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CT Attorney General to Investigate IDSA Guidelines on Lyme Disease

Process Gives Hope to Thousands of Lyme Disease Patients

HARTFORD, Conn.--

The national non-profit Lyme Disease Association (LDA), representing more Lyme disease patients than any organization in the United States, applauds Connecticut State Attorney General Richard Blumenthal for beginning an investigation into the Infectious Diseases Society of America (IDSA) Lyme disease guidelines development process. In an unprecedented move, the Attorney General's office filed a Civil Investigative Demand (CID) to look into possible anti-trust violations by the IDSA in connection with exclusionary conduct and monopolization in the development of the Lyme guidelines.

Although unprecedented, the LDA feels this action is vitally necessary to protect the welfare of chronic Lyme patients nationwide whose treatments have been impacted by the stance taken by the IDSA. Their guidelines deny the existence of chronic infectious Lyme disease and list as "not recommended" most of the conventional medical treatments prescribed by physicians as well as alternative treatments often chosen by patients for any Lyme manifes-



Connecticut's Attorney General Richard Blumenthal decides to investigate IDSA's guidelines for diagnosing and treating Lyme Disease.

tation. Even some nutritional supplements should not be an option according to IDSA.

Clinical guidelines now

drive the standard of care, and these IDSA guidelines have already been published on the

"Investigate"...cont'd pg 4"

Get Informed. Get Diagnosed. Get Help.

Hope for Chronic Fatigue Sufferers as CDC Recognizes it's a Disease

The Centers for Disease Control and Prevention (CDC) recently launched a national public education and awareness campaign on Chronic Fatigue Syndrome (CFS), a weakening and often devastating illness for millions of Americans. The campaign, called "Get Informed. Get Diagnosed. Get Help", is designed to increase awareness among clinicians and the public, because 80 percent of Americans afflicted with CFS illness may not know they have it.

"CFS is a terrible illness that prevents many people from taking part in everyday activities and participating in the things they enjoy," said CDC Director Dr. Julie Gerberding. "Fortunately, there are therapies for CFS that can reduce

much of the pain and suffering. For those to be helpful, we need to make sure people with this illness know they have it, and that's why this campaign is so important."

The campaign will provide the latest information regarding the diagnosis and treatment of CFS, and will feature a traveling photo exhibit by renowned photographer George Lange called "The Faces of Chronic Fatigue Syndrome." It also includes national print and broadcast advertising designed to raise awareness of the disease among patients and clinicians. A new website, www.cdc.gov/cfs, provides easy-to-understand, downloadable educational tools for patients, their families and health care professionals.

"This is an exciting day for Americans suffering from CFS and for the people who love and care for them," said Kimberly McCleary, President and CEO of the Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) Association of America. "This campaign will provide solid, scientifically based information for both patients and health care professionals on diagnosing and treating CFS."

CFS is characterized by incapacitating fatigue (experienced as profound exhaustion and extremely poor stamina), sleep difficulties, and problems with concentration and short-term memory. It is also accompanied by flu-like

"Chronic Fatigue"...cont'd pg 12

EDITORIALS & OPINIONS

Letters to the Editor

Dear Dawn:

My name is Roy Goodloe and I am with a microscope sales company in Texas. I am not a victim of Lyme Disease, but am concerned about its spread. In my investigation of this topic on various websites, I am not seeing anyone specifically address transfusions as a transmission vector of this disease.

I was demonstrating a darkfield microscope (provides high contrast cell images) to a local company treating people hyperbarically for Lyme disease. They had three patients in-house, and I was able to observe live blood samples that showed vividly the spirochetes inside of their blood cells moving rather actively.

One patient indicated that she had been incorrectly diagnosed with Fibromyalgia four years ago, but her joint pains only became worse. Only within the past year or so did her physician do further tests and determined she really had Lyme disease.

My thought was regarding blood donations. I approached people at Carter Blood Center and the American Red Cross, and asked if they would deny a donation from someone with Fibromyalgia. I was told it would be allowed. So, had this patient donated blood, her Lyme infection would be passed on to some unknowing patient(s).

I have since posted questions on LymeNet.com regarding Lyme Disease from transfusions and have received private responses from a number of people who admitted they had donated blood numerous times prior to learning they had the disease. Here is a response from one patient:

...Lyme disease and other tickborne illnesses are the elephants in the room for the blood bank. It does not seem to be being addressed.

Knowing what I know now, I have been symptomatic with Lyme disease since age 16. I am now 46. I have not always been as sick as I am now, but even during the 10 years when I was actively pursuing a diagnosis, I was told I was fine, and continued to donate blood.

I even donated platelets several times at the Dana Farber Cancer Institute in Boston in 1997 or 1998 so that I could get on the bone marrow donor registry, because my Harvard-staff doctor told me it was my lifestyle that was making me tired all the time. I wonder how many leukemia

patients got Lyme disease from me?

I do not plan to donate anything ever again, even if I become asymptomatic, because absence of symptoms does not mean absence of illness with Lyme disease.

I don't know, but my guess is that the problem is that there are no reliable and affordable tests available to use for screening. I will be very interested to learn what you find out. My concern is that you will be stonewalled because no one in a position to act on this will want to hear what you have to say.

I hope you will try, anyway

None of the blood centers I have talked to do any microscope inspection of the existing blood supply or of incoming donations. The initial reaction will be that it would be too expensive to purchase the microscopes and hire extra technicians to do this survey. A random review of blood in just a few centers would give an indication of the seriousness of this dilemma. The other choice is to ignore this component of the progression of Lyme disease throughout the country and let it spread unhindered through our population. A recent article in your publication noted that cases have been seen in all 50 states. Have the ticks really spread this far, or is it the national blood supply that is contaminated? I asked an instructor at a medical school, who teaches hematology, about testing for Lyme using microscopes. She was shocked at my findings, but came back with the response, "Oh no, not another blood test." But can we afford to allow it to spread?

How much of the blood in storage now is contaminated? I sent an e-mail to the CDC a few months ago and was told there has been no indication that Lyme disease is transmitted via blood transfusion. **Why is the CDC conducting research in Ft. Collins, Colorado on transmission of Lyme Disease via transfusion if there is no issue?** ("TRANSFER OF BORRELIA BURGDORFERI s.s. Infection via Blood Transfusion in a Murine Model" Gabitzsch ES, Piesna J, Dolan MC, Sykes CM, Zeider NS - CDC Div. of Vector-Borne Infectious Disease, Bacterial Zoonoses Branch, Foothills Campus, Ft. Collins, CO).

The notes I have read on various sites talking about moth-

ers, unaware they had Lyme disease, passing the disease to their children tells me that Mother's milk as well as blood and other bodily fluids are very possible transmission points for this disease.

Most of the grants and studies I have read about are looking for cures and trying to make people aware of the dangers from tick bites. People receiving Lyme from blood transfusion don't have a tick bite or rash as a warning.

I feel that one key component of defeating this disease is to prevent its transmission. It may not be a serious concern here in Texas, but in the Northeast, where the disease is concentrated, a random survey of the existing blood supply would no doubt reveal a shocking result. How many units of blood or platelets sitting in storage have spirochetes already? I have heard these spirochetes will exist in a blood sample for months, even under refrigeration.

I am reading the book Lab 257, so I am aware of what our own government has done to us, but it is not taking a strong position in fighting and preventing its spread. Now that Congress is through beating itself up, I would hope that there is some contact that has the influence to cause an investigation to be done. Do we have any contacts in Washington that are concerned enough about our public health to do something?

Regards, Roy Goodloe
Lewisville, Texas
Roy Goodloe1@Verizon.net

[Editor's Note: One important fact to remember when looking at the transmission of LD is that it is a spirochetal disease. Syphilis is also a spirochetal disease, which is a known sexually transmitted disease. Neurosyphilis has the same symptoms and manifestations as LD that has invaded the central nervous system (neuroborreliosis). LD spirochetes have been found in blood, semen, tears, saliva, and breast milk. LD is known to be transferred from mother to child in pregnancy. Infants born with congenital LD and later died were found to have siprochetes in their brain tissues.

Babesia is a LD co-infection and the CDC has a proven documented study titled, "Transfusion-Associated Babesiosis after Heart Transplant" located at <http://www.cdc.gov/ncidod/EID/vol9no1/02-0149.htm>. If the co-infection can be transmitted by transfusion it stands to reason the Lyme spirochete can as well.] *pha*

Public Health Alert

The PHA is committed to researching and investigating Lyme Disease and other chronic illnesses in the United States. We have joined our forces with local and nation wide support group leaders. These groups include the chronic illnesses of Multiple Sclerosis, Lou Gherig's Disease (ALS), Lupus, Chronic Fatigue, Fibromyalgia, Heart Disease, Cancer and various other illnesses of unknown origins.

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

PHA Staff

Editor: Dawn Irons
Assistant Editor: Brad Irons

Contributors:
Donna Reagan, Barbara Gerami, Ginger Savely, FNP, Marj Tietjen Scott Forsgren, Dr. J David Kocurek, Susan Williams, Laura Zeller, Sue Vogan, PJ Langhoff

Website:
www.publichealthalert.org
e-mail:
editor@publichealthalert.org

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Letters to the Editor

You may send letters to the editor:
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or by postal mail to:
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All letters to the editor must be signed, and include name, address, and phone number. Letters will be printed as space permits.

Letters to the Editor

Dear Dawn,

I found your excellent newsletter on the BetterHealthGuy.com website. I have been diagnosed Chronic Fatigue Syndrome / Myalgic Encephalomyelitis or CFS/ME (some refer to this disease as CFIDS or just CFS or the European ME, depending on the source). In January of 2005 I started getting devastating neurological problems (vision, balance, severe headaches, etc) heart problems and severe fibromyalgia (FMS), all of which hit me with great force and speed. The first doctor I saw insisted that I had "arthritis" and then tried to give antidepressants, but I was so severely ill I knew he was wrong. I went to a second doctor who diagnosed that I had CFS and FMS. I thought I would get over this quickly. I was wrong. I am still struggling in every way.

Just like Lyme disease, CFS/ME has devastating consequences on the life of the victim. Just like Lyme, the CDC government "health" agencies have covered-up, misrepresented, spent

enormous sums of research dollars on worthless psychological nonsense, all of which has been very effective in shaping negative public opinion regarding CFS as well as denying worthy research and denying that the disease existed so physicians had no base to even try to treat patients. The CDC has finally come out this year with lukewarm assertions that CFS is a "real" disease, but there are better and more extensive european gene studies, and the CDC has crafted their PR to the press for the public to perceive that CFS victims are just "people who can't handle stress." The CDC does not want the public to know the neurological manifestations of this disease. They just want them to think that the CFS victim is just tired and depressed because of "stress" and if they wanted to, they could get over it.

The toxic and crippling lab agents are out there and the public is at risk. If you went up to the average person that you meet on the street and told them they are at risk, they would probably laugh at

you. The National CFIDS Foundation is funding studies by Dr. Hokama who studied the sera of many CFS patients. He found that all patients had a neurotoxin similar in chemical structure to that of ciguatoxin, but not ciguatoxin. He analyzed the molecule bit by bit and parts of the structure were like ciguatoxin, and some parts of the structure were different in structure. The National CFIDS foundation president told me that is totally unlikely to happen in nature so why does this modified ciguatoxin-like molecule exist except that it was a lab hybrid. Q-fever, Lyme Disease, West Nile - why are all these diseases growing so fast and why are they happening now when 50 years ago they were unheard of? My question is why are so many people getting these neurotoxic diseases and why is the CDC still not telling the truth about his?

The really confusing part comes when so many of the symptoms of Multiple Sclerosis (MS), CFS/ME, FMS and Lyme Disease are so similar, many doctors may

diagnose a patient with one condition, when in fact they may have another. Scott Forsgren, who had your newsletter on his site, was originally diagnosed CFS, only to find out 40 doctors later that he has Lyme Disease.

I have forwarded your excellent newsletter to friends. I do hope that CFS, MS, FMS and Lyme group organizations learn more about each others concerns because the obstacles that we all face are similar.

Thank-you,
Margaret Simmons

[Editor's Note: Friend, I have walked in your shoes! The IDSA guidelines say "Chronic Lyme" does not exist and that people who have lingering symptoms after antibiotic therapy just have "post lyme syndrome and just need to learn how to cope with the aches and pains of daily living." How insulting!]

Your letter prompted me to write an article about the links between CFS & Lyme. Look for it in the the Features section of this issue!]

pha

Reagan's Ramblings Rants & Raves

The 3 Ring Circus: Welcome to the Big Top!

Part 2: Big Business. Meet the Snake Oil Salesmen

If memory serves me correctly - and by the way - it rarely does; but part of the history of the circus included those entrepreneurial spirits that would set up their traveling business outside of the Big Top in an attempt to mesmerize and trick unsuspecting circusgoers into parting with some of their money before they stepped foot into the circus tent. If memory serves me correctly, these entrepreneurs of old were called "snake oil salesmen", and while they may not be allowed to set up shop outside of the rare traveling circus of today - do not be mistaken - they are still very much with us.

When I think about the motivations behind the Infectious Disease Society of America (IDSA)'s new treatment guidelines for Lyme disease - I can sometimes hear the famous line from the hit movie, Jerry McGuire, reverberating through my head: "SHOW ME THE MONEY!" No, I'm not hallucinating or hearing voices - no need to send the men in white jackets; rather it's like a song you might get stuck in your head. Through all the rhetoric, all the medical jargon, and broo ha ha

- it seems this matter really all comes down to MONEY. BIG MONEY. After all, these guidelines are not really written for the benefit of the patient. The guidelines themselves are actually illogical on many levels. Feel free to read them if you dare (<http://www.journals.uchicago.edu/CID/journal/issues/v43n9/40897/40897.html>), but simply put - the entire assertion is the same that this institution and its key players have been alleging for years, and that is that Lyme disease is hard to catch, easy to treat, and anyone who continues to have symptoms is either experiencing normal "aches & pains" that come along with aging; perhaps they are just malingering hypochondriacs; or perhaps they've magically developed an auto-immune disorder now referred to as "post-Lyme syndrome".

That's pure stupidity. Or is it?

When it comes to situations in this world that I have a hard time comprehending emotionally, I am reminded of the tried but true adage: Follow the money.

Therefore, I have had to ask myself: "How are these new IDSA guidelines a financial 'coup' for the IDSA?" Naturally I won't admit to answering questions that I ask of myself because I don't want anyone to accuse me of being that one crazy person that talks to and answers herself...so let's just say in an effort to understand the incomprehensible nature of this travesty upon Lyme patients, I have had to make some speculations.

One is the fact that, by establishing themselves as THE authority on Lyme disease, the IDSA has established a situation whereby American health care providers will naturally follow their lead. After all, even the Centers for Disease Control (CDC) recommend their guidelines on the CDC's own website - so the guidelines are practically as American as apple pie & Chevrolet, right?

By establishing themselves as the authority, the IDSA make the effort to discredit the 'other' side, which is comprised of healthcare professionals devoted to specifically treating Lyme patients

on a daily basis. Those professionals to which I refer are members of the International Lyme & Associated Diseases Society (ILADS) and although they do not have the vast numbers of IDSA, they have truth and valor on their side.

Most Americans covered by health insurance must go to specific doctors from a list. It is that doctor's agreement with his/her insurance contractor(s) that stipulates an outrageous number of patients will be treated throughout any given day. It's almost like drive-through healthcare these days. Doctors do not typically have the time to spend with complicated patients and their multiple symptoms. If the physician does not dismiss the patient as having emotional/psychological problems as the basis for his/her complaints, then the patient may be referred to a specialist for whatever ails them. In the case of Lyme disease - the specialists to whom these patients are sent are...you guessed it...infectious disease doctors! After all, they are the authorities on the matter, aren't they?

"Big Top"...cont'd on pg 7

All Roads Lead to Rome?

Why do Commonly Misdiagnosed Illnesses Respond to Lyme Treatment?

by Dawn Irons



Recently the Centers for Disease Control and Prevention (CDC) have recognized Chronic Fatigue

Syndrome (CFS) as an actual disease, and not just a multitude of symptoms. This is a major breakthrough for those who have suffered from the disease for many years. More often than not, CFS patients have endured the scorn of both doctors and the general public. For ages, those who have battled CFS have been called lazy, hypochondriacs, and leeches to the social service system, for the help they needed and received, due to their illnesses.

It is estimated that more than 40 million Americans suffer from Chronic Fatigue Syndrome—now classified as an authentic disease. The CDC believes that only 20% of CFS sufferers actually get diagnosed. This is due, in part, to the lingering belief that CFS is a psychological illness and somehow imagined. CFS is characterized by incapacitating fatigue, sleep difficulties, problems with short term memory and concentration, and typically accompanied by flu-like symptoms.

In August 2006, Dr. Kenny De Meirleir, Professor of Physiology and Internal Medicine at Free University of Brussels in Belgium, released a new study on the advances of CFS testing and treatment. The study showed a wealth of confirmed biochemical abnormalities in CFS patients. Dr. De Meirleir's research showed that CFS patients can be differentiated from healthy people with 99% accuracy based on his test of low molecular weight (LMW) RNase L in the blood.

Dr. Jonathan Forester, of Pineville, Louisiana has been studying CFS in his medical practice for over 20 years. At one point in his medical practice he began noticing the striking parallels between his CFS patients and his Lyme Disease patients. He began testing his CFS patients for Lyme Disease and over 90% came back positive for Lyme. Of those 90%, when he began treating them for Lyme Disease, 80-90% were able to get into complete remission of the disease. Dr. Forester said, "Until proven otherwise, Chronic Fatigue Syndrome is Lyme Disease."

Lyme Disease has been given the nickname of "The Second Great Imitator". The original "Great Imitator" was syphilis, which is a spirochetal disease just as Lyme Disease is a spirochetal disease. Lyme Disease is notori-

ous for being difficult to diagnose and treat due to its similar symptoms to other diseases such as Multiple Sclerosis, ALS (Lou Gherig's Disease), Lupus, CFS, Fibromyalgia, Alzheimer's Disease, and Parkinson's Disease. Many a Lyme patient has received one or more of those diagnoses prior to getting their Lyme diagnosis.

In recent studies it has been shown that Multiple Sclerosis has been thought to be of a bacterial origin. When treated with long-term antibiotics, many of the MS patients had a significant return of bodily function. Many who had been in wheelchairs are now walking after treating with long-term antibiotics. New studies in Alzheimer's patients are showing the borrelia spirochete in both cpi-ral and cyst forms in almost 95% of the autopsied brain tissue samples. Similar results have been shown in studies involving ALS and Parkinson's Disease.

I just find it curious that all these diseases that Lyme sufferers were misdiagnosed with having, prior to getting their Lyme diagnosis and treatment, are now actually responding to the Lyme treatments of long-term antibiotics with great results and return of bodily functions!

Could it be that there may be one common denominator? Could the borrelia spirochete pos-

sibly be behind all of these? I suppose only time and more research will tell. At least for now, we know through research that ALL of these diseases are responding to one common treatment...the long-term antibiotic treatment used for Lyme Disease. Shakespeare wrote in Romeo and Juliet, "What's in a name, that which we call a rose, by any other name would smell as sweet...". Shakespeare makes a good point! Call it what you want...ALS, MS, Parkinson's, Lupus...but if it responds to Lyme treatment...give me the antibiotics and call it what you want! I prefer to keep my ability to walk and form clear thoughts. Let the scientists argue over what to name it...just give me the treatment that works!

After all, it should be an issue of informed consent, right? In a perfect world, patients would be made aware of these new research findings and given the chance to make the choice of available treatment options...but alas, we live in a day where every research foundation wants to collect dollars for their particular designer name disease, while the patients are left of suffer. Let the researchers call a rose "a daffodil" if they like, just give us the water for the roots! *pha*

Investigate...cont'd from pg 1

CDC website. They are being used to deny treatment reimbursement and will have a continued chilling effect on the small numbers of treating physicians, since clinical discretion is not recommended in the guidelines.

The October 2006 guidelines do not acknowledge that a complex bacterium such as the Lyme disease spirochete could possibly survive in the body and the brain, evading the immune system and short-term courses of antibiotics, nor do they take into

consideration any other professional diagnostic or treatment guidelines such as those published by the International Lyme and Associated Diseases Society (ILADS), which discuss chronic disease diagnostic and treatment modalities. The IDSA also refused to allow patient or chronic disease-treating physician input into the guidelines process through the LDA and ILADS, respectively, although both organizations requested to be a part of the process.

The national LDA and its affiliates Time for Lyme (CT) and the California Lyme Disease Association and ILADS, a professional medical organization, had appealed to the Attorney General on behalf of patients and treating physicians. We are encouraged by the issuance of the CID, and we hope that this will lead to actions that will guarantee patients the right to be treated and support physicians' right to treat using clinical discretion. *pha*

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Rarely Such a Thing as a "Textbook" Case

by *Ginger Savely, FNP-C*

Sandra looked thin, pale, and hunched over in obvious pain when I first met her in my office in June of 2004. The 37-year-old was at the end of her rope. She had been to several doctors, a gastroenterologist among them, and had submitted herself to numerous tests to find out what was causing her extreme abdominal distress. For two months she had been unable to eat solids and had survived on a liquid diet. The moment that food of any kind entered her stomach, she suffered excruciating stomach pains and nausea. She had lost her appetite and had actually become fearful of eating. At 5'3", she weighed in at 109 pounds and reported having lost 30 pounds over the previous two months. She had gone on temporary disability leave from her job as a hospital respiratory therapist. Sandra and her family were understandably very worried.

Gastrointestinal scopes and imaging studies, stool cultures, and extensive blood work including work-up for *H. pylori* (the causative agent of stomach ulcers) had revealed nothing. The gastroenterologist, having explored all of the standard possibilities, had suggested that her symptoms might have a psychosomatic origin and suggested psychotherapy as a way to get to the bottom of the problem. Sandra intuitively felt that this was not right and that something else was going on. She had a happy life with a good marriage and job that she loved. Besides, she had started to notice other new symptoms including fatigue, joint pain, muscle aches, and weakness. Her gastroenterologist had assumed these symptoms to be either related to the same presumed psychosomatic process or to poor nutritional status after two months of solid food avoidance.

Sandra came to me desperate for help. There was nothing unusual about her exam except for her obvious distress. I asked about her family's health. Although there wasn't anything out of the ordinary, something very interesting came up. Her sister had been diagnosed with Lyme disease the year before.

Sandra explained that she and her sister had lived in a rural setting six years before and had sustained many tick bites. In fact, as it turns out, Sandra had suffered

a prolonged febrile illness in 1998 which resolved spontaneously and had always remained a mystery.

I had read several articles about gastrointestinal manifestations of disseminated Lyme disease. What if this was at the root of her problem? Sandra certainly had the exposure potential and had other signs of the illness including fatigue and joint pain. The fact that she did not recall an erythema migrans, the classic "bull's eye" rash which is diagnostic of Lyme, did not concern me since only about half of Lyme patients have this.

It certainly didn't hurt to look. I ordered Lyme Western Blots and other tick-borne infection tests through IGenex Labs in Palo Alto, California. Sure enough, she was positive on both the Lyme IgG and IgM. Her other tick-borne disease tests - Ehrlichia, Bartonella, Babesia and Anaplasma - were negative. I started treatment with both intramuscular and oral antibiotics. I also encouraged her to take numerous nutritional supplements including probiotics to replenish the natural gut flora, and milk thistle and alpha lipoic acid to protect the liver from damage due to processing of the antibiotics.

The transformation was almost miraculous. Even one week after initiation of treatment, Sandra reported significant reduction of her symptoms. Per the ILADS (International Lyme and Associated Diseases Society) published treatment guidelines, I continued treatment, changing the antibiotic protocol every few months, until complete resolution of symptoms, which turned out to be 7 months. Sandra went back to work, took a trip to Italy a month later, and went happily on with her life.

Sometimes clinicians need to look beyond the obvious when the cause of a patient's distress seems elusive. Sir William Osler, the most famous physician, teacher and philanthropist of the 19th century, couldn't stress enough the importance of a thorough history in diagnosing a patient.

Apparently, the other important requirement is an open mind and a willingness to realize the myriad of atypical presentations that can be seen for various illnesses. After all, in the real world there's rarely such a thing as a "textbook case".

pha

When It Comes to Treating and Diagnosing Lyme Disease There are Certain Things You Should Know:

1. The correct diagnosis of this infection can be challenging in many patients.
2. Chronic antibiotic therapy alone is not the answer.
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Health Is Not Beyond Your Reach

An Interview with Oleg Reznik, M.D.

By *Sue Vogan*

When Dr. Oleg Reznik thought about practicing medicine, he envisioned Robert Young during the 1969-1976 ABC television show, "Marcus Welby, M.D." This fictional physician consistently dealt with long-term medical maladies tied directly to the patient's psyche and interpersonal behavior. Welby spent time with his patients and displayed a faithful bedside manner. The show was well received by patients because this is exactly what they wanted from their own doctors. However, the show didn't make the same impact on many attending physicians. Seems that they were finding it difficult to meet the Welby role model. Was the television show better for patients or was it behind more malpractice lawsuits? From Museum of Broadcast Communications, Joseph Turow writes, "According to an article in *McCall's* magazine, a doctor said to Young at a convention of family physicians, "You're getting us all

into hot water. Our patients tell us we're not as nice to them as Doctor Welby is to his patients." Young didn't mince words. "Maybe you're not," he replied."

The Marcus Welby, M.D. show has long been over and only a handful of physicians around the globe have a practice anything near Dr. Welby's. Why wouldn't the physicians want to give their patients the television-doctor treatment? As patients, would we not stand a better chance of feeling better or being cured? Would it hurt physicians too much if they spent time with us in the medical setting as the individuals we are and offer us healthcare that addresses our individualities?

Dr. Reznik explains, "It certainly does, if we think of the usual physician who is trying to fulfill all of the measurable requirements of the guidelines (getting the right tests done, blood sugar, cholesterol, monitoring for drug side-effects), while trying to make his ends meet. A doctor who

"Health"...cont'd on pg 10

Look Out Below: Ticks take on Xtreme Sports

by PJ Langhoff

What lurks beneath the camouflage of an outdoor leaf pile might surprise you. You've been there-camping, hiking, horseback riding, paint balling, whatever your outdoor preference. As you tediously scrape off the biodegrading gelatinous goo stuck to your gear, your boots and every article of clothing, you wonder what else you may have missed. A good hot shower after playing adventurer-in-the-woods is the best you can do for yourself, right? There is another key piece of equipment that should be standard gear for any outdoor adventure, and that is your eyes and the eyes of your fellow companions.

From May through October, in all fifty states (and other parts of the world), tiny voracious eight-legged critters are crawling, nearly undetected, right under your feet. And like tiny dive-bombers, they occasionally drop out of treetops onto your head and shoulders, looking for a quick blood meal like you. Their sci-fi sounding name is Ixodes, (Ick-zoe-deez), but you probably know them as the common tick. Wood tick, deer tick, lone-star tick, dog-tick, whatever the name, they are ugly, stealthy, and definitely packing.

What you don't know about them can ruin your life. Lyme-infecting tick bites happen to an estimated 200,000 people every single year. Most bites go undetected because these little buggers, in their nymph (larval) state, are no larger than the dot at the end of this sentence. Pretty scary, right-but they don't have to be.

Since the bite is painless, you may not know you have been bitten. Ticks often attach in obscure places like the nape of the neck, behind the ears, on the scalp, or under your arms. Children are more susceptible to tick bites and so are ground-hugging outdoor adventurers, because they are closer to the ground where the creepy crawlers live. Pets can also bring these arachnids (members of the spider family) into your home.

But the good news is that, as the season progresses, ticks grow larger and more easily seen. If you do find a tick attached to yourself, it can easily be removed by grasping the bug by its head, as close to your skin's surface as possible with a tweezers, and gently but firmly pulling the bug

out of your skin. Save the insect in a freezer bag so that it can be tested for Lyme disease and other nasty infections ticks usually harbor.

People think smothering ticks or burning them with a match are good removal methods, but in reality, that is not only harmful to the tick, but to you. Ticks tend to burp up their disease-carrying stomach contents when disturbed in this manner, so pulling them out with a tweezers by their head is the safest way to remove them and prevent them from transferring infection.

Statistics show it takes less than 24 hours for ticks to transmit Lyme disease. Assume that if a tick is attached, you could be exposed to Lyme and other co-infections. Contact your doctor as soon as you are bitten. This is important because early treatment prevents Lyme from invading your body, and the bug that causes Lyme can be coughed into your blood as soon as the tick begins feeding-yum.

The spirochete that transmits Lyme, *Borrelia burgdorferi* (Bb), lives in the saliva and stomach of the tick. Bb has an affinity for your brain and central nervous system and will make a beeline for them as soon as they enter your blood stream, often within hours or days. Once there, they are difficult to eradicate. These crafty little bugs have many forms and change their "camo" as often as you can reload a paint gun (or even your shoes), so its best to hit them when they are easily treatable: as soon as they are present. This is also your best opportunity to defeat these stealthy foes.

The most common symptoms occurring with Lyme disease are headaches, flu-like symptoms, nausea and stomach problems. Besides Lyme, ticks often carry other infectious diseases, called co-infections, and not all ticks carry Lyme. In Lyme infection, only about one-third of the time, a rash on or near the bite site occurs. Often rashes are ring or bulls-eye shaped, with a clearing around the middle or central part. Other types of rashes may appear, but often do not. Joint aches and pains, problems with extreme fatigue and memory also occur at the onset, as can flu symptoms, hallucinations and high fevers.

Symptoms can present hours, days or weeks after a tick bite, so be on the lookout for any physical symptoms, especially a sudden summer "flu". Lyme is

called "the great imitator" because its symptoms mirror many illnesses, like fibromyalgia, multiple sclerosis, ALS, Parkinson's disease, and others.

Sounds nasty, doesn't it? If Lyme disease is not diagnosed and treated quickly, it can lead to permanent disability, paralysis, stroke, cognitive problems, blindness, psychiatric illness, and even death. Lyme attacks every organ system in the body and is a multi-system infection. The co-infections that accompany the tick bite have additional symptoms of their own, but are also treatable with various antibiotics.

Finding a Lyme-literate physician (a doctor who knows how to diagnose and treat Lyme)

is critical at the onset of illness. Contact on-line Lyme support groups in your state to ask for a physician referral. You can request antibiotics from your doctor if you suspect Lyme disease, even if you show only one or two clinical symptoms, but may find it hard to obtain any as new "guidelines" published by the IDSA are attempting to make diagnosis and treatment of Lyme disease difficult, if not impossible for doctors who follow these "guidelines."

For victims of Lyme (those in the Lyme "community"), it is well known that Lyme disease is difficult to diagnose, treat, and eradicate. These new "guide
"Xtreme Sports"...cont'd pg 16

WHEN LYME PATIENTS HAVE CRUSHING FATIGUE, WHAT DO THEY DO?

"....In August 2005 I was diagnosed with Lyme disease. Vidacell managed the fatigue for me and I had my energy back to normal in record time until I ran out. I thought I was having a relapse...I was amazed once I started back on the Vidacell how my energy returned!"

Shari A. - Appleton, WI.

"...important part of my recovery from Lyme disease.....it has helped my organ systems get the energy they need to heal and has given me additional energy to function on a daily basis throughout my treatment..."

John S. - Milwaukee, WI.



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“Big Top”...cont’d from pg 3

Infectious disease doctors win the referral!

In addition to using their sheer number of 8,000 doctors strong, the IDSA also uses their 'behind closed doors' relationship with the CDC to lend credibility to their guidelines. (You can be sure the CDC has their own agenda for supporting these inappropriate guidelines, but that's another column for another time.) Besides, wouldn't the CDC NEED to have an undisclosed agenda to give not only a "thumbs up" to the IDSA guidelines, but to actually recommend them in order to totally disregard their own mission statement: "To promote health and quality of life by preventing and controlling disease, injury, and disability."

(<http://www.cdc.gov/about/mission.htm>)

On a more simplistic level, which is pretty much the level I live at, perpetual illness means perpetual business in the world of medicine. Perpetual illness = perpetual patients = perpetual monetary gain from those patients' illnesses. Remember, it just doesn't make good business sense to cure any disease. That, my friends, is precisely why we in America tend not to do it. We are all about creating the American dream...that is, at least for the healthy, and the rich.

Personally, I have taken antibiotics for close to 2 years and am just now feeling like I have turned the corner. At 14 days of antibiotics, I felt terrible. Why? It is because 14 days of antibiotics merely gets the spirochetes good and mad. Remember how the doctor and your pharmacist always remind you to take ALL of your antibiotic when you have strep throat or some other nasty bacterial infection? Why? Because if you don't kill ALL the bacteria off, the ones you're leaving behind are the stronger little buggers. The weakest are killed off first. If all the bacteria are not killed - then the most virulent are left behind...to reproduce and seek vengeance upon the immune system.

Taking 14 days of doxycycline, the IDSA's recommended medication and dosage, to "cure" a fully entrenched infection of *Borrelia burgdorferi* (Lyme disease) would have been like President Bush sending 10 troops to Iraq armed with only pea-shooters, yet expecting a quick "in and out" victory. And to demonstrate just how sane I am...I will now resist the urge to delve deeply into a discussion of politics.

However, how do you feel about religion? I sometimes wonder what kind of religion these individuals must practice in order to produce and recommend guidelines that will ultimately be a death or disability sentence for so many innocent lives - men, women, and even children. I wonder what they have to do in order to sleep peacefully at night. I don't believe my editor would allow me to refer to them as demon doctors or anything of that nature, so I shall once again, show restraint.

You'd assume whatever makes the health insurance industry sing and dance would naturally infuriate Big Pharma. However, the guidelines writers have discovered a way to have their funnel cake and eat it too.

With a documented disease, most insurance plans would require the insurer to pay for treatment to eradicate it. IDSA's new guidelines suggest a 2 week course of oral doxycycline - not an expensive solution (probably because its not really a solution...). Insurance firms, no doubt, rejoice at this. But what about Big Pharma? Where's their slice of this American monetary pie?

Let's consider for a moment that, when the infection is really NOT eradicated by the paltry amount of antibiotics, the symptoms will remain. Many symptoms are extremely painful; and when it comes to symptom relief - many will do whatever it takes to relieve those symptoms. For those of you who have ever suffered a great deal from painful or terrifying symptoms, you realize when people are suffering - they will pay. Because pain is a great motivator - patients may be willing to get a second mortgage; sell their home; even pawn their wedding rings - anything to afford the treatments that will remove or lessen the excruciating pain this disease can provide. And guess what? These guideline writers, the insurance industry, and big Pharma - they all know this.

As well as pacifying the insurance industry's need to keep their costs down, the IDSA guideline writers have often found themselves sitting on the side of the insurance company when it comes to litigation. Many guideline writers have been employed as 'expert witnesses' in cases against Lyme disease patients, and yes, even cases against Lyme-practitioners. One such example is Dr. Eugene Shapiro, who is up front in the trumped-up charges against Lyme specialist and pediatric champion, Dr. Charles Ray Jones.

Dr. Shapiro has made grievous allegations against Dr. Jones with regard to his work with children infected with Lyme disease, and at this writing, Dr. Jones is still fighting for his medical license. It is only fair to mention, though, that if Dr. Jones loses his license, Dr. Shapiro has so graciously offered to take on Dr Jones' 8,000+ patient load that he treats for Lyme Disease each year....again, follow the money! Taking on 8,000 more patients a year would surely increase his personal income as well.

I suspect this is not the first nor the last time that Dr. Shapiro will receive a healthy fee for his work as an "expert" - despite the fact that most in the Lyme disease community would seriously object to his being labeled as an expert, regardless of his Yale pedigree. No doubt Dr. Shapiro is not alone in building his retirement nest egg from the enormous coffers set aside by the health insurance industry to fight against claims they wish to deny. Who else in the list of the 14 guideline writers have sided with insurance - instead of the patient? Perhaps the better question would be - who hasn't? Let me know if you find one with clean hands.

Finally - it might be interesting to note many of those 14 guideline writers have been avid recipients of government grants for their continued research on Lyme disease. Hmmm. I find that quite interesting, don't you? Instead of treating patients, these "physicians" spend their time collecting research grant money; doing it year after year after year often "studying" the same aspect of this 'easy to cure' disease.

In the box above is a list of writers of the IDSA's Lyme treatment guidelines, along with the approximate number of grants obtained to date. This info is courtesy of the CRISP database, located for your perusal at: <http://crisp.cit.nih.gov/>

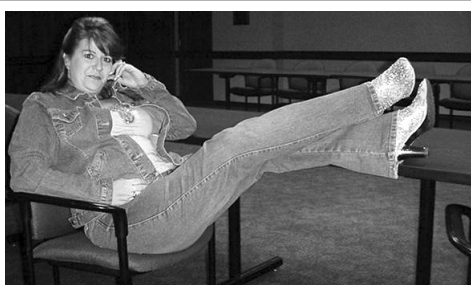
While a good journalist would have far more detailed information, and might have even tracked down the actual dollar amounts given toward each above grant, allow me to remind you I am not a good journalist, a good investigator, nor even a good writer.

I'm merely a ticked off homemaker, with nary an individual thought of my own. I'm sick, I'm tired, and most of all, I'm cranky that we, the chronically ill, must endure the nonsense perpetuated by the likes of the above individuals because of the darkness of their souls, the craftiness of their nature, and because it appears that more than anything, they worship at the altar of the almighty American dollar. In my opinion, they are not healers - they are greedy snake oil salesmen who give the word 'doctor' a bad name.

"Physicians...heal thyself." If you need any help - I've got some 'guidelines' for you! *pha*

The following chart shows a chart of the IDSA doctors/researchers who were also co-authors of the new guidelines that have received grant funding for Lyme research.

Gary P. Wormser	1 total for Lyme Disease granted 2006.
Raymond J. Dattwyler	16 total grants; 12 specifically for Lyme Disease since 1987
Eugene D. Shapiro	33 total grants; 8 specially for Lyme Disease since 1990
John J. Halperin	2 total grants since 1980; specific info not available
Allen C. Steere	69 total grants; 58 specifically or Lyme Disease since 1977
Mark S. Klempner	69 total grants; 37 specifically for Lyme since 1991
Peter J. Krause	112 total grants; 14 specific for Lyme since 1997
Johan S. Bakken	None Found
Franc Strle	None Found
Gerold Stanek	None Found
Linda Bockenstedt	24 total; 24 specific for Lyme Disease since 1996
Durland Fish	13 total; 8 specific for Lyme Disease since 1992
J. Stephen Dumler	16 total; 16 specific for tick-borne illness since 1996
Robert B. Nadelman	4 total; 4 specific for Lyme Disease since 1991



Donna Reagan is the President of the Texas Lyme Disease Association and she is also the local DFW Lyme Disease support group leader. She lives with her husband Tim and daughter Katherine in North Richland Hills. Donna is a freelance writer with the PHA and is a strong proponent of Lyme advocacy and patient's rights.

Review Panel Releases "Report Card" on FDA Practices Concerning Drug Safety

by Susan Williams



In response to growing public concern, the FDA asked the Institute of Medicine in 2004 to assess the U.S. drug safety system and make recommendations for improvements.

That 200-plus-page report, "The Future of Drug Safety: Promoting and Protecting the Health of the Public", was just released this September and contains plenty of suggestions for the FDA, although many of them would require approval from Congress.

The review panel, consisting of 15 experts drawn from various academic and professional organizations, was unanimous in endorsing the recommendations. Several of the recommendations have previously been requested by drug safety advocates for many years, but have been resisted.

Some of the suggestions include:

- * Newly-approved drugs would carry a special symbol on

the label, such as the black triangle required in Britain, warning consumers that their safety is still in question.

- * New drugs would only be approved for five years, at which point the FDA would again review their safety.

- * A ban on direct consumer advertising of newly-approved drugs during this probationary period.

- * The FDA needs to be given the power to impose fines and requirements on drug manufacturers.

- * Manufacturers should be required to register all clinical trials they sponsor in a government-run database to facilitate public access to drug safety information.

- * Manufacturers should be required to produce outcomes of all studies, not just those published in medical journals, which are more likely to show only positive results.

- * To reduce turnover and political interference, the FDA commissioner should be appointed to a fixed six-year term.

The panel also suggested that a "substantial majority" of

FDA advisory panel members not have any industry ties, and recommended a large boost in funding and staffing for the agency.

Although most of the panel's recommendations were focused around drug review, safety surveillance, and related activities, the panel also considered potential contributions of the pharmaceutical industry, the academic research enterprise, Congress, the health care delivery system, patients and the public.

During its research, the committee found that the perception and credibility of the FDA and of the pharmaceutical industry has been compromised. "FDA's credibility is its most crucial asset, and recent concerns about the independence of advisory committee members . . . have cast a shadow on the trustworthiness of the scientific advice received by the agency", the report said. The committee also reported that the FDA and the pharmaceutical industry do not consistently demonstrate accountability to the public.

While most interested parties -- the agency, consumer organizations, Congress, professional societies, health care entities --

appear to agree on the need for certain improvements in the system, the pharmaceutical industry questioned some of the conclusions of the report.

"It would be a mistake to accept the notion that the FDA drug safety system is seriously flawed," said Caroline Loew, senior vice president of the Pharmaceutical Research and Manufacturers of America. "After all, fewer than 3 percent of approved prescription drugs have been withdrawn from the American market for safety reasons over the last 20 years."

Scott Lassman, senior assistant general counsel for the drug industry group, said the industry is open to suggestions, but the FDA already has enough authority to act after drugs are approved. "The trade group also opposes mandatory registration of clinical trials because that would force companies to reveal trade secrets to competitors", Lassman said. "Manufacturers also oppose restrictions on advertising, as advertisements help educate patients about problems and treatments." *pha*

Sharing Our Stories...SOS

by Laura Zeller

Quest for a Diagnosis

Before I got Lyme disease, I was a mountain climber, and an athlete full of energy! I had an exciting career planned in the environmental field. Helping nature and animals was always my dream. My dreams motivated my life, and I had a passionate interest for the outdoors. As a teenager, my love for the outdoors led me to work blazing new hiking trails, and camping in dense wooded areas. Ticks were always crawling all over me, and I did not think it was anything to worry about. At lunchtime, I would take off my work gloves, and flick ticks off my arms and scratch them out of my hair. When I got home at night, I used tweezers to pull the ticks out by the dozens. Back then, what was Lyme disease? When I was growing up in the 1980's, Lyme disease was a new discovery, and thought to be easily treated with antibiotics. It seemed I had no reason to fear ticks, so I continued doing what I loved, being outdoors. Even if I had known about

the dangers of ticks, what was I supposed to do? Should I have avoided the woods and spent my summers indoors? The outdoors was my life!

I began to experience fatigue in my early teens, and questioned the possibility that I might have Lyme disease. My pediatrician tested my blood, which came back negative. Eventually, I returned to him and was prescribed ten days worth of Doxycycline, just in case it was Lyme. The medication made me feel worse, and the doctor told me to stop taking it after only three days, despite the fact that I had two bulls-eye rashes on my back. I was nauseated, exhausted, my joints hurt and I had pain in my eyes. All I wanted



to do was sleep. I grew so weak I had to drop out of my high school sports teams. I tested positive for mononucleosis, and was instructed to rest and it would go away by itself.

After another couple of doctors, I was told that my mononucleosis had progressed to chronic fatigue syndrome (CFS), and there was no cure. Months turned into years, and the overwhelming fatigue continued. I struggled my way through college with a limited course load.

In addition to the exhaustion, I began to exhibit new symptoms, including muscle and joint pain, swollen glands, fever, upset stomach, confusion, tingling sensations and sensitivity to light and sound. I was heartbroken that I could not do anything fun, and all my friends abandoned me.

As my symptoms increased, I sought the help of over 40 doctors. I was diagnosed with chronic fatigue syndrome (CFS), fibromyalgia (FMS), multiple sclerosis (MS), rheumatoid arthritis (RA), Lupus, chronic mononucleosis, and Addison's disease. Most of the doctors I saw referred me to specialists because they had no idea what was wrong with me. My symptoms progressed to the point of complete exhaustion. I was too weak to brush my hair, or even sit up to drink some water without assistance. If I did get up to go to another "hopeful" doctor, I would be wiped out for days afterwards from the exertion. I spent weeks in the hospital for CFS, still untreated for Lyme. I was given painkillers, anti-inflammatory drugs, and diagnostic tests. Even while lying in a hospital bed, and my Lyme tests were positive, I was never treated. The doctors determined that my positive

"Diagnosis"...cont'd pg 12



**Blood Donation
Can Save Lives...
Or Destroy Them.**

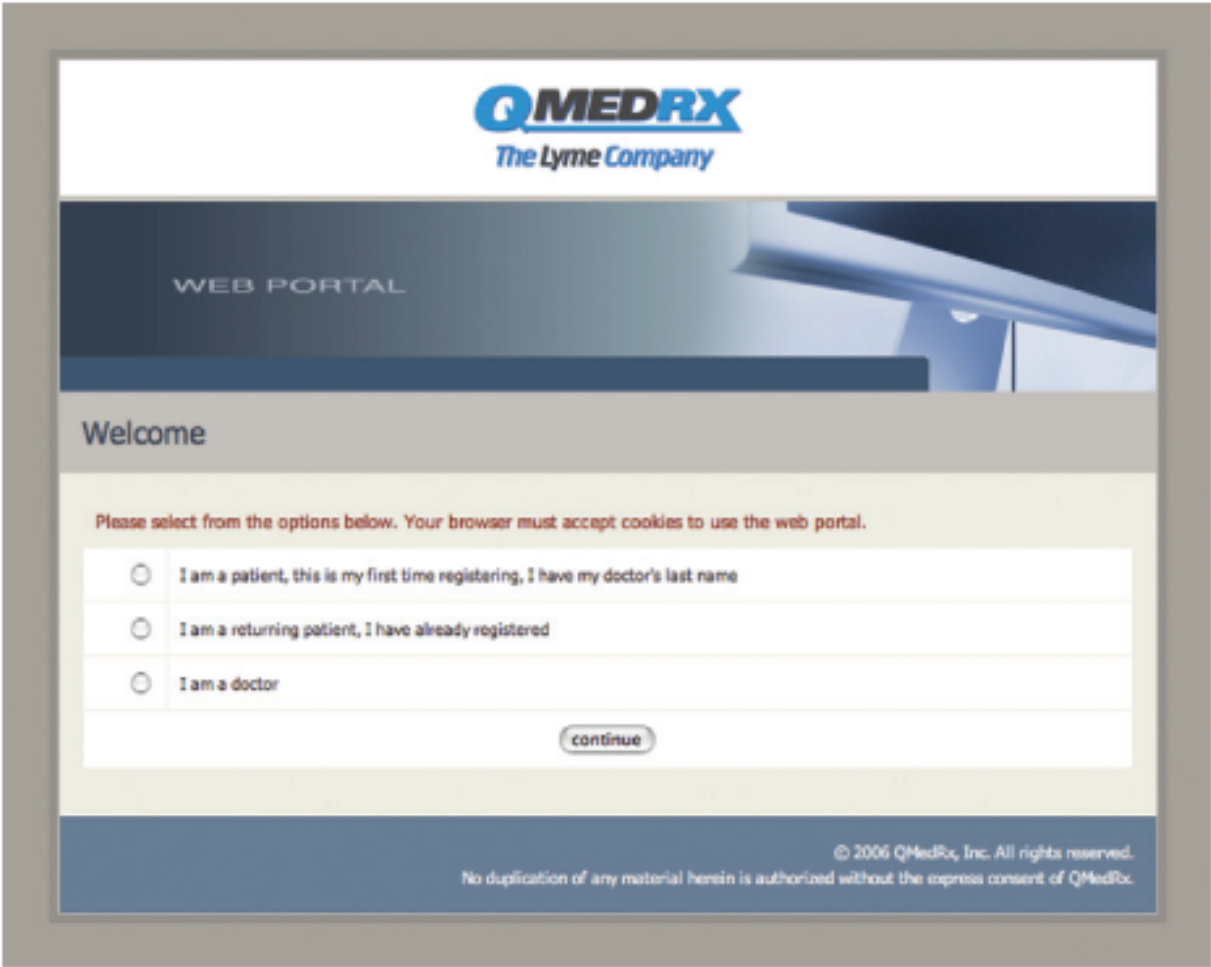
Lyme Disease is the second leading infectious disease in the United States. There is no test currently available to prove that Lyme Disease has been eradicated from one's blood supply.

The Red Cross does not screen the blood supply for Lyme Disease.

**A general rule of thumb if you have ever had
Lyme Disease:
Never donate blood or blood products
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“Health”...cont’d from pg 5

chooses to spend the allotted 10-minutes trying to understand his patient's unique situation and how that person's way of life may be contributing to the illness takes multiple risks." Reznik adds, "First, he risks not getting paid, since the payment system is based on the number of quantifiable items performed, and the new pay-per-performance system of reimbursement pays for the measurable/quantifiable aspects of care and physical procedures. Second, he runs the risk of being criticized by colleagues and by the insurance companies that do 'credentialing process' which again determines

the value of the physicians based on the rate of adherence to the guidelines (what percentage of patients are getting cholesterol tests, flu shots, mammograms). The usual criticism would be, what were you doing there talking to the patient, when you should have been convincing the patient to take the drug?" Reznik continues, "Third, the doctor feels exposed to risk, since whenever the guidelines are not obeyed the risk of successful lawsuit is higher. The reverse is true too, when the doctor adhered to the guidelines, he feels protected regardless of what happens to the patient from that point on.

Thus, a caring physician who tried to understand his patient beyond the quantitative parameters, has to allow his love of the patient overcome all of these obstacles."

Isn't it more difficult now to spend time with a patient and have a loyal bedside manner? There are more people in the world than in 1970's and the diseases are different (AIDS, Lyme disease, CFS, etc.). Dr. Reznik responds, "Population growth is important but, in my opinion, not a decisive factor. If our focus would shift from 'patching up the holes' to truly preventive strategies, med-

icine could become more effective and less costly, at the same time. As for the new diseases, they only came to replace the old ones. Only a century ago, a prominent physician William Osler said, "he who knows syphilis, knows medicine." Treatment of syphilis at that time was accompanied by many complications that required additional treatments, similar to today's AIDS."

Reznik continues, "As a mind-body physician (also practicing conventional medicine), I believe that most illnesses are rooted in our way of living and

“Health:...cont’d on pg 13

Special Moments...The Five Musketeers

by Barbara Gerami

Over 25 years ago I gave birth to my son, Isaac. For the first eight years of his life he was an only child. Isaac was five weeks premature, and we thought, very shy. He literally would hang on my leg in public. However, if there was a stage around, he would be up there in a heart beat singing. Fortunately, he could sing well. We started going to different churches and gatherings where he would sing a capella, from the time he was three years old. His songs to the Lord were so anointed.

When he was six, I took him to see the Texas Boys Choir. He listened in awe. When I told him I'd like for him to join when he was old enough, he told me he couldn't, because his feet needed to move. So, at ten years old we started him in a dance for boys class, and Isaac became a professional ballet dancer. He is now married, and works, but no longer dances at this time.

Isaac was 8 years old when I took in our first foster child. Isaac was very open to having a brother. They did many things together and when that child went back to his parents. Isaac seemed to adapt okay to that as well. At nine we met Joshua. Joshua was 11 and had Downs Syndrome, and they have been brothers from day one. Isaac and Joshua did everything together. They rode bikes, played with cars, swam, ran and just played. Isaac always included Joshua in everything he did with his friends.

I also had two foster daughters, a baby and a teen. The teen wasn't with us long, but the baby lived with us until she was two-and-a-half years old. It was like a death had occurred in our

family when she went back to her biological family. Isaac would cry when he would see little girl things in the department store window. He prayed for the baby every day. I suspect that he still prays for her everyday, even now.

Right after she went home,



we moved to Ft. Worth to bring home a little boy that was nine years old and had lived in the hospital all his life. Again, Isaac opened his arms and heart and accepted him as his brother and showered him with love. The next year we were blessed with two more boys, Donny and Gregory. Isaac adored all his brothers. I home schooled Isaac until he went to high school. He was given the choice to home school through eighth or ninth grade. He chose eighth grade so he could get acquainted with public school. During his time there, he had to make and write a little book. The title was *A Boy's Life*. I would like to share with you some excerpts from his Journal.

He starts out by writing, "This is what I call my Journal.

This is all about how I live, my life, and the things I love. This is my life. As my brothers sleep tonight I think about what is to come the next day. ...I look around the room and I know how exciting my life is having four good brothers. My brothers and I

get along very well. I think we will never break up, no one can take me from my brothers." Isaac went on to write, "Greg, Donny, Vanna, Joshua and I are like the three Musketeers, except we're five. All for one and one for all. We will stick up for each other for the rest of our lives."

Isaac not only adores his brothers, but also learned how to care for them. He could change a trach faster than some of the best nurses. We were on our way back from a trip, when Vanna's battery for his ventilator lost power. I had to stop at a Wal-mart to buy another battery. The ventilator has an internal battery that is supposed to kick in when the external one goes out. As I ran in to get the battery, Isaac realized that the internal battery never kicked in. He immedi-

ately took control of the situation. As I approached the car, he was bagging Vanna, (as in giving him breaths with the resuscitation bag via the trach), telling him to continue to take a breath, because no brother of his was going to die on his time.

The nurse was sitting there quietly, and said he had it all handled. We did get the ventilator working again, and continued our trip home. Several days later, Vanna contracted a serious virus and was in a coma in the hospital. We did not take him off life support, because that was between him and God. After several days, Isaac approached me and told me that I needed to let Vanna know that it was ok for him to go. He told me he knew his brother needed to hear from me that it was ok. I finally told him it was okay to go, and Vanna passed away a few days after Christmas.

A few years later, while Isaac was out of town at college, he called home in the middle of the night crying. He told me he had a dream and I needed to go check on Donny. I did, but Donny was fine. I told him it was just a bad dream and that everybody was ok. The next day Donny had a grand-mal seizure and ended up in the hospital for a week. He came home on oxygen. Although he is now off oxygen, the doctors don't know how long he has to live. What we do know is that, even though we have added three more kids to this bunch, Isaac loves each one dearly and will do anything for them. He has since moved back to Arlington, and enjoys his siblings with all his heart. I think some people were just not meant to be only children, rather to be a part of a tribe. *pha*

Public Health Medical Briefs

by Susan Williams

Elective C-Sections Significantly Increase Risk of Maternal Death

Women who undergo an elective Cesarean section have a much higher risk of death than those who choose vaginal delivery, according to a new French study reported in the September issue of 'Obstetrics and Gynecology'. Researchers found that 41.5% of women who died during or within six weeks of childbirth had undergone a C-section, compared to 14.9% of women who survived childbirth.

The increased mortality rate was mainly due to venous thrombosis (25.9%), infection (14.8%), and complications from anesthesia (14.8%).

Ventilation Fails To Control Secondhand Smoke

Newer "state-of-the-art" ventilation systems intended to clear cigarette smoke from bars and restaurants do not eliminate dangerous soot and carcinogens, researchers concluded, and can push their levels even higher in

nonsmoking sections than in smoking areas. While older ventilation systems attempt to dilute smoky air with fresh air, the newer displacement systems aim to use cooler air to force hot, smoky air up to ceiling ducts. Displacement ventilation has been proposed as a way to allow non-smokers and smokers to co-exist, as the systems theoretically remove pollutants from non-smoking areas. Heavily promoted by hospitality industry associations and tobacco interests, these newer systems have been touted to thwart adoption of smoking bans.

Lead researcher James Repace, a health physicist, second-hand smoke expert and professor at Tufts University School of Medicine, said evidence showed the complex, difficult-to-maintain ventilation systems were not functioning as claimed. While the ventilation systems may give restaurant and bar owners a false sense of security, Repace says, deadly toxins from tobacco smoke remain in the air.

The U.S. Surgeon General reported in June that "separating smokers from nonsmokers, clean-

ing the air, and ventilating buildings cannot eliminate exposures of nonsmokers to secondhand smoke." The report noted that the American Society of Heating, Refrigerating and Air Conditioning, the U.S. standard setters on ventilation, concluded that ventilation technology cannot remove smaller particles or gases found in secondhand smoke.

Safety Panel Rejects FDA Report on Dental Fillings

Government health advisors recently rejected a FDA report that concluded dental fillings used by millions of patients are safe.

The panel stated that the report was "unreasonable", in part because FDA officials failed to review all available studies, and said that further study is needed. The advisory panel also stated that the federal report did not objectively and clearly present the current state of knowledge about the fillings, and failed to answer concerns regarding why mercury - a known neurotoxin - is used at all.

The American Dental Association still maintains that amalgams should be an option for

decaying teeth. Amalgam fillings by weight contain about 50% mercury, in addition to metals such as silver, copper, tin and zinc. Millions of Americans receive mercury fillings each year, though their use has begun to decline as many dentists choose resin composite fillings that blend better with the natural coloring of teeth. Some studies have shown that mercury vapors can leach out of the fillings, especially when patients chew or brush their teeth. Critics contend that these vapors are absorbed into the bloodstream. When not encapsulated, the material itself is considered a hazardous waste.



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Diagnosis...cont'd from pg 8

Epstein-Barr virus titer was the cause of my complaints, and diagnosed me with Chronic Fatigue Immune Dysfunction Syndrome (CFIDS). I was released and sent home with antidepressants and rheumatoid arthritis drugs, and yet another diagnosis of CFS/CFIDS.

Countless frantic visits to the emergency room solved nothing. Sick and petrified, I would lie in a hospital bed dripping with sweat, high fever, my whole body numb, and tingling nerve pains shooting down my arms, legs, and back. My face drooped, I had facial flushing, and my body ached down to the bone with intense pain. The doctors would dismiss me as healthy on paper, and discharge me with orders to find a chronic fatigue support group and see a shrink. Lucky for me, I do not give up without a fight. My determined personality kept searching for help and answers. I spent hours researching medical literature and educating myself on the complex nature of tick-borne diseases. After arming myself with as much information as I needed, I found that my symptoms matched up closely with those of neurological Lyme disease. It all made sense to me, the years of tick exposure, hundreds of bites, the rashes, the exhaustion, all of it just "clicked."

With extreme luck, I ended up finding an amazing Lyme disease physician affiliated with the International Lyme and Associated Diseases Society (ILADS). He read over my folder full of lab tests, and my twenty pages of typed personal history of the previous ten years. He said I had been grossly under-treated and misdiagnosed. He said that although my health history was bad, that it was not unusual to him. Working

on the front lines of tick-borne disease, he had seen thousands of patients in his practice, many of whom had been turned away by previous physicians who lacked comprehensive knowledge of tick-borne disease. He examined me, discussed my diagnosis, and what treatment I would need. He said my case was severe, and that I may get over this all together but it would take a long time. All of my Lyme disease tests, plus a myriad of co-infections including babesia, Bartonella, and Ehrlichiosis came back positive. Finding my Lyme doctor finally ended my quest for a diagnosis. Personally, it brought an end to ten years of emotional suffering, misunderstanding and downright neglect from the medical community.

My treatment protocol included IV and oral antibiotics, malaria medications for babesia, and a combination of medicine for Bartonella, and monoplace hyperbaric oxygen therapy (HBOT). Combined with nutritional support and physical rehabilitation, my protocol made an enormous positive impact on my health. I went from being bedridden to being independent and functional again. I could do everything anybody else could; I just had to pace myself. It took three years of antibiotic therapy for me to feel back to my old self again. After 4 years of treatment, my symptoms lessened significantly. I have been off antibiotics for nearly two years now. Although not cured, my stamina and endurance have improved enough to get me back enjoying life once again.

I have since discovered the reason why it was such a battle for me, and countless others to receive a correct diagnosis. Based on my

personal experience, I estimate that an alarming percentage of primary care physicians and family doctors have no idea what they are doing concerning diagnosis and treatment of tick-borne disease. The reason for this is that the Infectious Disease Society of America (IDSA) has written guidelines for treating Lyme disease that in my opinion are inaccurate, outdated, and fatally flawed. The doctors I saw during my quest for diagnosis likely followed these guidelines, and therefore concluded that I did not have Lyme disease. Many Lyme patients fail to receive a conclusive diagnosis because the testing is poor and there is a serious lack of Lyme literate medical doctors (LLMD's).

In my experience, what many patients need to realize is that chronic fatigue, fibromyalgia, and arthritis are not diseases by themselves. Of course, they are real, but they are symptoms, not diseases. If you go to the doctor, and complain of being tired all the time, for six months or more, you are probably going to be diagnosed with chronic fatigue syndrome. You have to use common sense here. You have a symptom, and you are being diagnosed with a symptom. It makes no sense to me! I think you always need to find the cause. Patients will join chronic fatigue support groups, go on disability, and tell their family "I know what's wrong with me now, and I have chronic fatigue syndrome." I still find it amazing just how many people get sucked into what I believe is a giant conspiracy and illogical train of thought. None of it makes any sense to me, and yet we are so happy to have a diagnosis, we accept it. Meanwhile a cause is not

found, and the person is left with a strong possibility of undiagnosed and untreated infection.

Many thousands of people believe they have fibromyalgia, chronic fatigue syndrome, depression, multiple sclerosis and more, and still they have no idea what the cause is. In my opinion, normal, healthy people do not just suddenly come down with arthritis, or become exhausted all the time for no apparent reason; there is always a cause. The term "syndrome" bothers me to no end; it is just a word for a cluster of symptoms for which the doctors label a syndrome because they have no idea what is wrong with you. The same thing is true for treatment of diseases. Sick people seek out a cure for arthritis, for example, and what they get is not a cure, but medication to treat the symptoms. An example of this in Lyme disease is anti-inflammatory drugs, NSAIDS, or steroids prescribed to treat painful joints. The medications will work on the symptom, the pain, but the cause of the pain goes untreated. The smart treatment would be antibiotics, which directly kill the cause, plus supportive prescriptions to treat the symptoms and make the patient more comfortable. Therefore, in the previous example, the patient benefits from treatment aimed at the cure, plus they get symptom relief.

You have to become your own medical detective when faced with a chronic illness. It is your responsibility to arm yourself with the information you need to fully educate yourselves. My best advice is to remember my story and always fight to seek out the cause. *pha*

“Chronic Fatigue”...cont'd from pg 1

symptoms, pain in the joints and muscles, tender lymph nodes, sore throat and new headaches. A distinctive characteristic of the illness is a worsening of symptoms following physical or mental exertion.

Diagnosing CFS is a challenging process because there is no diagnostic test or biomarker to clearly identify the disorder. Diagnosis is primarily made by taking a patient's medical history, completing a physical exam and lab tests to rule out other conditions. If there are no abnormal test results or other physical ailments identified, clinicians can use stan-

dardized tests to quantify the level of fatigue and evaluate symptoms. Diagnosis can be complicated by the fact that the symptoms and severity of CFS vary considerably from patient to patient.

Because no cause for CFS has been identified, treatment programs are directed at relieving symptoms, with the goal of the patient regaining some level of function and well-being. Patients' prognoses greatly improve with early intervention. At least half of those with CFS can return to their pre-CFS level of health if treatment is begun early.

"The CDC considers

chronic fatigue syndrome to be a significant public health concern, and we are committed to research that will lead to earlier diagnosis and better treatment of the illness," added Dr. Gerberding. *pha*

For more information about CFS, visit www.cdc.gov/cfs.

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“Health”...cont’d from pg 10

experiencing the world. The body (or mind in a case of mental illness) speaks out in its own way, expressing our painful way of being in the world (for instance in fibromyalgia). Thus giving a drug or doing a procedure to dull the pain is likely to either be ineffective, or produce another illness, since the problem has never been truly addressed. So the names of the diseases keep on changing, and as we claim victory of some diseases, others invariably take their place."

Lyme disease patients, for example, are finding it more difficult to get insurance companies to pay for their medical needs. How does the insurance companies play into the healthcare treatment of a patient? Dr. Reznik was quick to reply, "There are several ways in which the insurance company affects medical practice. These involve reimbursement, credentialing, and auditing. Briefly, reimbursement is based on the number of questions the physician asks the patient relating to quantifying the disease (on the scale one to 10 how bad is your pain, etc), number of physical examination items, complexity of decision-making (expressed by ordering tests, for example), and procedures done (joint injection or procedure). So in order to get paid the doctor needs to fulfill these items first."

Reznik adds, "Credentialing assesses how compliant the doctor is with the guidelines. This usually translates into how good is the doctor at convincing patients to follow the guidelines that someone created for a generic patient (non-individualized). Auditing is a process of reviewing the doctor's practice to verify whether his billing is justified by documentation. If the doctor didn't document sufficient number of items to justify billing, he can be accused of financial fraud and fined large amounts of money. So if you wonder about all those standard questions that the doctor often asks and writes down without trying to get to know who you really are, this is the reason."

Speaking of guidelines, the IDSA just came out with a set of guidelines that has the Lyme disease community up in arms. Acne deserves long-term antibiotic treatment, but Lyme disease does not? Or, Lyme disease suddenly becomes another ailment after the initial treatment and we're told that too much antibiotic treatment causes the antibiotic to become ineffective. If cancer, AIDS, herpes, and acne do not become

"other ailments" after the initial treatment -- then why would Lyme disease suddenly become arthritis, CFS, or some other such malady? Who pays the people that make the guidelines? Dr. Reznik answers, "The issues surrounding Lyme disease have to do with the fact that it is not well-understood, or rather, very poorly understood, especially its long term sequelae. IDSA is trying to maintain an authoritative posture in the face of lack of understanding and data, which they themselves admit. In this respect, IDSA's rigid position about what to treat, what not to treat, and how long to extend the treatment is based on guesswork. All statements against any particular treatment are based on opinion, not on scientific evidence. To be fair I have to say that I don't see evidence of financial bias since most of the treatments they endorse are by the cheap off-patent drugs. There IS the usual conceptual bias that states that since we cannot find the material proof (the presence of the bacteria in this case) the problem doesn't exist, is imaginary, false or unreal. For anyone suffering from Lyme disease sequelae, I would recommend to explore a variety of treatment modalities and not give up. The fact that the main stream allopathic medicine does not offer an effective treatment does not mean that treatment and cure isn't possible, only that the infectious disease specialist won't provide it for you."

The FDA, a government agency, seems to be actually prostituting itself for the pharmaceutical companies. Why is this and how does this have an effect on the patient? Reznik responds, "I am not sure why, but my guess is that the pharmaceutical companies pressured congress to provide them with a mechanism for exerting financial influence on the FDA under the guise of expedited approvals for new and exciting drugs. None of these new drugs made a major difference and some had to be taken off the market later due to their harmful effects. I think an organization such as the FDA should be fully funded by the tax dollars, to preserve its independence and avoid corrupting influences of the vested interest."

What about the Avian Flu? Should we worry about it? Dr. Reznik offers, "I would recommend not worrying about anything, especially Avian Flu. First, it is unlikely to happen according to most experts and judging by our experience with other publicized

threats. You may recall some of them, including swine flu, SARS, mad cow disease, Y2K, and mass terrorist anthrax attack. None of them materialized on a large scale as we were suggested that they would." He continues, "If it should happen, nevertheless, there is still no need to panic. We can be assured that the current flu vaccine and flu medications won't work for this, by definition, brand new virus. So there would be no true need to worry about finding the shots and the pills. Instead, having a peace of mind is likely to help get over the flu rather than becoming the victim. This flu, as was the case in the 1918 epidemic, will not kill the majority of people it infects; otherwise it could not be transmissible enough to cause a pandemic. There is enough information to suggest that most people, who died in 1918, died of being panic-stricken and paralyzed by fear. Instead, go to work and maintain cheerful state of mind, then you will much more likely be among those with asymptomatic or minor infection. Like any flu, avian flu can be waited out with chicken soup and rest. Hoping that the technology, vaccines, or pills

will provide an answer is naive. But again, Avian Flu is likely to remain one of our scary non-materialized myths together with swine flu, SARS, mad cow disease, Y2K, and mass terrorist anthrax attack."

There's another vaccine that's been hitting the front pages lately. What are you thoughts regarding the vaccine for young women to guard against cervical cancer? Reznik answers, "In my opinion, there are several problems with this vaccine. As with most other vaccines, there is no long-term safety data. The researchers designing this vaccine looked only at one parameter-does it decrease HPV infection. At this time it appears that it does, but does that mean better health for women? For instance, while reducing HPV infection, are we going to increase other chronic illnesses? The vaccine produces a rise in antibody levels that are SEVENTEEN times higher than those produced by the natural HPV infection. Is such an intrusion into the immune system safe in the long term? We simply don't know, and for that reason I think that recommending vaccination to 12-year-old kids is very

“Health”...cont’d on pg 15

LYME DISEASE AND RIFE MACHINES

In the 1930s, a scientist named Royal Raymond Rife discovered a method for killing microorganisms with electromagnetic frequencies. What resulted was development of the "Rife machine," named after Dr. Rife. Although experimental, and not adopted by conventional medicine, the Rife machine proved to be useful in fighting numerous bacterial infections. In the 1980s, a mechanical engineer by the name of Doug MacLean adapted the technology into a device that he used to heal his case of chronic Lyme disease. Since then, hundreds of Lyme sufferers have followed in his footsteps. Today, Rife machines are considered by many patients and practitioners to be one of the most useful therapies for killing Lyme disease bacteria. In comparison with antibiotics, Rife machines offer several intrinsic advantages:

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Science Has No Conscience

by J. David Kocurek, Ph.D.
Austin/Ft. Worth



What? It's really not too hard to understand. When practiced by a well-established set of rules, science

is simply the means to advance knowledge and understanding. The product of a scientific endeavor is neither good, bad or even indifferent - until human intent determines the outcome.

Fortunately, most "scientists" do have a conscience, but it's those remaining few without a strong ethical compass that, when driven by unrestrained ego, the rewards of fame and attention, or at worse financial gain, perpetuate harm upon an unsuspecting community. The injury is further compounded to the extreme when those in positions of control and authority misuse a marginal scientific product whether with intent, through ignorance or careless management.

Of course, I'm continuing to address the impact on the quality of patient care, including access, the Infectious Diseases Society of America's (IDSA) 2006 Lyme disease guidelines are having on Lyme patients. Through my advocacy work with standupforlyme.org in Texas, the number of contacts from new patients and patients abandoned by caregivers who are choosing not to expose themselves to medical board scrutiny are ever increasing. The reason always tracks back to the IDSA whose guidelines are blindly accepted as authority by front line physicians and which form the basis for community standard of care enforced by the medical board.

Much has already been written as to how the guidelines effectively eliminate the disease by making its diagnosis highly exclusionary. The faulty logic and bad science, more commonly referred to in legal circles as "junk science" was readily identified as was the weakest level of evidentiary opinion that emboldened the IDSA to claim the guidelines to be "evidence-based."

The modern standard of evidence-based medical (EBM) practice that we hear so commonly referred to and its basis deserves some attention in order to understand if or how it varies from traditional medical practice,

and to understand what the IDSA is attempting to accomplish. Is the flaw in the method or the execution?

The underlying philosophy of EBM has its roots at least as far back as mid 19th century Paris, and has developed today into its own area of academic study with an abundance of literature and organization resources. Some describe EBM as a paradigm shift, but that contradicts the tenets of its traditional medicine roots as well as the evolutionary development of the modern practice. For these proponents the importance of process adherence exceeds the value of outcome.

Sackett et al in their editorial, Evidence based medicine: what it is and what it isn't [BMJ

1996;312:71-72 (13 January)]

succinctly describe EBM in their opening statement, "It's about integrating individual clinical expertise and the best external evidence." That sounds well grounded. How can one argue with professional proficiency backed with a command of the preeminent research in the field? Isn't that what has always been expected from the leaders in any field? There really isn't anything new in EBM when viewed from expectations of traditional practice. It's simply a systematic method to process patient care decisions.

Compare the eloquent simplicity of the definition above with the complex dissection given in the text Evidence-Based Medicine: A Framework for Clinical Practice [Edited by Daniel J. Friedland, MD, McGraw Hill (1998)]:

"The traditional medical paradigm comprises four assumptions:

1. Individual clinical experience provides the foundation for diagnosis, treatment, and prognosis. The measure of authority is proportional to the weight of individual experience.

2. Pathophysiology provides the foundation for clinical practice.

3. Traditional medical training and common sense are sufficient to enable a physician to evaluate new tests and treatments.

4. Clinical experience and expertise in a given subject area are a sufficient foundation to enable the physician to develop clinical practice guidelines.

The new evidence-based medicine paradigm comprises a different set of assumptions:

1. When possible, clinicians use information derived from systematic, reproducible, and unbiased studies to increase their confidence in the true prognosis, efficacy of therapy, and usefulness of diagnostic tests.

2. An understanding of pathophysiology is necessary but insufficient for the practice of clinical medicine.

3. An understanding of certain rules of evidence is necessary to evaluate and apply the medical literature effectively."

Notice the bias shift from practitioner expertise to reliance on the medical literature. I think I'm reliving the new math and open classroom era when I read this. Pathophysiology is a constant (only the depth of understanding changes) and hopefully that's what medical education and the literature reflect. It remains the responsibility of the practitioner to maintain contemporary skills, and to do so does require devoting the time to weigh and filter the literature for the best information. Again, nothing has changed except the name of the process. What is called for in EBM is the same process a competent traditional physician practiced by instinct, except in the "paradigm shift" model the responsibility is reallocated toward the literature which itself can bear no responsibility!

Now back to the IDSA guideline question of flawed process or flawed execution. The particular process used can't escape a large share of the blame because it appears to have been molded to provide desired outcome. Specifically, the authors failed to integrate clinical expertise with the best external evidence. Selective use of clinical experience and literature by preferentially restricting it to information, especially that from members of the author's own club, that supports the thesis is an unashamed deception within either EBM premise. This is also an elected blemished execution, and so the two areas of focus are inseparably convoluted.

The continued focus on acute phase disease when tens of thousands of late stage or chronic Lyme disease sufferers are known to exist by even the most conservative projections is an execution flaw. It's an intentional exclusion. The IDSA represents the medical sector that is most responsible for the care and well-being of Lyme disease patients, yet they continue to diminish the disease complex in its most insidious form. As physicians and scientists, why are they not aggressively researching diagnostics and treatments for all tick borne diseases, regardless of disease stage?

If the IDSA and its physician cohort devoted as much time and energy to legitimately working to improve the state of the science in all aspects of the disease, as they do to minimizing its toll on patients and discrediting those clinicians who make every good faith effort to competently treat, would they not be truly fulfilling their mission? The use of evidence-based concepts is merely a sideshow when one attempts to rationalize the IDSA's motive in approaching Lyme Disease. They use it wrongly and deceptively to accomplish some dangerous motive.

I'm still left with the thought that there must be something more valuable than reputation to protect when the IDSA and the guideline authors breach most every code of ethic that must be adhered to for true scientists to advance knowledge for the common good. *pha*

Through my advocacy work with standupforlyme.org in Texas, the number of contacts from new patients and patients abandoned by caregivers who are choosing not to expose themselves to medical board scrutiny are ever increasing.

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PageServer
1231 Greenway Dr., Ste.385
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s.melson@alsanorthtexas.org
972-714-0088
877-714-0088

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323 Route 5 West
P.O. Box 127
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Toll Free for PALS:
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Lyme Disease Association lymediseaseassociation.org/ Pat Smith 888.366.6611

Arizona

10440 N. Via Linda
Scottsdale, 85259
Group facilitators :
Karen Genest 480-632-6444
Larry Levy
Larry@valuepro.netbox.com
Northern Arizona - Tina Caskey:
tcaskey@safeaccess.com
928-779-2759

Southern Arizona - Donna Hoch:
nanandbo@cox.net 520-393-1452

L.E.A.P.
Tina J. Garcia
L.E.A.P. Arizona
Lyme Education Awareness
Program

<http://www.leaparizona.com>
480-219-6869 Phone

Arkansas

Mary Alice Beer
(501) 884-3502
abeer@artelco.com

California

ROBIN SCHUMACHER
1057 R St.
Fresno, CA 93721
Phone: (559) 485-5445
Fax: (559) 570-0500
Membership@Calda.org

Colorado

Mary Parker
303-447-1602
milehightick@yahoo.com

Alabama

Jim Schmidt (334) 358-3206
jschm47974@aol.com

Arkansas

Mary Alice Beer (501) 884-3502
abeer@artelco.com

Lyme Disease Support Groups cont'd Kansas

913-438-LYME

Lymefight@aol.com

Montana

bepickthorn@earthlink.com

Nevada

Rene Rothstein 702-256-9776
reen@earthlink.net

New Mexico

Veronica Medina (505)459-9858
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Pat Jackson (715) 356-3364
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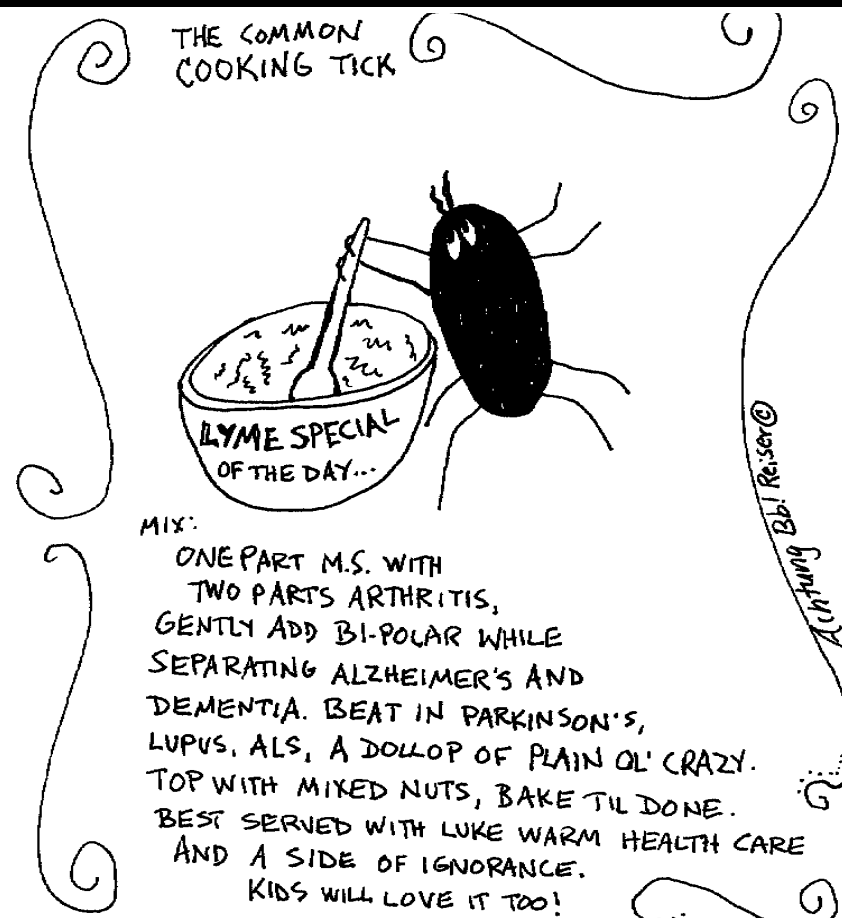
“Health”... cont'd from pg 13

premature. Another issue is something called genetic drift. It is a phenomenon well known in biology whereby the environmental pressure causes changes in the population. What that means in terms of HPV viruses, is that while the vaccine will provide protection against four most common HPV subtypes, very soon, probably in a matter of several years, other subtypes of HPV virus will become more common and those that are currently most common will recede into the background. So the 12-year-old kids that we try to vaccinate now aren't even likely to reap the benefit of protection against the most common HPV types, because by the time they reach age of sexual activity, the most common HPV subtypes won't be the ones they were vaccinated against. There are more than 40 known subtypes of HPV virus."

It's common knowledge that pharmaceutical companies use ghost-writers to promote their products. Does "ghost writing" hurt patients? Dr. Reznik believes, "'Ghost writing' hurts patients by promoting medical practices that are motivated by nothing more than a race for higher profits. It is one of the known tricks of the pharmaceutical industry to convince the guiding authorities (the organizations that create guidelines) and the rest of the medical community, that the newer, more expensive treatment is better than the old. Once the new treatment is incorporated into a guideline for treating one or more diseases, large profit is a guarantee. People's health, on the other hand, will often suffer. It suffers either directly from a drug that is later taken off the market for causing harm, or indirectly, by spending enormous amounts of

“Health”...cont'd on pg 16

Ticktoons



by Terri Reiser

“Health”...cont’d from pg 15

money on treatments that are no better than the old ones, raising the cost of healthcare and leaving more and more people beyond the threshold of affordability for basic health needs."

I asked Dr. Reznik if health-care and high-tech medical treatments really worked. He responds, "Here are some figures that you might find interesting. In the U.S. we spend 2.1 times what Canada, France, Germany, Italy, Japan, and the U.K. spend per capita on health care, but our outcomes are worse. Also, the total Healthcare Expenditures in the U.S. is now 3.6 times the spending on

defense, and 2.0 times the spending on education. It was projected to rise from 13.2% of GDP in 2000 to 15.5% of GDP in 2005. In 2004, the U.S. spent 14.6% of GDP on healthcare, compared with Germany's 10.9%, Canada's 9.6%, Australia's 9.1%, New Zealand's 8.5%, and the United Kingdom's 7.7%. This greater spending does not translate into better health, better longevity, or better quality of life.

The poor health outcomes in the US are mostly related to huge disparities between those who have access to healthcare and those who

don't. Giving more money won't solve this problem, as these additional monies will go for the high-end/high-tech research. The product of such research usually does NOT increase longevity of people, as was definitively shown in the studies of the elderly who die sooner when more aggressive medical management (i.e. Intensive Care Unit) is used in the last six months of their life. The product of such research is an increase in healthcare cost and in a disparity between those who have and those who don't." In conclusion, Dr. Reznik's advice on general health: "My general health

advice is not to accept a position of a victim, but to remain active in one's approach to health. Simply become a figure of authority (as in a case of an infectious disease specialist and Lyme disease) just because they cannot help you, does not mean that help and health are beyond reach. Take an active role and become your own healer. Find your own way, accept advice that feels right for you and reject what makes you feel helpless, victimized, and incapable. Breaking the idols of authorities is the first step toward new possibilities." *pha*

Xtreme Sports...cont’d from pg 6

lines" are sadly limiting very ill patients the fundamental right to be healthy. We might ask why Lyme patients are being singled out when other diseases are allowed carte blanche to treatment opportunities?

The answer is most likely to be, cost. Insurance companies, healthcare providers and others do not want to front the costs necessary to cure very ill Lyme patients. And there are other costs as well. One can only speculate whether tourism suffers if it is known that ticks are carrying infectious disease in this country. Or how many billions of dollars in hunting revenues would be lost if the extent of Lyme disease were openly shared with individuals in every state. There would be additional costs to educate physicians about the proper diagnosis and treatment of Lyme, as well as costs to educate schools to teach prevention techniques to students, and other costs.

And yet some governmental bodies, private agencies, physicians and others prefer to ignore thousands of studies and very ill patients and instead seem to promote the idea that Lyme is not a "real" illness, but simply a psychological manifestation of thousands of apparently delusional people. In the meantime, privately funded and federal disability costs skyrocket as people become disabled by Lyme disease. The cost to society is currently in the billions of dollars annually for sick and disabled people who can no longer work in a meaningful capacity and pay for insurance, consumer goods, and even taxes.

If your doctor refuses to acknowledge Lyme, you will need a second opinion, or a third, or a fourth. In fact, most Lyme patients have been to more than 10 doctors before their Lyme disease is properly diagnosed. This is not doctor-shopping. This is an attempt to find a Lyme-literate physician. Sadly, many physicians claim

Lyme is "not in" (enter the name of your state here). Unfortunately, many sincere physicians, even infectious disease specialists, are not trained at diagnosing or treating Lyme disease.

Lyme is a relatively newly emerging disease in this country (over the past 50 years), and there remains much disinformation about it. Most doctors have only basic training of, or have never seen a case of Lyme, up close and personal. Some will say "What's that?" when you ask them if they can tell you about Babesia-a malaria-like illness that often rides tandem with Lyme disease, and also known as just one type of co-infection.

Some may even tell you not to "worry" about Lyme or will only agree to treat you for 10 days or 21 days, claiming you are "cured" after that time period. To the dismay of many Lyme patients, this attitude could not be more wrong or dangerous. Lyme, when not treated adequately, leads to permanently disabling conditions and even death. Chronic Lyme does indeed exist, and there are thousands of patients and studies that support the evidence that it is real.

As we discuss treatment, there are currently two schools of thought. Some doctors feel twenty-one days of antibiotics is sufficient for a cure. Other physicians and their patients say the problems linger much longer and that Lyme should be treated as long as symptoms are present. Treatments for Lyme disease are not without risk, but not treating Lyme is devastating. As a patient, learning as much information about Lyme disease as you can is critical to receiving proper care.

It took this author more than a dozen years just to be properly diagnosed with Lyme disease, which she and her two children contracted while playing in a leaf pile in their backyard in southeast-

ern Wisconsin in 1992, a place doctors said "didn't have" Lyme. When finally diagnosed in 2004, it was far too late for an "easy" cure, and much damage was already done. IV treatments and years of oral antibiotics manage to keep us somewhat physically and cognitively functioning. If Lyme had been diagnosed and treated properly at the onset, our ordeal could have easily been avoided.

The good news is that Lyme is treatable if it is detected early enough. The key is in early detection and proper treatment. Lab tests are often relied upon by doctors, but labs may not process blood samples properly. Bb may be undetectable in blood, or cerebral-spinal fluid, your body may not make antibodies to Bb, and tests are not 100% reliable. Many doctors rely on outdated tests that are inaccurate, diagnose by CDC criteria meant for surveillance rather than diagnosis, and most testing laboratories use tests that are incapable of properly screening for Bb. Obviously more research is needed, and bills are currently before Congress (H.R.3427 and S.1479) to help aid in research and proper diagnosis and treatment of Lyme disease.

The bottom line is that Lyme remains a disease that should be diagnosed by a history of clinical symptoms, not upon the basis of results of one or two lab tests. Lyme is difficult to detect in the body, and timing is key. These "smart" spirochetes alter immune function so that our bodies don't see them hiding between our cells, leaving them to set up camp for an indeterminate amount of time to wreak havoc upon us.

Lyme is now the fastest-growing vector-borne (bite) illness in the world. Physicians who have treated thousands of Lyme-infected patients are the minority few who are courageously willing to stand in the forefront of proper treatment on behalf of their very ill

patients-patients who depend upon, and appreciate their honesty and dedication. These physicians are often forced to do so only at great personal expense, sometimes their own careers, because they understand how devastating Lyme disease and its co-infections truly are. These physicians are literal heroes to their patients. And yet they are sadly forced to approach treatment cautiously due to the great disparity of thinking in the diagnosis and treatment of Lyme patients.

Until the differing schools of thought attempt to work together and put Lyme patients first, we as patients will never make forward progress, taking steps back onto the road to wellness, but will remain permanently cast into the sea of denial, despair and disability that many of us are currently, and unhappily stationed through no fault of our own.

The best tool for fighting Lyme is prevention. Play safely by checking yourself and your gear. Wear light-colored clothing. Tuck socks into your boots or shoes. Wear long sleeves, long pants, and headgear. Use insect repellent containing 30-40% DEET. Stay off the ground when possible, and out of wet or damp areas. Check yourself and others for ticks as soon as you are out of the woods. Check the hairline and scalp. Use a mirror or someone else's eyes if necessary. Don't panic if you see a tick attached; be smart and remove it properly. See your doctor if you are bitten, or if you think you may have symptoms of Lyme disease. The earlier Lyme is treated, the better your overall outcome.

Now get outside and have a good time, but look out below. Ticks love Xtreme sports-or at least the adventurous folks who play them. *pha*