please explain why you included this after each therapy.

As I was putting all of the black-and-white definitions and descriptions of the therapies together it just didn't seem like it was enough to really explain what was going on. From my own perspective as a reader I wanted more, so it seemed like adding a little human color to each listing

would provide a more complete picture. What did it feel like? What were the effects? That's what I would want to know, so I added User Comments whenever possible. What I didn't expect was for that feature to become one of the most difficult aspects of the whole project.

The Health Concepts chapter is very informative - why did you feel it was important to include this chapter?

Can I tell you a little secret? I really wanted to get the amazing information about Dr. Bjorn Nordenstom's discovery of Biologically Closed Electrical Circuits at the beginning of the book. It occurred to me that there were several basic concepts that readers needed in the beginning to better appreciate and understand all of the therapies so the chapter of Health Concepts just sort of happened at that point. It sets the tone that there are new discoveries and old concepts that weave a fabric of healing that crosses all of human history and our world.

Most of the therapies in your book, I have never heard of. How long did you research for this book?

It took about a year to put it all together. It probably "UnBreak" ...cont'd pg 18

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Chronic Fatigue and Lyme Disease



by Dr. Jonathan Forester, MD

It is my opinion, along with other specialists in the field, that the bacteria *Borrelia* is one of the stealth invaders the primary causative agents in the epidemic of Chronic Fatigue/ Fibromyalgia and many other illnesses with unknown causes. Many times *Borrelia* is not a loner. It may be accompanied by other infectious agents such as Babesiosis, Ehrlichiosis, Tularemia, Bartonella, Rocky Mountain Spotted Fever, Mycoplasma and certain other viruses such as HHV-6. These aggressive microbial terrorists are often insidious and undetected by the average physician. They are, in general, opportunistic in times of stress, and where the immune, endocrine, and nervous systems are compromised.

Borreliosis is sometimes very difficult to diagnose, both clinically and by lab test. The average laboratory test may be negative or inconclusive. Many physicians are unaware that the diagnosis is made on basis of clinical grounds, not just by a test.

As much as 35% of people do not remember getting bit by a tick. The erythema migrans rash may have never occurred or not be remembered. The best to detect Borreliosis is a Western Blot IgM, IgG test at a specialty lab. Other testing such as EIA, ELISA, IFA, PCR, DNA probes are often negative. On that very complicated Western Blot test, if at least one of the major starred antibodies are positive or equivocal there is a 97% chance that the patient has Lyme symptoms that are correlative, based on research done by my colleague and friend, Dr. Charles Crist, of Springfield, Missouri.

Remember regular commercial laboratories are not equipped to screen for chronic Borreliosis. If one is uncertain about his negative equivocal test, a second Western Blot is drawn two weeks after a one-month therapy of antibiotics.

Borreliosis has at least three forms that we know of, a spiral form, a parasitic form, and an "L" form or also called the cell wall deficient form. The ability of the bacterium to transform its body shape and hide in cells and tissues requires many months of, and different types of, antibiotics. In addition, we also treat the common co-infections of Borreliosis. (As stated above).

Candidiasis is a common cause of fatiguing illness and indeed can be a co-infection. During antibiotic treatment, yeast also multiply in the gut due to the kill off of

friendly bacteria. It is therefore necessary for one to be on a low sugar diet take *Acidophilus* (gel cap form) and *Nystatin* on a daily basis. We believe once the stealth infections are eradicated, the *Candida* will no longer overgrow because the borreliosis and its crime partners incur the immune system, which in turn allows *Candida* to grow and multiply.

Upon taking these antibiotics for Lyme, there are at least four things that can happen:

- 1. An allergic reaction** - This would include rash, hives, itching, wheeze, etc. The antibiotics should be stopped, take an antihistamine and call your doctor's office.
- 2. Yeast overgrowth** - A side effect of medicines that can induce brain fog, abdominal discomfort, irritability and insomnia.
- 3. Side effects** - These might include nausea, gastritis, esophagitis, diarrhea, headache, etc. Discontinue the medications and call your doctor.
- 4. A Herxheimer reaction** - usually called "Herx" for short. This is simply a worsening of symptoms, which may include chills, low grade fever, achiness, etc. The antibiotics should be discontinued for approximately two days and then restarted.

Treatment of Lyme

My antibiotic of choice is Doxycycline (it eradicates some co-infections) started at 100mgs twice a day for a week and gradually increase to 200mgs twice a day for approximately four to eight weeks. If one continues to improve, then he should stay on the antibiotics indefinitely. However, if he plateaus or gets no response after eight weeks, we will switch to Flagyl. Since this is the most common antibiotic that can cause a Herx, we do Dr. Crist's protocol beginning with low doses and increasing. This will help kill the parasitic form of the disease. Many physicians use penicillin or cephalosporin to begin their treatment.

The L form of the bacteria is treated with either Zithromax or Biaxin for one or two months. This should be taken along with Flagyl which are synergistic in their effect.

Once these cycles of antibiotics are complete, we then go after babesiosis which is a malarial type illness generally causing low grade chills or feverishness, achiness and symptoms similar to Lyme. Our choice so far is to use Clindamycin in increasing doses to the fifth day, which one will take every five hours and that will continue to the tenth day. At the fifth day one will also start taking Quinine at one or two twice a day for the next five days. We do not do testing for Babesiosis because one may get a false negative and, these antibiotics will also kill the *Borrelia*. To date there is no absolute accurate testing for Babesiosis, but we know it is present in many ticks. I also alternate Amoxicillin every ten

days along with the Clindimycin/Quinine treatment. One continues this until he plateaus or has no response.

Rifampin is generally used to treat Bartonella, (the bacterium of cat scratch disease). Studies that have been done on Bartonella reveal that it can cause a wide array of gastrointestinal problems from ulcerative reflux and irritable bowel type symptoms. Again, this bacterium is also present in the saliva gland of the *Borrelia*.

After completing the Bartonella treatment with improvement one may be discharged from clinic and followed again by his primary care doctor. If symptoms persist, we will then perform certain laboratory tests which could confirm other stealth infections that may be important in causing chronic fatigue symptoms.

There are some patients that require the use of IV antibiotics which can be given through a PICC line. This PICC line is placed inside a vein at your local radiology department in the hospital. Instructions and antibiotics can be supplied by local home health care providers or specialized IV therapists. Our approach is to avoid IV antibiotics, if possible, since the trouble and expense are obvious. Most insurances will pay for this type of therapy.

We are beginning to address the problems of hyper-

coagulability which can cause aching and fatigue. It has been shown by Dr. David Berg and others that low dose Heparin therapy can be quite dramatically improve these symptoms. We draw blood in our office and send Hemex lab in Phoenix, Arizona where highly specialized testing is performed.

In addition, a disregulated endocrine axis can also be problematic producing many symptoms. In addition to thyroid which you already test, we perform estrogen, progesterone, adrenal, pituitary, DHEA, and other hormone testing. If one meets the symptom criteria and their blood tests are in the low normal range, we are equipped to begin certain, careful low dose therapies. There is positive response to the balancing of this system.

Generally, I believe when one rids the body of stealth infections the need for Heparin, hormones and other medications *may not be necessary*.

One other area in which I am very excited about is Dr. Patricia Kane's research in fatty acid exchanges. She is one of the *world's authorities* on essential fatty acids. This procedure, which she developed and implemented, may have the ability to remove lyme toxin and prevent and alleviate the "Herx" syndrome.

It is true that not everyone treated for Lyme gets bet-

ter, but it is our experience that most patients have a dramatic improvement in their quality of life. It is also true that symptoms may periodically return and can be addressed. We have seen incredible improvements made by people who have been in very severe pain due arthritis and Fibromyalgia. I am amazed about what God is doing in directing our lives in order with this growing epidemic.

Remember, there is HOPE and help for most who have a fatigue syndrome, but it is a very complicated process. Therefore, be patient with the treatment. Over a period of time it may be, that you can discontinue most of your FMS/fatigue medicines! *pha*

Dr. Jonathan Forester operates a family practice in Pineville, Louisiana.

He has taken an interest in mentoring and training other physicians and physician assistants in Lyme protocols. He has a LLPA on staff at his office.

Dr. Forester spent 25+ years specializing in Chronic Fatigue Syndrome. When he began testing his patients for Lyme, he was impressed with the vast number that was actually testing positive for Lyme disease.

In 2007 Dr. Forester and his P.A. began seeing pediatric Lyme patients.

Dr. Forester is a member of the International Lyme and Associated Disease Society.

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IDSA's Published Papers Contradict Treatment Guideline Protocols

Connecticut Support Group Leader Randy Sykes Launches 'Lyme Crymes' Website to Dismantle IDSA's Guidelines with Their Own Research

by Sue Vogan

Randy Sykes lives in Lyme disease endemic Connecticut. He knows how bad it is because he runs a support group and hears from other victims on a daily basis. Those who have Lyme disease and others who suspect they have Lyme disease call Sykes for doctors' names and support. Just a kind word and a sympathetic ear is sometimes all it takes to make their day.

Catching up with Randy proved rather difficult --calls from people in Connecticut and Lyme disease victims from all over the country takes priority with Randy Sykes - interviews come far down on the list. There were so many questions I wanted to ask of this intelligent and caring man. I was grateful for the time Sykes allotted me for this important interview.

Before we began, Sykes was excited about the last call he had taken. It was from an undisclosed source, but the caller revealed that the panel that sentenced Dr. Charles Jones to a \$10,000.00 fine and 2-years probation might be an illegal call - if it goes to an appeal, Dr. Jones just may win this case."

But he wasn't charged with

any Lyme disease guideline neglect or mistreatment," I remind Sykes.

No, but they are going over everything. All he did was refill a 10-day prescription of antibiotics.

That's not serious - not serious enough to bring this type of sentence.

No. Not when it was reported that Dr. Schiano (another doctor on trial before a medical board) was dealing drugs and later said a friend stole his prescription pad - though he never reported the "theft".

Even if Dr. Jones was handing out antibiotics like M & M's, that's not as dangerous as Oxycontin."

And what did that doctor (Schiano) get?

A 30-day suspension of his license and no fine - according to The Republican American - July 22, 2006.

And no one is looking over his shoulder?

"Legal and money troubles seem to follow those physicians who get into trouble with the DPH. Take Dr. Carl

Schiano, who practices internal medicine in Naugatuck. The DPH determined that he had diverted and abused controlled substances since 2002, and had provided negligent and/or incompetent medical care to at least four patients. His license was suspended between July and November 2006, when his license was reinstated. Since then, he has been a party of three collections' lawsuits.

Identified as a top doc by Connecticut Magazine in 2005, Schiano's substance abuse problems resulted in the DPH placing him on probation through July 2009. He is now subject to random drug screening and to random reviews of 20 percent of his patient records, and may only practice with at least one other physician who is not in his employ or under his supervision.

Additionally, Schiano may not prescribe controlled substances for at least 18 months." (<http://hartfordbusiness.com/news1807.html>.)

With Dr. Jones' panel, they went one better - they modified the mandate with the probation. It has to be an *Infectious Disease Pediatrician*.

And who might that be?

Probably Shiparo out of Yale. They say that they want

this to start immediately because they have already had a year-and-a-half of waiting through the duration of the trials.

What about the hearings? I know that you attended all of the hearings and his sentencing on December 18th.

There were probably less than 200 people there. I didn't count them, but the room was not packed. Many people don't seem to care. When he goes down the people will be crying for a doctor. My advice to them is to get off their butts and do something.

You are a victim of Lyme disease. When and where did you become ill?

I was checking generator installations - they were out in the woods - repeater stations for the police department.

Because no one wants an antenna in their back yard, these generators are stationed in rural areas and on top of mountains. I had to go up and check that the transmitters were working. This was 1998-1999.

In 1998, I was having wicked fibrillations of the heart and they couldn't figure out what was causing it at the time. It was so bad that wherever I was, I would have to lay down.

I was weak, dizzy, and felt like I couldn't get any air.

Were you getting any of the other symptoms of Lyme disease?

I was getting fatigued and had the aches and pains. But I figured that I was 40-something and this was all happening because I was getting older.

It wasn't anything serious, at first. Then the "flu" kept coming on. It kept getting stronger and stronger.

I was told that one of the problems might have been that I hit the police gym every morning. I would run over two miles on a treadmill before going to work. It was air-conditioned and heated. I was told by one of the doctors that it's like the old saying, when you don't feel well, rest. The doctor said it could have driven the infection further into my body.

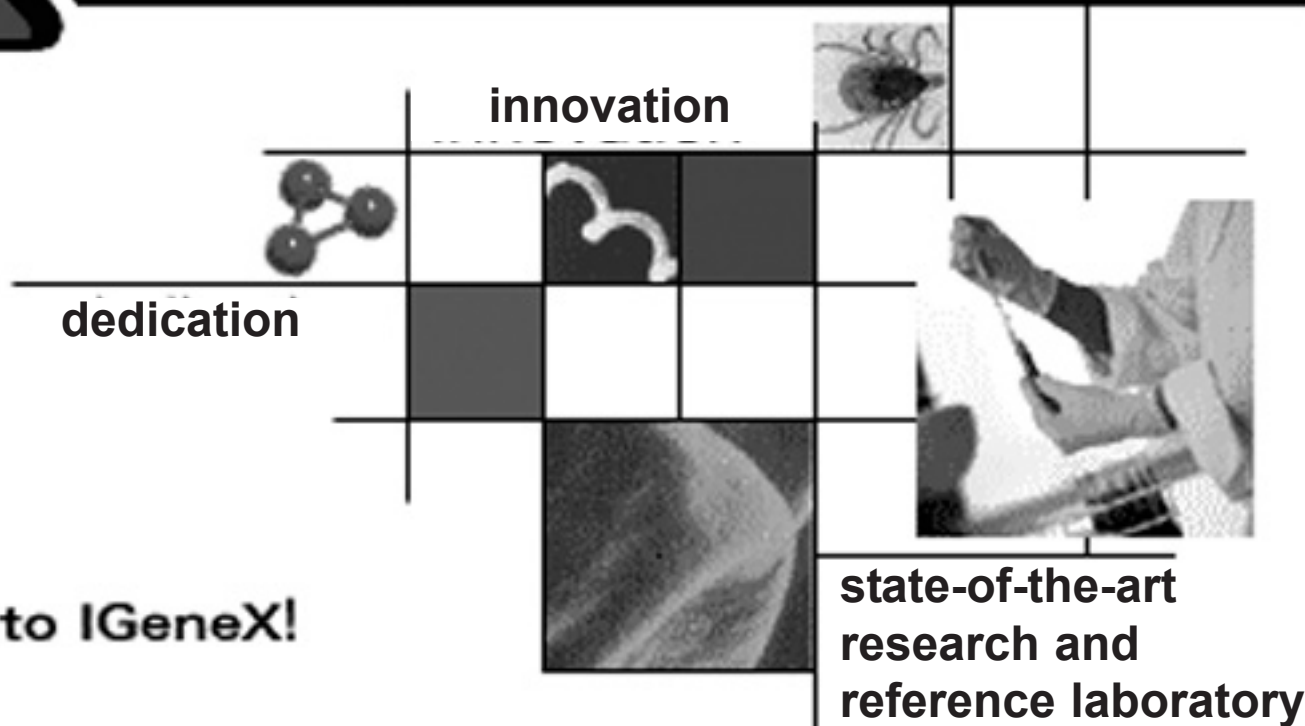
I didn't know what was wrong, but I tried running it off. It was eight months before I finally crashed.

Who diagnosed you with Lyme disease?

Dr. Kessler in Madison, Connecticut. I went to her and I "Lyme Crymes" ...cont'd pg 12



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Study of Malaria Parasite in Patients' Blood Finds Distinct Physiological States Not Seen in Lab Cell Cultures

States may be linked to variable course of disease; Insight flows from unique approaches to analyzing genomic data

by Harvard School of Public Health

Cambridge, MA - The malaria parasite has been studied for decades, but surprisingly, little is known about how it behaves in humans to cause disease. In a groundbreaking study published November 28, 2007 in the advance online edition of Nature, an international research team has for the first time measured which of the parasite's genes are turned on or off during actual infection in humans, not in cell cultures, unearthing surprising behaviors and opening a window on the most critical aspects of parasite biology.

That insight springs from the genomic analysis of parasites in their natural state, derived directly from patients residing in Senegal, and also from the researchers' use of innovative computational approaches to interpret their results. These computational methods helped to identify three distinct biological states of the malaria parasite: an active growth-based state, a starvation response and an environmental stress response, presumably related to the body's inflammatory response to the parasite. This physiological diversity was previously unknown and may help explain the widely varying course of the disease in different patients, from mild, flu-like illness to coma and even death.

"For the first time, we have glimpsed the biology of the malaria parasite in one of its most important environments - humans," said co-senior author Aviv Regev, a core member of the Broad Institute of MIT and Harvard and an assistant professor of biology at MIT. "Our unique computational approach holds promise not only for understanding the malaria pathogen, but likely other important microbes as well."

"This work illustrates the true power that comes from developing the right computational methods and applying them to important biomedical

problems," said co-senior author Jill Mesirov, director of Computational Biology and Bioinformatics at the Broad Institute of MIT and Harvard. "Even more importantly, it reflects scientific research at its best - a global effort that brings together clinicians and researchers with diverse expertise, working directly with patients in areas hardest hit by disease."

In its natural state, the malaria parasite, Plasmodium falciparum, leads a complicated life. It proceeds through a series of distinct developmental stages both in humans and in mosquitoes, the main vector for disease transmission. Malaria researchers typically circumvent this complexity by studying the parasite in cultured cells. Yet in this artificial setting, few differences have been found in the genes that are turned on or off in various strains of P. falciparum. That uniformity is surprising, because it fails to explain the drastically different courses experienced by malaria patients.

To explore the basis for these differences, first author Johanna Daily, an infectious disease physician at Brigham and Women's Hospital, assistant professor of medicine at Harvard Medical School, and a researcher at both the Harvard School of Public Health and the Broad Institute, set out to observe P. falciparum in its natural environment: the human circulation. Using small samples of blood collected from more than 40 malaria patients in Senegal, Daily and her col-

leagues worked meticulously to devise a method for isolating genetic material from parasites, allowing them to determine which of the nearly 6,000 P. falciparum genes are switched on or off during infection in humans. Importantly, all of the patients involved in the study harbored similar-looking parasites, yet their symptoms varied widely.

These clinical research efforts were led by Professor Souleymane Mboup and Dr. Daouda Ndiaye at Cheikh Anta

patients' blood, the researchers simultaneously measured the activity level, or "expression", of every P. falciparum gene. Co-author Elizabeth Winzeler, an associate professor at The Scripps Research Institute, led this aspect of the study. "The ability to look across the parasite's entire genome was essential," said Winzeler. "We uncovered extraordinary things about parasite biology - things we could not have even imagined."

Winzeler, who is also head of malaria research at the Genomics Institute of the Novartis Research Foundation (GNF), where much of the genomic work was performed, is grateful that organizations like GNF choose to encourage these types of high-risk studies. "We are especially excited about using these observations to guide our drug discovery efforts," she said. The key to interpreting these results lay in two computational tools, first developed by Mesirov and her colleagues to study the genomics of human cancer cells. By adapting

these tools for malaria, the researchers were able to identify distinct groups of parasites, each marked by characteristic sets of active and inactive genes. The biological underpinnings of these groups were made clearer through a second innovative approach: systematically comparing P. falciparum - whose genes and genome are poorly understood - to the baker's yeast, an organism that has been extensively characterized at the genetic level. Since the malaria parasite and the baker's yeast are both single-

celled eukaryotes, it is possible they may share some of the same cellular machinery and could also respond in some similar ways to their surroundings.

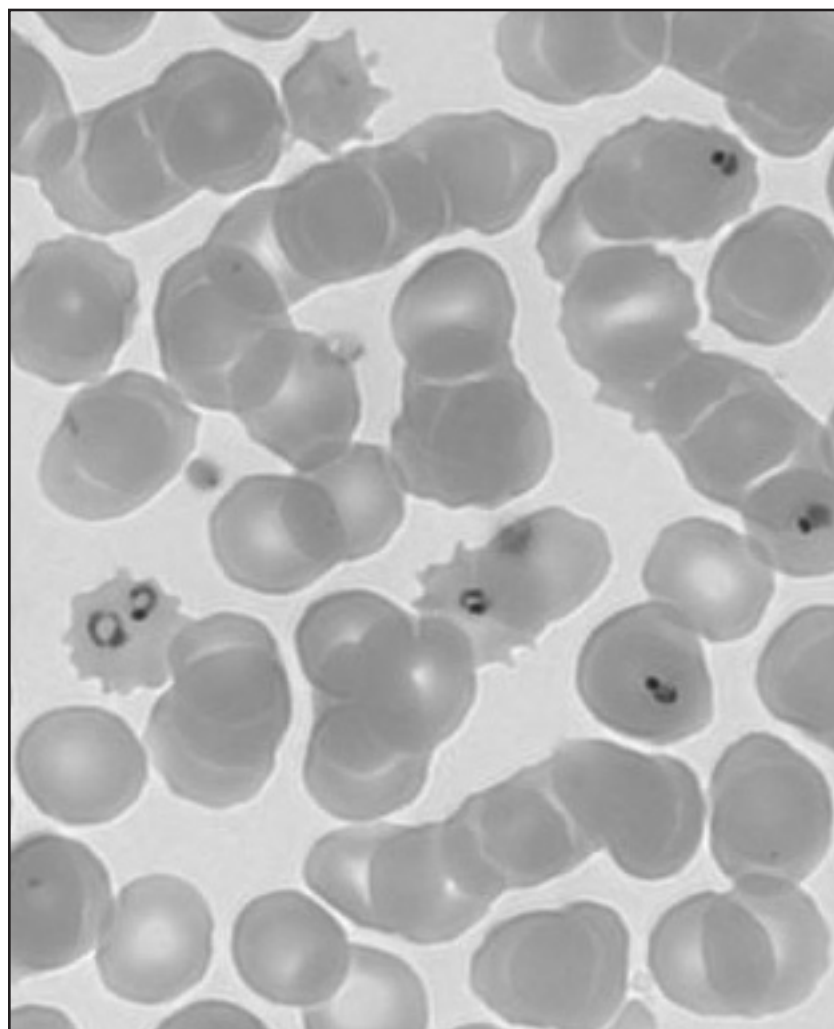
With this unusual approach, co-senior author Regev and her colleagues were able to describe three different classes of parasites, one of which displayed features associated with a well-known form of parasite metabolism. The other groups, however, were very unusual, reflecting modes of parasite behavior that had never before been described.

One of these novel groups seems to signal parasites that are under extreme environmental stress. Importantly, this group shows a clear correlation with patient symptoms, including high fevers and elevated levels of inflammatory markers in the blood. "This is a remarkable result - it suggests the malaria parasite can sense what is happening within its host and adjust its biology accordingly," said Daily. "That interaction signals a fundamental shift in the way we think about malaria, one which will hopefully lead to more effective treatments - particularly for the most severe cases of the disease."

The other parasite group is associated with an alternative form of parasite metabolism, which relies on two specialized cellular compartments called the mitochondria and the apicoplast. That result is particularly surprising since mitochondria in P. falciparum were previously thought to be non-functional.

"For decades, our knowledge of the parasite has been driven solely by studies in cultured cells, not in humans," said Wirth. "Our work underscores the importance of studying the malaria parasite in its natural environment and will hopefully spark novel approaches to malaria drug discovery."

pha



"Ring forms" of the Plasmodium falciparum (malaria) parasite, inside red blood cells. Microscope image using 100x oil-immersion lens. From a blood smear, stained with hematoxylin. Photo used with permission by Michael Zahniser.

Diop University. "This project would not have been possible without the dedicated work of our collaborators in Senegal," said co-author Dyann Wirth, a professor and chairman of the department of immunology and infectious diseases at the Harvard School of Public Health and the co-director of the Broad Institute's Infectious Disease Initiative. "We are grateful to them and to the many malaria patients who generously volunteered to participate in this study."

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President of L.E.A.P Arizona Addresses Governor Corzine on Need for Lyme Legislation

Dear Governor Corzine:

I am a chronic Lyme disease patient and advocate who founded a 501(c)3 non-profit, public charity in 2005 called Lyme Education Awareness Program, L.E.A.P. Arizona. Our charity provides education to the public about tick-borne infections and financial assistance to patients for their treatment and necessities of life. I receive requests for information and financial assistance from Lyme disease patients from many states. As a national Lyme disease patient advocate, I am responding to correspondence sent to you in 2007 from Dr. Henry Masur, President of the Infectious Diseases Society of America (IDSA).

Legislation that favors healthcare choices is in the best interest of chronic Lyme disease patients. Citizens suffering from late-stage Lyme disease, a virulent bacterial infection, should have the right to treatment options that include long-term antibiotics. This treatment decision should be made jointly by the patient and their treating physician. According to the American Medical Association's (AMA) Informed Consent Guidelines, it is the responsibility of each physician to provide all treatment options to their patients, regardless of cost or whether such treatments are covered by insurance.

Physicians access information from medical organizations such as the Infectious

Diseases Society of America. It is for this reason that the IDSA should abide by AMA Informed Consent Guidelines by disseminating information to physicians that encompass all treatment options, not only those written by their guideline authors. Informed consent is an important principle that the IDSA is blatantly ignoring. The IDSA is wrenching healthcare choices from the hands of those who should be making those choices, that is, the individual physicians and their patients. Lyme disease patients and their physicians have the right to choose for themselves the course of therapy they think is most beneficial.

The IDSA has made it their business policy to interfere with Lyme disease legislation that affords patients and their treating physicians to retain these individual healthcare choices. Treatment for chronic disease is a personal matter that does not need to be authoritatively determined by a few individuals with conflicts of interest speaking on behalf of the IDSA. Most people readily learn about the disease that afflicts them, whether it is Lyme disease, cancer, diabetes or other debilitating condition. Misdiagnoses prompt Lyme disease patients to become quite educated with regard to their illness. In addition, the majority of Lyme disease patients are knowledgeable of several treatment options that are available to them.

Lyme patients know that they have a choice of short or long-term antibiotics for treatment of their disease. Cancer patients have the right in choosing to undergo chemotherapy or radiation treatments, therapy that brings them close to death's door, and they are not stripped of the right to make those healthcare choices for themselves. I feel comfortable in speaking on behalf of chronic Lyme disease patients, many of whom have suffered without being diagnosed or given any treatment at all for years, in saying that they also deserve to undergo treatment of their choice without interference from the IDSA.

The IDSA is oblivious to the excruciating musculoskeletal pain, crushing fatigue and debilitating cognitive dysfunction that chronic Lyme disease patients are forced to endure due to the IDSA's treatment-restrictive guidelines that are utilized by insurance companies and promoted by the Centers for Disease Control and Prevention (CDC). The IDSA's ongoing effort to minimize our suffering is obvious in their constant referral to "so called chronic Lyme disease." The IDSA's inference that our daily sufferings are either figments of our imaginations, fictitious diagnoses by our physicians or an infection that just doesn't exist is ludicrous, and in my opinion, appears to be inhumane malicious criminal intent against a patient community as a whole.

With regard to the 14-member IDSA panel and the review of research by these IDSA guideline authors, it is evident that they did indeed deem some Lyme-related research as not meeting "rigorous scientific standards." It is astounding that some of the research the IDSA panel members chose to ignore was their very own. Let me provide you with a few examples.

The following is a quote from a published abstract from an article co-written by Allen C. Steere, one of the authors of the 2000 and 2006 IDSA Treatment Guidelines, in the New England Journal of Medicine, Nov 22; 323(21): 1438-44, which refers to a study of *Borrelia burgdorferi*:

"These chronic neurologic abnormalities began months to years after the onset of infection, sometimes after long periods of latency, as in neurosyphilis... The typical response of our patients to antibiotic therapy supports the role of spirochetal infection in the pathogenesis of each of the syndromes described here... The likely reason for relapse is failure to eradicate the spirochete... This last article is one of many studies that show continuing symptoms are most likely due to persistence of the spirochete."

I ask you, doesn't Dr. Steere adequately describe "so called chronic Lyme disease" as persistence of infection?

The following quote is from another published article

by Dr. Allen C. Steere: [Steere, AC., 1995, Musculoskeletal manifestations of Lyme disease. American Journal of Medicine, 1995, 88:4A-44S-51S.]

"...a 1-month course of oral antibiotics may not always eradicate viable spirochetes."

More from Steere:

[Steere, AC., et al., 1994, The long-term clinical outcomes of Lyme disease. A population-based retrospective cohort study. Annals of Internal medicine, 121(8):560-7.]

"Ten of the 38 patients with Lyme disease reported relapses within 1 year of treatment... and had had repeated antibiotic treatment (5 patients with intravenous ceftriaxone)... Patient 4, in addition, had had second degree atrioventricular block with acute Lyme disease that resolved with penicillin treatment. Her irregular rhythm recurred 2 years later, resolved temporarily with ceftriaxone treatment, but progressed to complete heart block requiring a pacemaker... Patient 12... was treated with 2 weeks of parenteral penicillin. She later developed a progressive speech disorder, bradykinesia, and abnormal ocular motor function. Magnetic resonance imaging of the brain showed scattered white matter lesions in the hemispheres and pons... she was re-treated with 2 weeks of parenteral ceftriaxone in 1989 that had no effect

"Letter" ...cont'd pg 17



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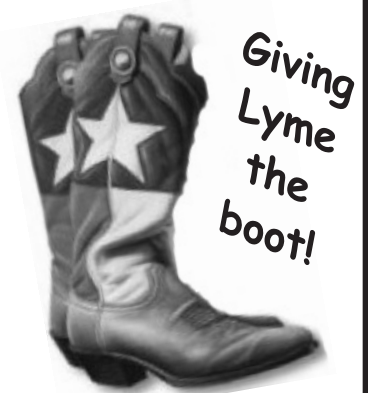
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CALLING ALL TEXAS LYME PATIENTS AND CAREGIVERS!

STAND UP FOR LYME (SUFL) invites you to join our email list to receive news of advocacy activities and events promoting awareness of and solutions to issues faced by Texas patients.

To join the list, go to www.standupforlyme.org and click the "Contact Us" link in the left hand side menu bar. Then have a look around the site to learn more about Lyme in Texas and the nation.

SUFL has been busy cultivating important state legislative supporters to develop a strategy which will lead to protection of our Lyme Specialists, and our work continues.

We are planning important future events for all to participate in. Please join the SUFL list for news and coming announcements with all the details!

Working together we can make Texas a leadership state for quality care of those suffering from Lyme and associated vector-borne diseases.

Join us!

The STAND UP FOR LYME Team

www.standupforlyme.org

Ticktoons



by Terri Reiser

“Lyme Crymes” ...cont'd from pg 8

could hardly walk or talk.

Is that still who you see for Lyme disease treatment?

I was one of the hard cases, she's in Connecticut (the arm pit of this mess), and she's not one of the three specialities that Connecticut mandates - infectious disease, rheumatology, neurology. So I went to Dr. Donta.

You have a support group. When was it established and how many members are there?

It was established in 2001 and we have roughly 90 members. On an average, we have 40 members at each meeting.

When and where does your support group meet?

We meet every third Wednesday of the month at the Farmington-Unionville Senior Center in Farmington, Connecticut. On our website, CTLYMEDISEASE.org, we have provided a place to type in your address and it will map the directions to the center.

You had a meeting at two o'clock on December 18, 2007, with a state representative. Who was that?

That was Linda Schofield. We met in her office in the legislative office building in Hartford, Connecticut.

She asked how I could argue with the IDSA when they have pretty much proven that Lyme is cured in 21-days?

I asked her if she had seen my website. She said that she hadn't had a chance. She went on it, looked at a couple of things, and then the subject changed.

I think these legislators have been told that this is over their heads and not to mess with it. It's tabu and they're not going to change this.

I am going to do a follow-up with Ms. Schofield. I want to ask her again where we stand. I am not going to drop this and I am not going away.

Lyme disease has not gone away in all these years, and I believe they know we are not going away.

There was a doctor on Dr. Jones's panel, *the panel that passed judgement on him*, that said he had been treating Lyme disease since 1967. That is humorous since Lyme disease wasn't even named until much later.

According to the Lyme Disease Foundation website:

"In 1970, for the first time, an incidence of EM known with certainty to have been acquired in the United States was reported by Rudolph Scrimenti, who diagnosed and treated a patient who had been bitten by a tick while hunting grouse in Wisconsin and acquired the disease.

In 1976, the first US case of clustering of this disease was reported by researchers at the Naval Submarine Medical in Southwestern Connecticut.

In 1977, physician Allen Steere et. al, described the first clustering of the disease misdiagnosed as juvenile rheumatoid arthritis. They named this condition 'Lyme arthritis'.

In the early 1980's, an entomologist at the United States Rocky Mountain Laboratories of the National Institutes of Health by the name of Willy Burgdorfer, MD, Ph.D., was investigating outbreaks of Rocky Mountain spotted fever.

Research scientists Jorge Benach and Edward Bosler, Ph.D. collaborated in the dogged and dangerous work of gathering and testing ticks for disease-causing pathogens.

During the course of the research, attention shifted from dog to black-legged ticks and in the fall of 1981, one of the batches of ticks yielded something dramatically new.

Burgdorfer noticed an embryonic form of parasite in the body fluid of two of the ticks. Guided by his extensive knowledge of the early scientific writings of European researchers, he undertook a very close inspection of the tick--and found poorly stained, sluggish spirochetes.

Within a year, the spirochetes had been named *Borrelia burgdorferi* (Bb), in his honor, and definitely identified as the causative agent of Lyme disease. Dr. Burgdorfer was the partner in the successful effort to culture the spirochete, along with Alan Barbour, MD.

Next came a period of consolidating and expanding of knowledge. After the discovery of Bb and the diseases associated with it, researchers began to learn more about how the infection lodges itself in the body.

In 1985, Paul Duray, a Lyme disease researcher, declared that the Lyme disease bacterium disseminates itself through the body early in the course of infection. The prevailing wisdom at the time was that infection was slow too. Duray's findings are now the prevailing thought.

Also in 1985, Burgdorfer was able to demonstrate that ticks infected with the Lyme spirochete could be found across the country.

In 1988, the LDF was founded and started the major push to bring Lyme disease in the spotlight. It was the effective partnerships among patients, government officials, and researchers that enabled volunteers around the world to bring Lyme disease the attention that has helped make it a household term."

You can't argue with documented facts - can you?

What was Dr. Jones originally charged with?

We don't really know. The only thing they have him on is refilling a prescription for antibiotics for a child's cough.

So he was not actually treating Lyme disease long distance?

No. This was supposed to have nothing to do with Lyme disease. In fact, he had all the blood work for the children done, documented the tick attachment and exposure, and when the blood work came back positive, he made an appointment and treated them *after* he saw them.

He did refill a prescription for a chest cold because

the child was not able to go to school because of a wicked cough.

What was Dr. Jones's sentence for refilling an antibiotic prescription?

A \$10,000.00 fine, a 2-year probation and somebody has to look over his shoulder for the next two years.

This is ridiculous. He didn't do anything. He hasn't done anything wrong - refilling a prescription is something that most every doctor does.

Dr. Shapiro would call people and say don't even bother bringing your son in because he can't have Lyme disease.

[This would be Eugene Shapiro, M.D. that Sykes is speaking about.]

And you have proof of this, right?

Yes...and the panel would not let her testify at the hearing.

Let's talk about Connecticut legislation. What does Connecticut have and how does it benefit the people?

Connecticut had a mandate that was passed in 1999. The mandate states in the mandatory coverage section [38a-492H] that as of January 1, 2000, the insurance provider shall provide coverage for Lyme disease treatment, including not less than 30-days of intravenous antibiotics and not less than 60-days of oral antibiotics - or both.

It depends on what the doctor wants to do. The mandate says insurers shall provide further treatment if recommended by a certified rheumatologist, neurologists, or infectious disease physician.

Once you get the brand of approval from one of those three specialists, you have open-ended, unlimited antibiotic treatment and the insurance company has to pay - as long as they are based in Connecticut.

But isn't that contrary to the IDSA guidelines?

Oh, yeah. The reason there's so much going on in Connecticut is because it's always been the focal point: Lyme, Connecticut.

The reason all this attention is coming into Connecticut now is because Attorney General Richard Blumenthal said the insurance companies are going to follow this mandate and they are going to pay for treatment.

The IDSA has a stronghold - they have Yale and the University of Connecticut here. A stronghold... and the guys there are corrupt. They won't back down."

So Attorney General Blumenthal is investigating? Who is he investigating?

IDSA. In fact, he subpoenaed their records (we have their records on our new website). IDSA wants the information removed because it proves they are lying.

Where is he in this investigation?

As far as I know, the IDSA have not turned their records over to the AGs office.

Blumenthal's office seems to be backing off of giving information out to the public because too many things were getting back to the IDSA. Information in the Lyme disease community travels pretty quickly.

What have you done in the past to bring attention to Lyme disease?

Our group was responsible for the hearings in 1999 and 2004.

What happened at those two hearings?

Legislation came out of the 1999 hearing that is basically a fool-proof policy. Once you get an opinion or diagnosis from one of three specialties, you have open-ended and unlimited antibiotic treatment: oral and IV.

The only way the legislation could have been better is to add more specialties in the list -- pediatrics, Internal Medicines, etc.

It would open more doors, but the insurance companies will probably be coming against this mandate anyway. Why should they be paying for treatments when IDSA says it's

cured in 21-days?

In 2004 the CDC and NIH came under protest. That was when the Connecticut Lyme Disease Coalition was imploded - destroyed by people who could not play by the rules. We sent a letter off to every Senator and Congressman in Connecticut and they demanded that the CDC and NIH send someone.

CDC and NIH did come; they brought their attorneys. They were going to get back to us with answers to various questions we had asked regarding guidelines and diagnoses. They never got back with us. We inquired a couple of times, but to no avail.

So, they just let it drop?

Yes. It's hard when you can't get an answer from them. Connecticut has no federal authority to command them to answer.

You have a \$20,000 reward publicized. Tell me about this.

I started that out with \$1,000 because we had to have a new angle.

Instead of running around as if we were chasing our tails, we needed something new. No one came after the reward, so I went to \$2,500,

"Lyme Crymes" cont'd pg 15

Lyme Awareness Art Project

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The first submission for the Lyme Awareness Art Project read:
"I'm not afraid of Lyme disease. I know I can beat it. I'm tough and strong and I can be as mean as a dinosaur. This disease can't slow me down." Jeff - age 6 - Middlesex, VT

Tell Us Your Story!

The guidelines for submitting your story and photo are simple. Write a short paragraph or poem describing your experience with Advanced Lyme and send a photo that you feel visually expresses the experience you have written about. Include your name, your age and the city and state in which you live.

I will paint my interpretation of the submissions for what I hope will be a traveling Lyme Awareness show. Please be sure that you send me your contact info in case I need to ask you something about your submission!

Send Photo and Story Submissions to:

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Therapy for the Thyroxine-Resistant Hypothyroidism

A Tale of Unnecessary Chronic Suffering

by Eric Pritchard

The tale of unnecessary suffering from the chronic symptoms of hypothyroidism in thyroxine-resistant victims began some years ago but has not seen the end yet. It began when my long suffering wife came home and complained that her doctor would not listen to her. He would only consider the laboratory tests. This reminded me of the crux in another research project, translating the artistry of vacuum tube guitar amplifiers to solid state. The subjective opinions of the musicians were disregarded in favor of the "objective" engineering tests. After years of failures, I decided to check for the validity of my engineering training and experience for the exactness of mathematics. Just how much of engineering has a direct connection to physics? How much of engineering comes from rules of thumb and over simplifications of reality? It had not taken long to realize that even the very basic equations of circuit analysis had a hidden flaw. There are missing terms that a derivation from physics' Maxwell's Equations would have produced. The textbook derivation hid underlying assumptions that distant electric and magnetic fields were negligible. Although they are generally negligible, they are not insignificant in high-gain guitar amplifiers.

Engineering made other assumptions along the way to its way to evaluating amplifiers. First, amplifiers are not supposed to be driven in to distortion, but guitar players do. Second, human hearing does not produce harmonics of what is heard, but it always happens.

A description of the philosophy of Behaviorism made things clear. Behaviorism distrusts the mind and subjective judgments. Only the objective can be considered scientific. [1] Consequently, objective measurements, no matter how poorly they are formulated and executed, are better than subjective judgments, no matter how expertly they are observed. So when my wife complained that her physician would not consider her complaints or her clinical presentation and would only consider her laboratory assays, I knew that this was a vestige of Behaviorism and there had to be a hidden assumption that would produce conflicting assays and clinical presentation. All I had to do was find it.

The Internet produced medical research papers that disclosed the underlying issues with thyroxine-resistant victims of the symptoms of hypothyroidism. My wife took them to her appointment with the second endocrinologist, now nearly two years into her miseries. He rejected all that wisdom with, "You can prove anything with medical research papers." However, he did notice that the token dose of Cytomel®, prescribed by the first endocrinologist, should be given three times daily. Before her blood tests were analyzed, she was feeling substantially better. Nonetheless, this endocrinolo-

gist refused to see her vast improvement. He insisted upon her not taking what relieved her symptoms and insisted upon doubling what had not worked. He was quite adamant. My wife opted out of his services and convinced the first endocrinologist to continue her tripled prescription.

My wife was lucky. Her misery only lasted two years. Others in our support group have not been treated properly for decades - even more than a half century.

More Internet research found a position paper by the American Thyroid Association (ATA) castigating "Wilson's Syndrome." [2] Wilson advocates the prescription of triiodothyronine (T3) containing hormone replacement. This ATA paper claims, without supporting citation, that T3 replacement is not needed because the peripheral conversion of thyroxine (T4) to triiodothyronine (T3) is regulated. In other words, the replacement T3 is not needed because this conversion never fails. Somehow, a community of physicians who have studied and experienced somatic failures all their adult lives accepts an unsubstantiated claim of somatic perfection. "Wilson's Syndrome" goes further to discredit thyroid pioneer's Dr. Broda Barnes low basal temperature indicator [3] and promotes the "nonspecific symptom" excuse for the lack of proper diagnosis and therapy. It does so by citing studies that did not exclude subjects with hypothyroidism [4,5] to exclude hypothyroidism - a logical faux pas. [6]

The ATA paper also claims that T3 is dangerous. This danger is alleged to exist in the short half-life of T3 in the serum as that would indicate substantial somatic swings. Anecdotally, this is not true. Further, a study [7] found that the intracellular effects of T3 have a much longer half-life of 50 hours. The action that counts is in the cells, not in the blood:

"T4 . . . is not the active ingredient. T3 is the active ingredient, and it's the thing that accounts for the thyroid hormone action. As I've been reminded many times, there are no intracellular events that we know that can be described by T4 at the level of the nucleus. Only T3. T4 is not the active compound. Likewise, the site of action is in the nucleus. The site of action is not T4 in the plasma." - Dr. E. Chester Ridgway [8]

The endocrinology establishment has effectively ignored all of the post-thyroid operations upon thyroid-related hormones that were discovered circa 1967-1970. [9,10] The peripheral cellular hormone receptors for triiodothyronine were discovered in 1967 by Refetoff, et al. [11] The peripheral hormone conversion was

discovered in 1970 by Braverman, et al. [12]

Physicians are exposed to these discoveries, but then are taught to ignore them in diagnostics and therapies. This can be seen in a comparison of Tables 1 and 7 in the Continuing Medical Education course. [9]

The above examples of the lack of linguistic precision prompted me to apply for grants to improve the conveying of information. For example, the crash of the Mars Lander and the loss of \$300 million was created by a simple lack of communication of the units of navigation constants. However, no application was accepted. The National Institutes of Health gave me drop dead application scores

It began when my long suffering wife came home and complained that her doctor would not listen to her. He would only consider the laboratory tests.

twice.

Letters to Secretary Leavitt of the Department of Health and Human Services accomplished nothing but apologies for my wife's unfortunate condition in letters from his various agencies, including the National Institutes of Health and the Agency for Healthcare Research and Quality. The Office of Research Integrity repeatedly denied jurisdiction. The Food and Drug Administration has refused to act upon my Citizen's Petition to reduce the indication for levothyroxine sodium to the classical etiologies of hypothyroidism and exclude those alleged peripheral etiologies of hormone conversion and reception. The best wishes for my wife's health were not accompanied by any action.

Once I learned that the federal government was given an executive order by President Clinton to abstain from medical practice policy making, I wrote to West Virginia's Governor Manchin. This, too, was denied by the West Virginia Board of Medicine as an attempt to change the medical practice guidelines. This excuse was used repeatedly even though my requests had shifted to the underlying crux of the abuse of these thyroxine-resistant victims: the definition of the word "hypothyroidism." West Virginia rejected my pleas five times and ignored others. West Virginia rejected all possibilities for mercy for its few thousand suffering thyroxine-resistant citizens and for saving millions in medical expenses.

There are two defini-

tions for "hypothyroidism." One is thyroid centric as the "-ism" suffix implies. The other is broader and symptom oriented. Although these definitions were believed to be equivalent, the discoveries of peripheral operations upon thyroid hormones have made them unequal. [6,13] The inconsistent use of these definitions presents two problems: (a) improper diagnosis and therapy, and (b) improper formulation and interpretation of studies.

The medical practice guideline for hypothyroidism by the American Association of Clinical Endocrinologists (AACE) [14] effectively uses both definitions. The broad, symptom oriented definition is used to include patients in the guideline's protocol. However, the diagnostics and therapy are strictly thyroid centric. Only the input to the thyroid (thyroid stimulating hormone), the output of the thyroid (free thyroxine (T4)), and thyroid internals (antibodies) are tested. The tests for any of the potential peripheral deficiencies, serum triiodothyronine (T3), serum reverse triiodothyronine (rT3), and urine T3 are not recommended.

A paper by Brady [15] recommends the use of the rT3 test to verify post-thyroid deficiencies. A study by Baisier, et al., [16] recommends the 24-hour urine test for T3. It also discloses an evaluation of a combination of eight symptoms to accurately clinically diagnose all etiologies of the symptoms of hypothyroidism. Additionally, these doctors successfully treated the failures of the endocrinology establishment with natural desiccated thyroid, Armour Thyroid® for example. Brady and Baisier are indicative of many more studies on the use of a triiodothyronine replacement. [for example 17-20]

The improper formulation and interpretation of studies can be found in the many studies attempting to discredit the use of any triiodothyronine replacement. This was done by selecting subjects with known primary hypothyroidism or thyroidectomies, ignoring low percentage successes, and/or providing insignificant doses. The results were then implied to cover all etiologies of all the symptoms of hypothyroidism - another logical faux pas. [6]

More recently, two impacts upon the definition issue were uncovered. First, the lack of any stipulation for the definition of "hypothyroidism" is contrary to the American Association of Clinical Endocrinologists' protocol for authoring medical practice guideline, [21] which demands such stipulations for critical and readily misunderstood terms. This protocol indicated that the AACE should have acted upon my letters that complained of the inconsistent usage of the definition for "hypothyroidism" and thereby

alleviated suffering in so many world wide. Unfortunately, the AACE guideline is not alone in its failings. Studies of guidelines [22-24] disclose a wholly unsatisfactory standard of medical authorship, with numerical grades near or below 40%. Second, the patient information from the AACE [25] and the ATA [26] stipulates that hypothyroidism is a result of deficient secretion by the thyroid. This stipulation implies that the hypothyroidism guideline applies only to deficiencies of the thyroid and not to post-thyroid deficiencies.

If this narrow definition of hypothyroidism were known to my wife's physicians, she would not have suffered unnecessarily. If the limited scope of the hypothyroidism guidelines were recognized, unnecessary medical bills could have been slashed. Further, the members of our support group, mostly women, would not have suffered unnecessarily. And the hundreds of thousands of Americans would not suffer unnecessarily. In spite of the horrendous damages caused by this lack of information, it is not the fault of the practicing physician - they have been taught this way [8,9,13] and these incomplete teachings are enforced by the boards of medicine. If physicians were taught properly, would there be a 13% dissatisfaction rate among patients treated for hypothyroidism? [27]

With all professional and governmental appeals apparently exhausted, my legal studies began in earnest. I studied Constitutional, tort, and antitrust law. Constitutional law organizes and limits government to keep it from abusing its citizens by law, regulation, or ruling. Tort law was established to preserve life as it replaces ancient bloody revengeful reprisals. Antitrust law addresses conspiracies to abuse customers. But all of these matters take time and have a secret life. It is quite unfortunate that government and medicine have forced this issue into the legal arena. But it must be because they have not had a meaningful, merciful concern for the unfortunate, unnecessary suffering by the thyroxine resistant victims of the symptoms of hypothyroidism.

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“Book Burning”... cont'd from pg 4

Lyme disease was discussed. From the abstract, we learn that Lyme borreliosis acquired during pregnancy may be associated with stillbirth and fetal malformations.[8]

By 1989 the understanding of Lyme disease is growing, and more scientists are realizing the complexity of Lyme's vast neurological symptoms. In a Scottish article from the same year we read about a "triad" of neurological symptoms of Lyme. "...meningoencephalitis, cranial neuritis and peripheral neuritis is unique to the disease..." But the list doesn't stop there. The author describes the following manifestations: "...pseudotumour cerebri, hemiparesis, demyelinating disorders, optic atrophy, recurrent laryngeal nerve palsy and meningitis so that Lyme disease must now be considered in the differential diagnosis of a wide range of neurological disorders."[9]

Two studies from 1993 examined the relationship between adverse pregnancy outcomes and maternal exposure to Lyme disease. One study of 5,000 mothers with infants who participated in a cord blood serosurvey showed that cardiac manifestations in the exposed infants were significantly higher within the endemic group.[10] The other study (Westchester County, NY) involved questionnaires to 2,000 women and showed that "tick bites within 3 years preceding conception were significantly associated with congenital malformations."[11]

In a 1994 letter to the editor of the *Journal of Clinical Microbiology* regarding an article by Dr. Kenneth B. Liegner, we find a patient treated for 5 days with oral doxycycline following tick removal. Three months later the patient presented with fatigue and other symptoms. He ignored these until progressive muscle hypotrophy, neurologic, gastrointestinal, genitourinary and cardiorespiratory symptoms occurred. 27 months after tick bite, he was initially diagnosed with a psychiatric disorder. 41 months following the bite, he was diagnosed by a Neurologist as having "probable encephalomyelitis due to Bb." This case was included in the profile of patients with circulating immune complexes to Bb and poor response to "standard" treatment for Lyme disease. The letter points out the "unreliability of available laboratory tests" and stresses the importance of clinical impressions when patients are seronegative. The letter also describes a proactive approach to prophylactic and therapeutic treatments, as in such cases like the patient above which "could have been prevented." The author's reply stated that European literature describing "progressive" borreliosis encephalomyelitis may be progressive because it was inadequately treated. He further states that the lack of appreciation for the chronic form of Lyme disease results in an "overreliance on treatment protocols developed before a clear understanding of the pathobiology of the infecting agent was possible. Now, with a clearer

picture of pathogenesis, physicians may offer prolonged treatment."[12,13]

In a continuing education videotape from 1997 issued by the NCME, our pretend Federation's (IDSA member) Benjamin Luft (co-author of the controversial IDSA Diagnostic and Treatment Guidelines) goes on film to iterate the 1997 current IDSA beliefs about LD which include the following, important statements:

1. Lyme disease is a multi-systemic disease.
2. It is often difficult to diagnose.
3. Diagnoses are based on clinical findings, and not solely on lab tests.
4. The presence or absence of infection should not be based solely on a positive (+) or negative (-) test result.
5. Consideration should be given to the limitations of tests.
6. Lyme disseminates very quickly - within 2-4 weeks.
7. If left untreated, Lyme has a period of latency which can be a period lasting years, only to become reexacerbated later in life.
8. In 46 children followed by Steere et al. (*NEJM* 1991;325:159-163), none received treatment for at least 4 years after tick bite. 39 patients were followed for 10-13 years, and most had symptoms including arthralgias and neurological symptoms.
9. Testing in the early stages of LD may lead to false negatives.
10. Immune response varies.
11. Antibiotics given early may reduce antibody production.
12. Serology may initially be negative, and if so, a 2nd serum sample should be performed 4-6 weeks later where seroconversion may be seen.
13. More sensitive and specific testing is needed.*
14. For severe cases of LD, the duration of treatment should be based on severity of infection and the patient's response to treatment.
15. The causes of Lyme treatment failure were noted as (in part) poor absorption to antibiotics, advanced illness (CNS Lyme), and concomitant tick-borne illnesses.[14]

* This information was taught to physicians during a time period **AFTER** the 1994 Dearborn, MI criteria-establishing conference which included *IDSA members Steere, Barbour and associates* - criteria which are said to have been designed to facilitate the emergence of the LYMERix vaccine (subsequently pulled from market); criteria which are called "flawed" by Lyme-literate physicians, patients and advocates because they are said to miss the majority of Lyme patients; and criteria which are heavily promoted by the CDC and the IDSA (and its guidelines), today.

We hold these (patent) truths to be self-evident:

In (1988) U.S. patent #7,045,134 we read: "Current technology enables correct diagnosis of certain infectious diseases only after the disease has progressed to a certain maturity. By that time, however, treatment is more diffi-

cult..."[15]

Patent #4,721,617, says: "The etiological agent of this disease is the spirochete *Borrelia burgdorferi*, which is primarily transmitted by Ixodes ticks...The spirochete has also been found in deerflies, horseflies and mosquitos..." It goes on to describe: "...As many as two-thirds of the people that become infected by this spirochete are unaware of the tick bite because of the painless bite and the small size (several mm) of the nymphal stage...The early phase of the illness often consists of the ECM, headache, fatigue, muscle and joint aches, stiff neck and chills and fever. This phase of the disease may be followed by neurologic, joint or cardiac abnormalities..."

And we learn about the chronic form of LD and other issues from this same patent: "...The chronic forms of the disease such as arthritis (joint involvement), acrodermatitis chronica atrophicans (skin involvement), and Bannwart's syndrome (neurological involvement) may last for months to years and are associated with the persistence of the spirochete..."

And more alarming: "...A case of maternal-fetal transmission of *B. burgdorferi* resulting in neonatal death has been reported.....For every symptomatic infection, there is at least one asymptomatic infection. Lyme disease is presently the most commonly reported tick-borne disease in the United States..."

Last, we learn about the effectiveness of treatment: "...The infection may be treated at any time with antibiotics such as penicillin, erythromycin, tetracycline, and ceftriaxone...Once infection has occurred, however, the drugs may not purge the host of the spirochete but may only act to control the chronic forms of the disease. Complications such as arthritis and fatigue may continue for several years after diagnosis and treatment..."[16]

So how is it that so much was known (and there are thousands of examples over the few mentioned here), about *Borrelia* beginning decades ago, but those facts have now become a "hot potato" of contention between scientists, medical boards, government entities, treating physicians, patients, and insurance companies? Why are the Infectious Disease "stormtroopers" using the media to eradicate any mention of the truth about Lyme disease which has been known for 3 decades, to re-spin it in favor of minimalism?

Enter an era of self-interests, profit margins, pharmaceutical interests, government-funded research, spin-off company ownership and patent royalties held by the Federation members. This information at the very least, is likely to come to light when the CT AG investigation is completed. At best, time, publications and clinical studies will reveal the truth around Lyme disease regarding its prevalence and persistence. We find these relationships particularly interesting when we explore Federation "members" like (IDSA member) Durland Fish's involvement in patents,

research, and government-sponsored epidemiological studies using satellite technologies to map vector-transmission, among other things. The Federation of course would benefit from the censorship of the civilian mindset regarding Lyme disease - because therein an epidemic can be controlled and slow-played for maximum research dollars, profits for insurance companies and pharmaceutical and diagnostic test manufacturers. And many of the Federation members are paid spokespersons for these entities, not to mention that they are patent-holders on the technologies which are used for diagnostics and vaccines. But they won't necessarily tell you that, because disclosures and conflicts of interest might bring their motivations under careful scrutiny - something the CT AG may currently be pursuing.

Unfortunately for my imaginery Federation, the patients, advocates, and their physicians who call themselves "Lyme-literate," are not going to go away. They are going to continue to trumpet loudly that Lyme disease in a chronic form exists, and that it must be acknowledged, and allowed open-ended, individualized treatment. Although a few pioneering physicians may be reprimanded for real or imagined "disobedience," like Dr. Jones, the number of Lyme-literate physicians opting off the managed care merry-go-round will continue to increase as they answer the call of their ill patients. These brave physicians will continue to train in tick-borne illness diagnosis and treatment; which won't necessarily include the ideology of the IDSA's impractical guidelines - because for these physicians, patient care comes first over profits.

The number of academic, peer-reviewed articles proving the existence of a persistent form of LD will also increase, as will the number of patient cases with disability. Advocacy groups will not be silenced by a handful of ID stormtroopers attempting to censor civilian mindset. Unfortunately for the Federation, just as in Nazi Germany, their "regime" may indeed be falling. We see evidence in the loud, defensive protestation of subpoenas issued by the CT AG office; their "astonishment" of an investigation of their guidelines; and their increasing fears being revealed in their own publications. We witness their desire to remain highly visible within the media in staunch defense of self-serving guidelines and ideology; and most recently, their strategic presence when a beloved Lyme physician is under fire, and we see can see a transparent house of cards beginning to tumble.

Federation aside, in the end, within the world of Lyme disease, because of the controversy, patients are not being treated, illness is going unacknowledged, and the media is driven to distraction while innocent people are suffering. We suggest as patients and advocates, that the Federation go back to page 1, re-read their own previous research and publications, and leave the book

burning, virtual or not, to history.

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pha
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“Lyme Crymes” ...cont’d from pg 12

then \$5,000, \$7,500, and \$10,000.00.

Finally at \$20,000 it's getting attention and running on a couple of television stations. *The Public Health Alert* ran the offer a couple months ago.

What does someone have to do to collect the \$20,000.00 reward?

They would have to use the current ELISA and Western blot tests to prove that Lyme is cured in 42-days.

We aren't even looking for the 21-day cure that IDSA states it can be completely cured. We have doubled it,.

If they can prove it, we will give them \$20,000.00.

If they care to challenge us, they must agree to put up the same amount of money.

If they lose, they donate the \$20,000 to our group.

All we have to do is use their own research against them - we have them already.

We are also taking donations so that we can start running ads in newspapers to advertise the \$20,000.00 reward, as well as this website."

You have a new website. Tell me about this site.

It's LymeCryme.com. [Note that "cryme" is spelled with a "Y"] We have a petition there and when I last checked, there were over 200 signatures. There is a place for comments - there are some posts there that are tear-jerkers -- about people dying.

People are also offering information. It's an excellent place for people to go for information -- everything is backed up with the links, too. It's not hearsay - that doesn't hold up.

This site can be used to gather information to defend doctors in court - it's a database to show the IDSA is lying.

We have the files online and backup hard copies in case it just disappears. All they would have to do is pull it and all of their previous words would be gone from the public forever.

What do you hope comes from all of this effort?

I don't have much faith in the majority of politicians. They are all experts at window dressing - making everything look good. But I am hoping that a couple of attorneys will latch onto this and use the database. It proves what we have been saying all along.

What, that Lyme disease is not cured in 21-days?

Right. Allen Steere, the guru of IDSA, (in his research) says that after multiple antibiotic courses, patient number 12 dies. They cultured spirochetes from her brain. These guys have hung themselves. I think they can say what they want and get away with it... no one challenges them. We have no avenue to challenge them.

When you say "they," you're talking about IDSA?

IDSA, and doctors out of Yale and UConn are calling the shots. I honestly believe

they control the Connecticut Health Department. You have to read between the lines when you hear these guys talking, or their affiliates talking, you know they are in "the program".

There was a story in the news recently that someone died from complications of Lyme disease. Do you know anyone who has died from Lyme disease complications?

You can type in your internet browser "Lyme Memorial" and there is a whole list of people. Usually you die from complications. I also worry about the children and

I have been on antibiotics for seven years.

And you're still not cured?!

No. There's no cure for Lyme disease. The antibiotics beat it down. There are some days when I can go out and do something; there are other days when I can't do anything except get out of bed. I still do that - no matter how bad I am feeling.

In your opinion, where did Lyme disease come from?

There is a lot of research talking about mycoplasma being in 80% of the ticks. There is also a new

attention.

Before long, the CDC and NIH notified people that they had updated their websites with the "new" report. Our site has *both* reports. The only difference? The words "Lyme disease" were removed from the second report. That was the modification on their websites. I suppose someone "slipped it in there" - oops! They thought we would never catch it.

So, if anyone gets an idea that they can shut you down, you still have all the hard copies as backup?

It happened once already. Don't know if someone hacked into the site or what, but

Legislation right now could hurt us with the IDSA guidelines. If the IDSA guidelines aren't shot down, then the IDSA guidelines are going to be dictating the legislation.

So what you're saying is that we need to prove that the IDSA guidelines are wrong?

The Lyme Crymes website will do it. We can do it by people signing the petition and leaving their comments.

Maybe an attorney will pay attention if we get enough patient stories on there. There are already doctors signing the petition, and authors, too. They are really showing interest in this.

You have all these documents on the website. How are these going to show everyone that what IDSA put in the guidelines is wrong?

These documents are their own words and their own research.

So these are published papers they have written - that shoots themselves in their own feet?

Absolutely! Next, we are going to publish on the site an IDSA timeline and how they flip-flop between saying that Lyme is chronic, Lyme is deadly, Lyme is a cakewalk! All of a sudden, around 2000, something changed.

What do you think changed?

I don't know. I wish that I did. We have suspicions as to what happened - insurance companies or the pharmaceutical companies prefer it this way.

Say you treat someone two months with tetracycline who has Lyme, most likely it will knock the infection out and that is about \$15.00 a month.

The pharmaceutical company is in the business to make money - there's no money there! Let that same person go a year or two with chronic Lyme, then you have them on the hook. Now you are on the *antibiotic-of-the-month club*.

And if they don't think it's Lyme - there's always MS, Parkinson's, Lupus, depression, fibromyalgia - you stay in the *drug-of-the-month club* for the rest of your life.

Les Roberts, author of *The Poison Plum* said that if there was a cure for Lyme disease, it would bankrupt the insurance companies.

I believe there is a cure - so I see that if the cure was offered, it would bankrupt the insurance companies.

What is your take-away message here?

When are those in the Lyme disease community going to draw the line in the sand? This isn't about who gets a pat on the back, or whose is the best. We have to start working as team because we are losing ground. We also need honest news media. *pha*



Randy Sykes is a CT Lyme Support Group Leader. He has recently launched the website “Lyme Crymes” which is a data base of conflicting IDSA research with regards to the new guidelines.

the suicides.

I understand in a follow up in one woman's death that she had committed suicide. I can understand. The complications get so bad that you just want to give up.

You have to wonder how many people with Lyme at one point or another thinks about suicide. It probably crosses about 90% of the minds of victims with Lyme disease.

I have not spoken with one Lyme disease victim yet that has not contemplated suicide at some point.

How did you get to the point of functioning again?

Long-term antibiotics. When I went to Dr. Donta, he discovered I had several co-infections. I just started pounding the antibiotics and got to a point where Biaxin, Plaquenil and Minocycline were the antibiotic cocktail mix that helped me the most."

How long were you treated?

PubMed article added to the LymeCryme website proving experiments at Plum Island were done on the Microplasma.

Recently, I read that it came out of a bio-warfare facility.

On our website, www.ctlymedisease.org, we have links for documents that state they (CDC and other agencies) were studying Lyme as a bio-warfare weapon.

There is a bio-warfare laboratory opening that is studying all of these deadly diseases like Avian flu, Anthrax, and others. Lyme disease is on that list. Yet, officials say it's not a deadly disease.

On our website, we have the original article where the CDC identified Lyme as a potential bio-terroristic agent. It was reported by MSNBC.

The CDC and NIH were upset because we posted the PDF file. A week later, it was gone from their website. It couldn't be found anywhere on the internet. They really wanted that story out of the public

it was shut down for a short time. It's on two other servers as backup, too. Everything on both websites is backed up.

What do you think should be done so that Lyme victims get diagnosed and treated?

The American public has to get off their butts. Like I have said a million times... "Where is your line in the sand?"

A handful people show up for Jones's hearing. How many kids has this guy helped? The general public is too lazy and selfish, they don't want to be bothered or inconvenienced.

What if someone is too sick?

Too sick? You can still make a couple calls. There was a lady doing her IV treatment at Jones's hearing! That's dedication.

So, do we need legislation, to ban together more, or what? What do you think we need to do?

Treating Lyme Disease With Homeopathic Medicine

by Maggie Sabota

Over the years my mother has been prescribed countless different medicines to treat her Lyme disease. Unfortunately none of these treatments have been successful because she has an antibiotic resistant strain of the disease. Recently, she has begun treatment with homeopathic medicine and herbs. She has also been receiving acupuncture treatments to aid in pain relief. Under careful doctor's instructions she is now experiencing some relief from some of her most chronic symptoms.

Most recently, she has been having KMT microcurrent treatments in conjunction with her other herbal and homeopathic treatments. The KMT treatment, or Klinghardt Matrix Therapy Microcurrent, helps to eliminate unhealthy microbes from the body. The treatment painlessly delivers electrical currents to the body. It focuses on dilating the lymph and blood vessels, calming the sympathetic nervous system, and deterring the growth of toxins and microbes. This treatment helps to wake up the immune system and aids in detoxification from heavy metals. In my mother's case, she has high levels of mercury in her system which the doctor believes is contributing to the Lyme symptoms.

Different frequencies are used to treat various conditions; some are used to specifically treat Lyme disease. These microcurrent frequencies focus



in on the biofield of the patient in four different ways. Some frequencies are pulsed into the field, the cells maintain this frequency, and it is impossible for bugs to live. Other Frequencies help to make the Lyme bacteria more receptive to medication. Still another activates the patient's immune system. Finally, there are frequencies to help remove broken down microbes from the system.

The benefits and changes seen from this treatment seem to long lasting. Initial treatments occur every four to seven days. The number of treatments depends on the type of problem and will be determined by the doctor. Many people experience permanent changes from this treatment.

As more and more stains of Lyme disease are becoming resistant to antibiotics, this treatment offers hope to people who did not experience relief from traditional treatment. The most important lesson that we have learned from the homeopathic treatment route, is to have an open mind. These treatments are very different from the traditional route. I am so grateful that my mother has been experiencing some pain relief from this treatment.

* Information was obtained from www.comprehensive-naturopathy.com *pha*

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Dr. Schaller is the author of 23 books, some of which relate to tick, flea, and other infections that cause chronic illness and fatigue. Dr. Schaller is the author of *The Diagnosis and Treatment of Babesia*, *Mold Illness and Mold Remediation Made Simple*, *The Complete Guide to Artemisinin*, *When Traditional Medicine Fails*, *100 Solutions to Out of Control Youth*, and *Suboxone: Pain Treatment with Addiction Relief*. He is currently preparing the most up-to-date textbook on Bartonella. Schaller thinks it may be among the top vector infections in the world, and may be more common than Lyme.

Dr. Schaller has approximately 20 national and international medical publications in such journals as *JAMA*, *Medscape*, and some of the largest pediatric journals in the world. He was the first to publish a practical cancer cure which blocks a single enzyme for a deadly blood disease, Idiopathic Hypercosinophilia Syndrome (HES). It is a standard treatment internationally. Further, he has designed nutritional products, and published nutrient and herb purity and potency research. Dr. Schaller strongly advocates getting to the root cause of illnesses and tailoring treatments to the individual. His primary web site is www.PersonalConsult.com.

As a full-time researcher, Dr. Schaller is uniquely able to study and invent individualized cures to heal his patients. Dr. Schaller has invested countless hours creating treatments to give hope to the hopeless.

Dr. Schaller lives with his family in Florida.

PJ Langhoff is a prolific writer, science editor, and medical researcher. She is the author of many tick-borne illness books and articles, and has experienced tick infections first hand. She operates a support group for Lyme patients at www.sewill.org.

Randall S. Blackwell is a medical research librarian in southeastern Pennsylvania.



Milestone: 3 Million Visitors at Lyme Information Site

by *LymeBlog News*

The end of 2007 brought the 3 millionth visitor who sought information about Lyme disease on the LymeBlog website (www.lymeblog.com).

The increasingly popular site-among Lyme disease patients, the public, and news feeds features the latest articles about the illness, commentary, and personal stories.

The emphasis is on patient experience, and so personal journals (blogs) by Lyme disease sufferers are a major feature. Currently, membership is around 4,000. Access to news, editorials and many areas of the site do not require membership.

Mac McDonald, a former computer consultant who became disabled by Lyme disease, created LymeBlog in December 2003.

“Letter” ... cont'd from pg 10

on her neurologic symptoms. During the time of observation, this patient died. At autopsy...[using] Dieterle silver stain, a spirochete was present in the cortex and another was exterior to a leptomeningeal vessel."

Is this the "Post Lyme Syndrome" that the IDSA guidelines refer to?

From Raymond J. Dattwyler, another author of the 2000 and 2006 IDSA Treatment Guidelines:

[Dattwyler, R.J., et al., 1988, Seronegative Lyme disease. Dissociation of specific T-and B-lymphocyte responses to *Borrelia burgdorferi*. New England Journal of Medicine, 1988, 319(22):1441-6.]

[From the abstract:] "We studied 17 patients who had presented with acute Lyme disease and received prompt treatment with oral antibiotics, but in whom chronic Lyme disease subsequently developed."

"...chronic Lyme disease subsequently developed." Is this the Post Lyme Syndrome referred to by the IDSA guidelines?

This scientific published research by Drs. Steere and Dattwyler, members of the esteemed IDSA panel, for some odd reason does not meet the IDSA's "rigorous scientific standards" and does not support the IDSA hypothesis that chronic Lyme disease does not exist. The IDSA guideline authors demonstrated that chronic Lyme disease is caused from persistent bacterial infection. So, the IDSA guideline panel ignored published research from its own members in the formulation of their 2000 and 2006 guidelines for the treatment of Lyme disease.

If the IDSA chooses to ignore research and publish treatment guidelines by falsifying their panel's own research, that is their choice, unfortunate as that may be taking into consideration the damage the guidelines inflict upon patients who become victims of such misguided medical advice. In my opinion, the IDSA and its guideline authors are exposing themselves to legal liability for medical malpractice by ignor-

While desperately ill with the infection, he sought deeper understanding from friends and family but eventually turned to the Internet for the empathy of fellow patients.

Although moderated bulletin boards provided help, he felt a site devoted to personal journals and news could offer greater insight and camaraderie. He created LymeBlog to fill that need, and soon others began flocking there to find the personal help they craved.

Lyme disease is among the most rapidly growing epidemics in the United States today with about 200,000 new cases each year. Cure is possi-

ble with early and adequate treatment. Chronic suffering and disability can result if diagnosis is delayed or treatment is inadequate, withheld or prematurely withdrawn.

Patients suffering from chronic Lyme disease have increasingly turned to the Internet for help and hope and to find others who can understand their experiences.

LymeBlog reaches out to spread the word about the Lyme patient experience.

We want to make sure that others, our children and grandchildren, will not have to endure the experience of misdiagnosis and improper treatment.

---Mac MacDonald

We want to make sure that others, our children and grandchildren, will not have to endure the experience of misdiagnosis and improper treatment.

---Mac MacDonald



LymeBlog has been a significant source of info and support for parents who seek out help and experience from other people who have had to navigate through the "Lyme Wars" to get proper treatment for Lyme.

Often people are too ill to have a lot of in-person meetings so the help of an online blogging community has been invaluable!

ing research performed by its own guideline authors. Now that the IDSA and guideline authors are embroiled in a legal civil investigation by Connecticut Attorney General Richard Blumenthal, their aggressive position against state legislation that provides for individual healthcare choices, although not a new position for them, becomes a brazenly bold move. Letters such as Dr. Masur's should cause serious reflection and inquiry into the possible motives behind such a business policy.

Rebuttal to specific points in Dr. Masur's letter:

* There is no widespread consensus within the medical and scientific community about appropriate treatment for Lyme disease. There is only one treatment guideline being forced upon physicians. This so-called consensus is not based upon all the research and guidelines that are available. If the CDC provides only one published guideline on their website, namely the IDSA guideline currently under investigation for possible antitrust violations, when there is actually another published treatment guideline from the International Lyme and Associated Diseases Society (ILADS) that should also be made available to physicians and patients, this constitutes a failure to provide informed consent by the CDC. There cannot be a consensus when all the options are not placed on the table for intelligent discussion and decision.

* Realistically, it is quite difficult to obtain a Lyme disease diagnosis from an infectious disease specialist specifically because they defer to the IDSA treatment guidelines. Therefore, Dr. Masur's assertion that IDSA members "care" for Lyme patients does not stand up to logic. If the IDSA guidelines state that chronic Lyme disease does not exist, contrary to their authors' own research, then their own 8,000 members will most likely NOT diagnose a case of chronic Lyme disease, resulting in patients going for years without

diagnosis and treatment, which is the crux of our problem.

* "Some patients may continue to experience these symptoms even after a course of antibiotic therapy has killed the Lyme disease bacterium." First of all, I challenge Dr. Masur to present to both of us the test that can be performed that proves that all Lyme bacteria are killed after one course of antibiotic therapy. There is no definitive test that proves such a claim. Repeated courses of antibiotics must be given based upon the patient's continued symptoms or relapses.

* One of the authors of the American Academy of Neurology (AAN) Lyme treatment guidelines is an author of the IDSA guidelines, also, John J. Halperin, M.D. I assert that the IDSA has attempted to bolster their biased position by enlisting the assistance of the AAN in publishing treatment guidelines that copycat those of the IDSA. The AAN Press Release dated May 23, 2007, a copy of which is enclosed, states:

"Patients who have received acceptable antibiotic regimens for Lyme disease sometimes have persisting symptoms, often referred to as Post-Lyme syndrome (PLS). This guideline states that long-term use of antibiotics does not improve the outcome in people with chronic symptoms after customary treatment of Lyme disease. Specifically, further treatment does not improve overall health quality of life, memory, or depression."

I must emphatically testify that long-term antibiotics have enabled me to not only walk again and function at 50% of my ability prior to contracting Lyme disease, which is an obvious improvement in the quality of my life, but have also improved my memory, other cognitive functions and depression. What causes me consternation now are these aggressive efforts by the IDSA and AAN to obliterate my experience with chronic Lyme disease and long-term antibiotic treatment, along with not some, but thousands of other patient experiences, as though we count for

absolutely nothing. The focus should be on listening to the patients, not pushing them aside and perpetuating their suffering. Patients are losing their health, their jobs, their homes, their marriages and their families.

I am the first to acknowledge that long-term antibiotics do not always cure a long-standing Lyme infection. I am not yet cured myself and truly doubt if I ever will be cured at this late stage. However, long-term antibiotics should not be withheld from patients due to uncertain outcome. This therapy can be managed by physicians and could be managed even better if patients were not forced to administer and watch over their ports themselves, because insurance denies home health coverage based upon IDSA diagnostic and treatment guidelines.

It would be considered barbaric to deny cancer patients additional treatment when they relapse, even treatment that is deadly in and of itself. It is ironic that we now have interventions that force children to undergo dreadful and ravaging chemotherapy treatments, yet the IDSA is battling Lyme patients in receiving long-term antibiotic therapy. We are quite able to assess and accept the risks ourselves without this pseudo-paternal intervention from Dr. Masur/IDSA.

Research is not being performed to find better treatment options. This is extremely unfair to patients. Of course, there are risks associated with all treatments. There are risks associated with all surgeries. However, patients should have the choice of accepting risks through informed consent with their treating physicians. I ask you to seriously question why the IDSA is on such a fervent mission to prevent patients from obtaining medicine that truly does improve their quality of life. What is driving Dr. Masur to fight such an inhumane battle against those whom his members serve? Could it be the close financial associations shared by the IDSA guideline authors in the form of patents for Lyme disease test

kits, vaccine development and research grants for studies that further their personal gain and do nothing to improve the situation for patients?

These are valid questions that hopefully will be answered through Mr. Blumenthal's investigation. I am hoping that this investigation will open the door to legal remedies for the many patients who have been harmed by the IDSA guidelines and a few of the guideline authors for many years now. Lives are being ruined and lost due to deliberate neglect in providing informed consent. Dr. Masur would have you believe that Lyme disease patients must be sacrificed on the altar for the good of all in protecting fallout from drug-resistance. Dr. Masur conveniently omitted any attacks against long-term antibiotics commonly used to treat tuberculosis and even acne. Lyme patients are requesting the same treatment afforded those with other infections requiring long-term antibiotic treatment. For instance, I have heard reports of acne patients receiving months of oral antibiotic prescriptions for Doxycycline, a common antibiotic used to treat Lyme infections.

I appreciate your consideration of the position I have outlined on behalf of Lyme disease patients. I am requesting equitable healthcare options as afforded to other patient groups through enacted legislation that allows patients and their treating physicians to pursue all treatment options available. I am also requesting that the IDSA cease from further efforts at sabotaging legislation that will allow Lyme disease patients to make personal healthcare choices. If further information is needed, I would be more than willing to provide it to you.

Sincerely,

Tina J. Garcia
President L.E.A.P. Arizona

“UnBreak”... cont'd from pg 6

would've taken a lot longer if I hadn't been trained as a journalist many years ago. Reporting this wonderful health news was kind of like riding a bike, once I got back on it, I made pretty good time.

What one thing stands out to you after your research?

The thing that stands out is that there is so much hope out there to end pain and suffering today. We're at the threshold of a new era of medicine but the gatekeepers of vested interests are holding us back. If the first generation of medicine was Physical, the body of bones and muscles, and the second generation was Chemical, the pills and potions so popular now, then the third generation coming up is Energy. This is the world of Star Trek medicine where healing takes place with incredible speed and efficiency.

Are these therapies all one needs to get and stay well?

I suppose it all depends on the "one". Each of us is a unique human being, a whole entity of not only body but mind and spirit or living energy as well. That means even though we may have the same symptoms and label on our health problems we actually have a unique situation, which will require a one-of-a-kind solution. I like to think of it as a combination lock and we all have our own special combination to unlock our body's healing ability. That means each one of us has to take responsibility for our own health, and

that's a tough message for many people. I certainly hope these therapies are beneficial. For some the right combination may be here but my guess is that for some people there are discoveries left to be made.

Can we look up a disease and find the cure in your book?

Nope. I didn't include any diseases or conditions in the Index on purpose, against the very strong urging of my publisher. It was my way of getting the reader to make a commitment to their own health by actually reading the whole book. It was a method of getting readers to accept responsibility for their own lives rather than simply looking for the fast, easy fix.

This is almost like an "encyclopedia." Do readers find it too complicated to navigate?

I hope not! I've tried to make it as easy to understand as possible. The only complaint I've had so far is that reading the book is like eating popcorn, it's hard to stop. Readers are tempted to say "just one more, just one more" and suddenly they've been reading it for much longer than they expected.

Isn't it easier to go to a physician and get a prescription?

Absolutely, especially when we're all bombarded every day with ads for prescription drugs on TV. Did you know America is one of only two countries in the world that allows direct-to-consumer drug advertising? America has less

than 5% of the world's population but we consume about 48% of the world's prescription drugs.

If we were the healthiest people in the world then I'd say it was wonderful but the fact is we rank #40 in longevity, even worse in other categories. For example we're #41 in Motherhood Mortality. There is one death for every 4,800 pregnancies in our country but only one for every 47,600 in Ireland, so it's clear our current medical system based on prescription drugs isn't working.

Do most doctors know about these therapies? If so, why are they not suggesting these even along with the prescriptions? If not, why not?

Great questions and I wish I had great answers to the problem. Did you know it was only 20 years ago that the federal courts had to get involved to protect chiropractors from the attacks of the American Medical Association? Change happens very slowly with mainstream medicine. Remember how it took them 10 years to accept the discovery from Australia that ulcers were caused by bacteria?

Most doctors don't know about the world of complementary and alternative medicine because they aren't taught about it in medical school. They're taught about drugs so that's the type of medicine they practice. No one is knocking on their door every week to promote it, just drug salesmen pushing their newest product.

What's scary is how the

attack on CAM (complimentary and alternative medicine) continues to this day. In fact, in many ways it's escalating. People need to become aware that they're losing the freedom to even choose their own health care, they need to join the National Health Freedom Coalition and their local state chapters to protect their rights.

The good news is they'll change when they lose patients. With the growing popularity of complementary and alternative medicine (CAM) there are doctors beginning to add CAM to their treatment options because it's what their patients want.

What is the take-home message for your readers?

There is always hope. Just because the doctor says there isn't anything more that he can do, it doesn't mean there isn't anything more that can be done! Each of us has our own healing journey to make, and it's challenging to find the right path, but it is worth it.

"CAM is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. Conventional medicine is medicine as practiced by holders of M.D. (medical doctor) or D.O. (doctor of osteopathy) degrees and by their allied health professionals, such as physical therapists, psychologists, and registered nurses. Some health care providers practice both CAM and conventional medicine. While some scientific evidence exists regarding some CAM therapies, for most there are key questions

that are yet to be answered through well-designed scientific studies--questions such as whether these therapies are safe and whether they work for the diseases or medical conditions for which they are used.

The list of what is considered to be CAM changes continually, as those therapies that are proven to be safe and effective become adopted into conventional health care and as new approaches to health care emerge."

Complementary medicine is used together with conventional medicine. An example of a complementary therapy is using aromatherapy. A therapy in which the scent of essential oils from flowers, herbs, and trees is inhaled to promote health and well-being to help lessen a patient's discomfort following surgery.

"Alternative medicine is used in place of conventional medicine. An example of an alternative therapy is using a special diet to treat cancer instead of undergoing surgery, radiation, or chemotherapy that has been recommended by a conventional doctor." -- nccam.nih.gov

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“Thyroid”... cont'd from pg 13

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Obituaries

Joan Friedenberg

Joan Maura Friedenberg of Bethesda, who owned a new media consulting firm, died Nov. 29 She had Lyme disease for quite a while which seemed to be under control. Joan died suddenly after unexpected complications. She was 53.

Born in Richmond, Friedenberg earned a bachelor's degree in communications from Ohio University in Athens, Ohio, and a master's degree, also in communications, from Boston University.

She worked for a number of media organizations including McNeil/Lehrer Productions, ABC News and National Public Radio.

In 1995, she became the founding editor of the Online NewsHour, the Web site for The NewsHour with Jim Lehrer. In 2003, she started her own new media consulting firm, Joan M. Friedenberg LLC, in Bethesda.

Friedenberg was a member of Congregation B'nai Israel in Rockville and the Ashburton Elementary School Parent-Teacher Association.

She is survived by her husband, Jonathan Salant; her son, Isaac Salant; and her mother, Lorraine Friedenberg of Rockville.

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Joseph Burrascano, M.D.

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I prescribe this to my patients because it provides a noticeable improvement in their energy levels. By promoting healthy mitochondrial membrane repair (and not through the use of any stimulants), most of my patients report that they feel better.

I discovered this product at a medical conference, and was intrigued by the research. One of the published studies reported that patients experienced a 40% decrease in fatigue(1) in eight weeks. The product is formulated to deliver a stabilized unique phospholipid matrix (this is what composes the mitochondrial membranes), wrapped in pre and probiotics as well as Mitochondrial Pro Regulator™ to optimize mitochondrial function, Krebs Cycle Glucose Absorb™ to propel the burning of glucose, creating energy and removal of excess ammonia which can cause fatigue, and RN Fatty Acid Metabolizer™ to maximize ATP production by regulating fatty acid buildup which, if left unchecked reduces mitochondrial function and increases cellular toxins. Normally, cells produce and repair their own mitochondrial membranes. However, these membranes may become compromised during long-term illness or interestingly, intense physical exercise by healthy individuals. This product helps the body help itself. By improving cell membrane potential, nutrients are better able to enter the cells for greater ATP fuel production, toxin removal is improved and oxidative stress is reduced.

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I actually tested the blood level of a patient on this product versus another well-known CoQ10. The patient using CoQ10 Power™ had three times the CoQ10 in the blood than the other product. The product is produced in the preferred soft-gel form, allowing the oil base to optimize absorption. As I have come to expect from Researched Nutritionals®, the raw material is of the highest quality and is imported from Japan.

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Best Regards,
Dr. B.



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