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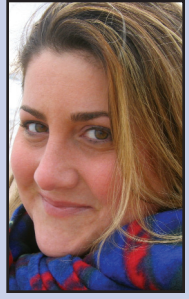
# PUBLIC HEALTH ALERT

Vol. 2, Issue 12

Investigating Lyme Disease & Chronic Illnesses in the USA

December 2007

## In This Issue



**Laura Zeller:**  
 Interviews author of *The Poison Plum*  
 p. 1-2



**PJ Langhoff**  
 Dying to Serve:  
 A look at the military's anthrax vaccine.  
 p. 4



**Maggie Sabota:**  
 Making the best of every situation.  
 p. 5



**Joan Vetter's Faith Factor:**  
 Eye Opening Faith  
 p. 5



**Columbia Univ. Medical Center**  
 leads first placebo controlled study of cognitive impairment with Chronic Lyme...p. 7



**Dr. Joseph Jemsek**  
 exposes the fallacies of the NEMJ presentation of Chronic Lyme...p. 8



**Dr. Joseph J. Burrascano Jr.**  
 invites physicians to participate in the Lyme Registry  
 p.9



**Grace & "Muriel"**  
 Pilot takes message of Lyme awareness across the world. p.9



**Your Doctor Said What?**  
 Sue Vogan interviews Dr. Terrie Wurzbacher  
 p. 13



**Eight-month-old held hostage by hospital**  
 p.16

## Reality or Fiction: Thoughts to Ponder

Laura Zeller interviews Les Roberts, Author of *The Poison Plum*

This is Georgia born Les Roberts' first and perhaps only novel. It was inspired by a true life experience with a bizarre and mysterious disease which remained un-diagnosed for ten years, almost claiming the life of the author. Les felt led, after self (correct) diagnosis and professional treatment, to put a human face to an epidemic now sweeping across America. Blessed, or perhaps cursed, from young adulthood with a fertile and vivid imagination enhanced by recurring episodes of precognitive dreams and apocalyptic visions, the idea and basic plot for this novel was revealed to Les in a space of only five minutes. Resisting the urgings and later proddings from the Almighty for a period of time, Les finally relented, grabbed a legal pad and began writing.

Les Roberts was born and raised in Northwest Georgia. At the time of the onset of symptoms of Lyme disease, he had been living in South Alabama for sixteen years. So much for the nonsense of; "You can't possibly have Lyme disease... you don't live in an endemic area." In 1979, Les founded an investment brokerage firm in Pensacola, Florida which he sold in January of this year. Les is now retired from the investment business but not from the business of battling Lyme disease, and those with strident voices that make it their business to tell us and the media that we are not sick. Les Roberts is a brilliant Author, on a mission to spread the truth

about Lyme disease to the entire world through his absolutely jaw-dropping work of passionate creativity! Welcome Les!

### Can you share with me your personal struggle with Lyme disease?

A brief summary is as follows: In 1990, I began experiencing fatigue and a feeling that something was just not right. Attempts to continue my vigorous lifestyle of running, biking, swimming and lifting weights left me exhausted with a fatigue more intense than anything I had ever experienced. A few weeks after those symptoms began, my heart quite suddenly became very weak. I was rushed to an emergency room and immediately placed in intensive care with symptoms of a heart attack. Blood tests revealed that it was not a heart attack. A subsequent echo revealed that one wall of my heart was akinetic (not moving). The doctors were puzzled, and I was transferred to a larger hospital for further tests and evaluation. This began a series of hospital visits, more extensive tests, referrals and finally a third cardiologist's opinion that my heart had been attacked by a virus of some type.

Having said that, the cardiologist told me that there was nothing he could do for me, and I was either going to get better, or I was not. In other words, you are either going to live or you are going to die so you may as well get out of here! I was eventually released



with a discharge diagnosis of myocarditis, cardiomyopathy and depression. I had no rashes, no joint or muscle pain, paresthesias, etc. The only other discomfort that was not related to my galaxy of heart problems was an aching in the eyes. I immediately began a routine of vitamin and mineral supplementation that included approximately 36,000 milligrams of vitamin C taken in divided doses throughout the day in an attempt to kill whatever virus I was suspected to have.

Someway, somehow, I gradually improved and after about four years I was approxi-

mately 85% of my former self. Even back to running some 5-K races (slowly). Then, in 1998, my symptoms returned. This time I had it all. Along with the heart problems that resurfaced, I had every other symptom imaginable except irregular menstrual cycles (I'm male).

### You struggled for so many years; did you finally receive a diagnosis of Lyme disease?

Finally, after seeing 23 doctors, representing every specialty you can think of, losing 53 pounds and coming very, very close to death, I *"Poison Plum"...* cont'd pg 2

## Prominent Attorneys Join Forces to Protect Alternative Practitioners

by CAM News

A new concept in the delivery of legal services has been announced by four of the nation's most experienced attorneys in the complementary and alternative medicine ("CAM") and health care community. These independent attorneys, with over 60 years of combined experience, have launched a collaborative effort to provide comprehensive support and responsive legal services to integrative physicians, CAM practitioners, and their organizations.

Al Augustine, Alan Dumoff, Rick Jaffe and Jacques Simon have announced the formation of a legal consortium, the first such group formed in the history of the CAM movement. While these four attorneys will remain separate entities, they have agreed to offer their combined talents to selected clients, and collabo-

rate on a series of projects and exchange ideas in order to better serve the integrative medicine and CAM communities.

The Consortium's attorneys will assist clients in avoiding scrutiny or handle investigations by professional boards, regulatory agencies, or insurance companies, as well as in the prevention and defense of malpractice claims. The group can help clients bring their practices into legal compliance, and if necessary, provide representation before licensing boards or take court actions seeking to stop boards before they act to sanction health care professionals.

All four attorneys have nationwide experience representing providers in a wide array of circumstances:

\*Algis Augustine, a former professional board counsel himself, is well known for his defense of doctors and dentists utilizing alternative techniques;

\*Alan Dumoff counsels integrative physicians and CAM practitioners on legal compliance in addition to defense of disciplinary matters;

\*Rick Jaffe focuses primarily on criminal, licensing and appellate matters related to licensed and unlicensed professionals, and is most widely known for his successful defense of Stanislav Burzynski, M.D., Ph.D.;

\*Jacques Simon has brought a number of key state and federal constitutional and court legal challenges to state disciplinary actions against practitioners.

Working closely together, this "dream team" of attorneys will strive to:

\*Provide rapid response to protect CAM providers;

\*Pool their collective experience and information in order to better protect integrative physicians and CAM providers;

\*Work to create a database of nationwide legal issues relative to CAM; and

\*Collaborate on cases, where appropriate.

Ultimately, the group's focus is to match the correct legal talent to cases and, under independent arrangements with each client, advise and defend CAM professionals faced with state or federal regulatory, disciplinary or licensing matters, while providing insight into strategies CAM providers can implement to avoid liability all together. The importance of having access to this comprehensive representation when faced with any type of liability and the ability to have four separate attorneys, who are willing to collaborate in pursuit of the ultimate defense, can not be overemphasized.

"Dream Team" ... cont'd pg 5

## “Poison Plum” ...cont'd from pg 1

diagnosed myself, and demanded to be treated for Lyme disease. I think the internal medicine doctor I was seeing thought I was either going to commit suicide, kill him or both of us, because he whipped out a prescription pad and within thirty minutes nurses were sticking a needle in my arm for the infusion of Rocephin®.

The antibiotics induced a massive Herxheimer reaction so severe that I could not walk. My clinical Lyme diagnosis was also confirmed by a positive Lyme PCR, and Lyme Urine Antigen Test, (LUAT). I eventually had 136 infusions of Rocephin® (2 gm), 73 IV Zithromax®, 16 weeks of Bicillin LA® in the buttocks and years of orals. Was I cured? No!

### Why did you decide to write a book?

Anger! One afternoon as I sat on my deck looking at the waters of the beautiful lake I live on, I glanced down at the PICC line hanging out of my arm, and began pondering my plight. Lyme disease had wrecked my life, my previously excellent health, my respect for a sizeable portion of the medical profession, and my bank account. I was out at least a quarter of a million dollars in lost business and non-reimbursed medical expenses. I had been through hell sideways with all of the problems and obstacles I had endured and I was, and still am "mad as hell!"

### So there you sat suffering, looking down at your PICC line, and realized you had a message to send to the world?

I realized at that moment that something had to be done to get our message to the general population. The book is designed to appeal to a very broad audience of people that may be simply looking for a good read but come away with much, much more.

### Can you tell me a little about the plot of *The Poison Plum*?

The heroine of the book, Susan Collins, is a single mother with an eight year old son that becomes ill with a mysterious disease shortly after they relocate to Connecticut for her to accept a position as a microbiologist with the Plum Island Animal Disease Research Center. As the plot unfolds, and Susan's son Toby becomes sicker and sicker, the reader shares Susan's concerns, fears and revelations of discovery as she

experiences fully the gamut of mystery, intrigue, suspense, frustration, government lies, cover-ups, murder and deception that are so very much a part of the Lyme disease conspiracy.

### What do you know about the real Plum Island?

Plum Island is but one of several top-secret government biological research laboratories that are scattered about the nation. Their stated objective is defensive germ research designed to protect us and our livestock population from diseases. In my humble, personal opinion, the research is also offensive; meaning they are genetically engineering germs to be used as biological warfare agents. I think Lyme disease is but one example of this type of research and development. Offensive not defensive!

The end sheets of my novel are maps of the coastline of Connecticut and the tip of Long Island which are constant reminders to the readers of the very close proximity of Lyme, Connecticut to Plum Island.

### How is *The Poison Plum* different from other books on Lyme disease?

To my knowledge, *The Poison Plum* is the first and only novel to be written about the shadowy and murky world of Lyme disease. It is a novel with powerful and passionate fictional characters which portray, clearly, their real life counterparts. Some have called the book "true fiction" and perhaps that is a good description. Some readers have suggested that I changed the names of the guilty and they are correct. Indeed, on the title page, I have the admonishment that "The guilty among you will know who you are."

### What are the most interesting discoveries you've made about Lyme disease?

First, Lyme disease is unique in that it is a "do it yourself" disease. All too often the hapless victim must endure the gauntlet of a frequently inept, if not downright hostile medical community, to finally diagnose themselves, develop through an extensive research program a treatment regimen,

properly treated, the resulting financial strain would bankrupt every health insurer in the nation!

Obviously, insurance executives are not stupid people. Clearly, they understand these potential risks to the bottom line of their companies' balance sheets and it is certainly logical to assume that at least some of the opposition to long term antibiotic therapy, indeed the very existence of Lyme disease as a common health

problem, emanates from this quarter. The squeaking wheel will get the grease as members of state legislatures and state attorney generals respond to the outcries and there will appear many more Blumenthals stepping up to the bat on our behalf.

The final crisis will be the launching of a massive class action lawsuit against the government's bio-labs that will make the government's compensation payments to the Tuskegee syphilis experiment's survivors look like a Sunday school picnic.

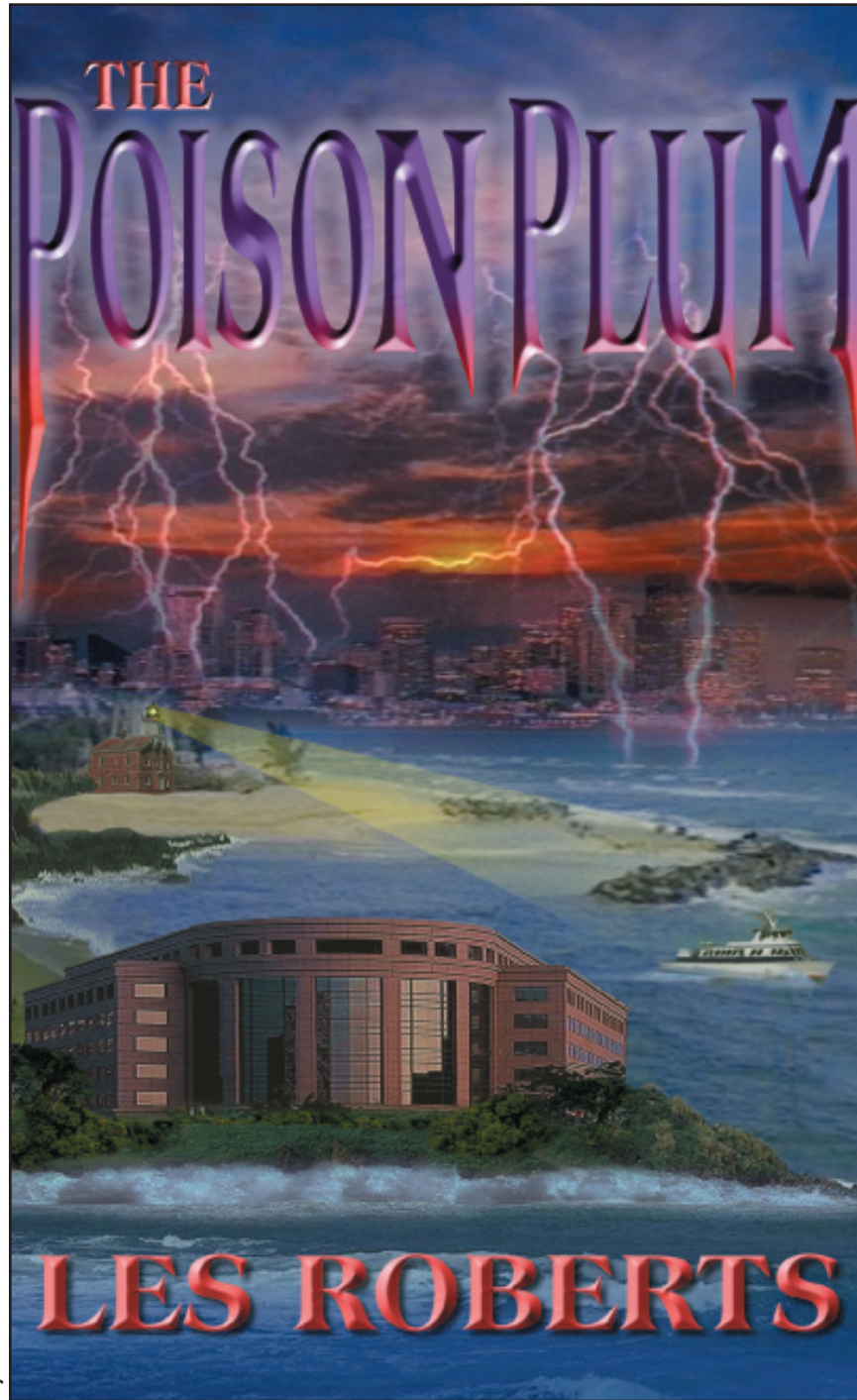
### Thank you Les, you certainly hit the nail on the head with your answers. Any parting thoughts?

In conclusion, I would like to make one more point. If the doctors that are members of the IDSA and others of the "No Such Thing as Chronic Lyme" camp; Feder, Shapiro, Steere, Wormser, Johnson, O'Connell, et al, are so firmly convinced of the correctness of their positions, I would suggest it's time for a public affirmation of their faith. I would like to offer several pints of my blood which the doctors with compatible blood types could infuse into their bodies to prove beyond a shadow of a doubt that the four years of antibiotic therapy I received completely eradicated every single wiggling and twisting spirochete in my body. I will hold my breath while eagerly awaiting a volunteer to accept this challenge.

Les Roberts' website: [www.poisonplum.com](http://www.poisonplum.com)  
Purchase *The Poison Plum* at [www.poisonplum.com](http://www.poisonplum.com)

For the readers that might want all of the lurid details of Les's story it is available on Scott Forsgren's website, [www.BetterHealthGuy.com](http://www.BetterHealthGuy.com). Look for the article entitled "Les Battles Lyme." There, Les includes a long and comprehensive list of what treatments were beneficial and those which were a waste of time and money.

A portion of the article also deals with interactions between Les and various physicians which should be sufficient to raise the average Lyme's blood pressure. *pha*



### What has the feedback from the general readership audience been?

Stunning! I have been surprised and delighted with the book's reception! Every single reader to date has responded very positively with several purchasing additional copies to give to friends and associates.

### Have you received any negative feedback from the anti-Lyme camp?

Yes. Some of my paid advertising for the book has been rejected

with no explanation provided and I have been the target of some very vicious blogs. All of this and more I fully expected in the beginning.

We must realize that this is a war that we are engaged in. Now is not the time to make nice or equivocate on issues to which we are strongly committed.

The closer you get to the truth, the more you are attacked. Expect it!

### What do you feel has to be done to give Lyme disease the awareness and respect it deserves?

Unfortunately and unpleasantly the problem will be self-resolving. Let me explain: As the numbers of sick and dying Lyme victims contin-

and then somehow find a doctor that will agree to their self-prescribed treatment protocols. How much sense does any of that make? This insanity has to end and it has to end now!

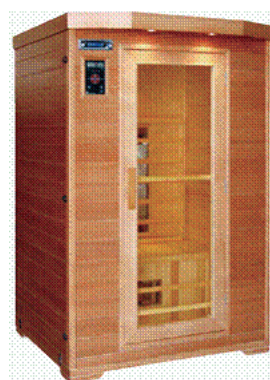
Secondly, as an investment professional, my personal research quickly revealed to me that with the current infection rate of Lyme disease throughout America, it will only be a matter of time before our nation will be facing a health crisis of unprecedented proportions.

### How serious of a national health crisis do you think Lyme disease truly is?

It is my personal opinion that if every person in the United States that is currently infected with the Lyme germ were properly diagnosed and



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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 nationwide 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's attention. We seek to make sure that anyone struggling with these diseases has proper support emotionally, physically, spiritually and medically.

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## Letters to the Editor

Dear Editor,

Hoarding, a little known side affect of Alzheimer's disease, has strangled my father's life.

Webster's Dictionary defines hoarding as the "act of storing up," but how does hoarding relate to Alzheimer's? Is physically "storing up" the off-the-mark antidote for mental wasting away? Or, do seeds of hoarding, planted long ago, grow like kudzu with Alzheimer's?

In his younger days, my eighty-six year old father warned against going off "half-cocked." No matter where we chose to go, preparation was key. Beginning weeks in advance of any vacation, Dad prepared for the trip by mounding gear in his den--a first-aid kit and tools for any emergency, clothes for all types of weather, and food to suite every whim.

At age seventy, when

my dad purchased a vacation cabin in Minnesota's north woods, the preparations turned to fortifications; our family stronghold amid the pines and birches would hold everything, want for nothing.

By age seventy-one, Dad could drive to the cabin by rote but he had no sense of direction, recognized no landmarks. Since he had been a navigator in the Second World War, we knew something was wrong. My sisters and I later learned disorientation often marks the initial stages of Alzheimer's disease.

Over the last fifteen years Dad's "supplies" for the cabin filled his GMC Suburban from bed liner to head liner may times over; consequently, our refuge in the woods has become as cluttered and disorganized as his mind. Hoarding tens, twenties, and thirties of useless items is Dad's compul-

sion, his obsession, his raison d'etre.

Books on Alzheimer's disease connect hoarding behavior with hiding things and offer some strategies for controlling hiding compulsions but offer no advice on hoarding. Public Health Alert readers may want to know how the hunter/gatherer stage of a parent's Alzheimer's disease affects loved ones. I'm sending you my "hoarded" 900 word reflection for your consideration.

Marina Andrews  
(out-of) Luck, WI

*[Editor's note: Marina, I will print your reflections on hoarding below.]*

Dear Editor,

In my "Sitting on the Fence: Looking at Lyme Disease" article I made a mistake.

I attributed the Acrodermatitis Atrophicans (ACA) rash of Lyme disease to Dr. Rudolf Scrimenti. According to Karen Vanderhoof-Forschner's book--"Everything You Need to Know About Lyme Disease"--Dr. Scrimenti recognized the Erythema Migrans (EM) of Lyme disease not ACA, in 1970. Scrimenti sent his findings to Dr. Allan Steere when Dr. Steere was looking into the "juvenile rheumatoid arthritis" cases in Old Lyme, CT five years later.

Dr. Paul Lavoie and his associates are credited by Vanderhoof-Forschner with finding the ACA rash in California in 1986.

I apologize for the error.

Johanna Lake

## Alzheimers and Hoarding Behaviors

### A Daughter's Reflections

by Marina Andrews

The solace of our primitive north woods cabin evaporates as I open the door. Signs of my father's advancing Alzheimer's reign: an open can of black olives stands suppurating on the table; braided rope dog toys lie in the dish rack; two more dogs toys are pinned to the bulletin board; and mouse-attractive suet cakes and a birdseed bell share counter space near the sink.

Having to empty the can of olives and finding coffee molded over green in the pot on the stove makes me angry. Since months might pass between cabin visits, leaving everything orderly for the next visit or visitor has been standard practice. Why did my dad leave the cabin this way? Would I find another part of his brain crumpled into the chaos he left behind?

Sitting on the floor near the bunk beds are two large clear-sided storage boxes of "supplies" Dad hauled to the cabin. Obviously unopened and not put away by my dad on his last visit, the contents of the first box yield, on opening, several sets of barbeque tools, eight bars of bath soap (for a cabin with no running water), twelve-packs of dishcloths, decks of playing cards, thousand-count packages of rubber bands, wood chips for grilling, and more suet cakes, birdseed bells, and dog toys. My frustration with the excess turns to tears. Why? My dad is hoarding. He's been on a buying binge for years.

Looking around the cabin I note areas of Dad's concerted efforts. Fourteen flashlights fill a bin on the buffet; a wire shelf sags with enough aerosol cans of bug spray and air freshener to alleviate the insect bites and foul smells of a small nation; and a kitchen drawer no longer shuts over so many new kitchen towels a tract home subdivision could enjoy a never-ending supply. I open a cupboard. I count eleven boxes of cereal, eight unopened. Eleven boxes of cereal on a shelf in our one-room cabin, a

cabin used thirty days a year.

Dad spends whole days shopping dollar stores and routinely makes a beeline for the clearance area in any store. Most of the things he buys are "for the cabin," though he constantly unloads "gifts" on his daughters and sons-in-law. He's also fond of sale catalogs of discount merchandise, buying such useful items as brass-plated, Bozo-the-Clown horns with black bulbs that leave dark sticky residue on palms each time the horn is honked.

According to the books I've read, hoarding and then hiding the hoarded items is a behavior pattern typical of

Alzheimer's disease. My dad doesn't hide his purchases. I don't think he has time. He's off compulsively buying them.

When my sisters and I consult a specialist on aging to ask about hoarding, I emphasize the bounty of cabin supplies by recounting the plight of a friend in difficult circumstances:

"From the cabin I outfitted my friend with everything from a coffee pot--there are still three left--to bed linens to Band-Aids. I took enough food to last her for a month, too, and my dad never missed a thing!"

The specialist nods and tells us nothing will stop the hoarding unless we are willing to extract the one remaining credit card and all the cash from Dad's wallet. We concede we're not willing to do that--yet.

We've learned not to praise the rain gauges, notepads, grass seed, paper plate holders, and salt and pepper shakers effusively, or we're likely to receive more of the same and we've learned to say nothing is needed at the cabin because

Dad buys in triplicate, forgets, and buys in triplicate again.

Returning items to stores would be an option if Dad could remember to save receipts; he can't. Talking to him about his buying and hoarding draws a hurt look and I feel badly for saying anything, though ten seconds later Dad forgets what was said and asks for the millionth time about buying storage units or adding on to the cabin to

hold all the "junk." We've tried taking away the excess, he simply buys more.

Because I manage his checkbook, contributions to Dad's favorite charities have ceased. He doesn't understand his spending supersedes monetary

requests of The Little Sisters of the Poor or The Union Gospel Mission. "Dad," I chastise him, "Stop buying all this stuff! Hungry people don't need barbeque tools! They need something to eat!"

I've given food from the cabin to a foster home and kitchen utensils to a cabin neighbor. I've passed on "gifts" to friends, too, and last Christmas, our family held a white elephant exchange, recycling countless "gifts" Dad had already given.

I often wonder what part of Alzheimer's prompts his buying/hoarding frenzy. Do "BUY!" signs spin round and round in my dad's brain like a hamster on a treadmill? Like Post-it notes on a Ferris wheel? Or are his thoughts lodged like a cork pushed into a wine bottle? Is the buying and hoarding pattern the same one responsible for the stories dad tells over and over? He cranks up his stories like an ancient gramophone. Each story is new to him, told to entertain us. The

same stories heard fifteen times a day are heartbreaking. So and so called yesterday, he'll tell us, though the call may have come years ago.

My husband says Dad's memory loss means he's "just getting old." I know it's more than that. I know Alzheimer's is likely to envelop my dad in clouds far blacker than the buying compulsion. Right now he still knows who we are, he's not wandering away from home except in the aisles of stores, and he hasn't lost his wallet due to hiding it--lately. Nevertheless, the buying bothers me. "Leave your dad alone," hubby says, "He likes buying stuff. It's what he does."

One part of me says my dad should spend his money any way he wants to spend it, that I should be thankful he doesn't gamble or drink the money away, but another part of me wants to scream out loud as I view the contents of the other storage box at my feet: thirty-packs of purse tissues, twenty bright orange emergency rain ponchos, fifteen extra-long bungee cords, and seven giant-sized bottles of Lawry's Seasoned Salt. I know Dad's trying to provide for us, to make sure we never run out of anything--that the cabin's always well-supplied--but his preparations remind me of pharaohs tombs lined with treasures for the "journey." Whose journey is this?

Both the wasting of my father's mind and the waste of money bother me equally. *pha*

### Author's note:

Two years after I wrote this story, I learned my father had Lyme disease. I believe he struggled with the illness all his life and was re-infected while working on an addition to the cabin over the spring, summer, and fall of 1990. His blood tests were CDC-positive.

# Dying to Serve

## A Spotlight on the Military's Mandatory Anthrax Vaccine Program

(Part 2 in the vaccine series)

by PJ Langhoff

I watched a recent episode of the Montel Williams show, with keen interest. Having several generations of family members who served in the military, including but not limited to my father, brother and nephew, I wanted to learn about the military's implementation of vaccines to its soldiers. The subject matter of this show was the anthrax vaccine in the military's voluntary / mandatory vaccination programs. I listened to several medically discharged Air Force veterans describe how the receipt of the anthrax vaccine, quickly, dramatically, and permanently altered their lives.

One victim described how at age 35, she was told that her neurological problems, slurred speech and the documented shrinking of her brain's cerebellum (the portion controlling motor skills, coordination, and balance); and damage to her frontal lobe were "possibly" related to her receipt of the anthrax vaccine. She had genetic testing done to prove her illness was not a predisposition. According to the guest, at the onset of her illness, she was told by the military that it was "normal" and that it would "go away in a month". She also describes how she was told to "go home and see if friends or family noticed" her disability. She was eventually honorably medically discharged and given 100% disability.

A guest of the show was Scott Miller, who created the film documentary "A Call to Arms", which he said was "too controversial" for television and film festivals. His film included a female pilot who felt "betrayed" by the army's implementation of the anthrax vaccine, after which she says she suffered memory lapses, weight loss and horrible seizure-like brain activity following meals, which left her within minutes, curled in the fetal position crying.

Other guests described how 55 of 120 military pilots (about half a squadron) walked out of a May 1999 Dover Air Force Base (Delaware) meeting

on anthrax, and quit because they refused to take the then-mandatory vaccine. A retired Sergeant, after receiving one of the six-shot series, had a reaction and filed a VAERS report, (vaccine adverse events reporting service) which prevented him from being forced to receive the balance of the immunizations. Surveillance for adverse events following vaccination is monitored and jointly managed by the FDA and the

8/15/05, which described 6 reports of women who received the vaccine while pregnant. Spontaneous abortions, renal failure, birth defects, and deaths were reported, suggesting that the vaccine "may" be linked to an increase in the number of birth defects when given during pregnancy.[1] The package insert dated January 31, 2002 from Biothrax (Anthrax vaccine adsorbed [AVA], Bioport, Inc., Lansing, MI), says the

unknown at that time period.[2]

Data from the VAERS Vaccine Reports from 2005 discusses 390 (9.1%) "serious" adverse events reported out of 4,279 received. This is significantly higher than the manufacturer's reported adverse events rate of 0.2%. These numbers are more likely 5-35% according to the Anthrax Vaccine Network, Inc. ([www.mvrd.org/AVN/](http://www.mvrd.org/AVN/)), an informational web site about

making standardization difficult..." (Patent #7,261,900). Admission that anthrax is a "complex, poorly understood disease..." can be found within U.S. Patent # 7,279,320, filed in June 2003. Patent #5,840,312, filed in October 1994 for recombinant Baccillus anthracis strains, discusses the swapping of anthrax protein plasmids (gene manipulation) to create within the body, the desired protective antibody effects. This deletion of genes and insertion of a "DNA cassette" changes the coding for anthrax proteins which normally create a toxic effect. There are 3 proteins in the Anthrax toxin; protective antigen (PA), lethal factor (LF) and edema factor (EF). Neither LF nor EF is toxic alone, but combined with PA, they can produce deleterious effects. The reengineered proteins which should be rendered harmless cause the body to produce antibodies to anthrax. This process is not dissimilar to the way that other vaccines might work. But since anthrax is admittedly poorly understood, recipients might want to question the vaccine's safety and efficacy and examine available research.

While there are a number of studies describing the safety and efficacy of the vaccine, one study of adverse reactions monitored 129 vaccine recipients (including 24 who had been immunized 7 years previously and subsequently re-immunized). Participants were monitored at 0, 3, 6 and 24 weeks. Initial adverse reactions were reported in 63% of patients. Out of those with adverse reactions, 45% caused incapacity. At 24 weeks, only 22% had completed the vaccination series. The study concluded that immunization with anthrax resulted in a higher prevalence of adverse reactions, and initial incapacity of "military significance" of 18%. The study also indicated that "poor completion rates necessitate development of a new anthrax immunization strategy." [3]

Indeed what is the safety and efficacy of a vaccine "soup" which consists of addi-

"Anthrax" ...cont'd pg 6



CDC, who together with the NIH and Department of Defense, say that the anthrax vaccine is "safe and effective." From 1990 to 2001, over 2 million doses of the anthrax vaccine were administered in the United States, with approximately 1850 (6%) spontaneous, "serious" reports of adverse events following vaccination.

The program discussed the fact that military women who received the anthrax vaccine are advised not to become pregnant within 18 months following the receipt of the vaccine, because of pregnancy problems and "possible" birth defects. Images of many children with missing and disfigured limbs were shown on the program. These recommendations are echoed within documents such as the Review of VAERS Anthrax Vaccine Reports Received Through

same thing, according to unpublished Department of Defense data. The insert recommends "Although these data are unconfirmed, pregnant women should not be vaccinated against anthrax unless the potential benefits of vaccination have been determined to outweigh the potential risk to the fetus", and administration of the non-live vaccine during breast-feeding was also medically contraindicated. The frequency of reactions following vaccination would appear minimal according to the package insert. And yet the CDC indicates in a Notice to readers dated 02/15/02 (just one month later than the creation of the package insert), that with respect to Anthrax, "no studies of animals or pregnant women have been conducted" which would seem to indicate that safety and/or efficacy were

the vaccine, including suggestions for military members facing mandatory vaccine receipt. The VAERS Reports list whole-body, nervous system, cardiovascular, musculoskeletal skin, digestive and respiratory adverse events as the most common, with many problems surfacing within the first 90 days, including 3 suicides, at doses 2, 3, and 4, at days 875, 1150 and one day, respectively, following vaccination; 3 reports of bipolar disorder following 1 dose, and 13 reports of depression after between 1 and 6 doses of the vaccine.[1]

Patent applications for the U.S. licensed vaccine for anthrax Anthrax vaccine adsorbed (AVA) indicate that "AVA elicits a relatively high degree of local and systemic adverse reactions probably mediated by variable amounts of undefined bacterial products,

May be useful for:

- \* Heavy Metals
- \* Liver detoxification
- \* Weight loss
- \* Cholesterol
- \* Lyme disease
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## Making the Best of Every Situation



by *Maggie Sabota*

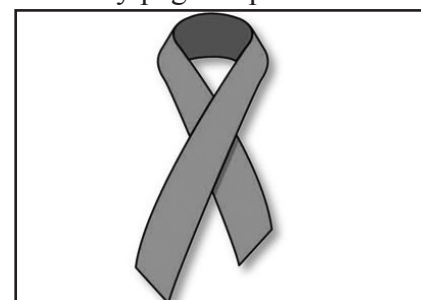
When someone you love is diagnosed with a chronic illness, it is so easy to question why this happened to them. My mother has had Lyme disease for the past fourteen years and I still haven't found a good answer to that question. One thing I do know is that many blessings in disguise have come from her illness.

First, I have come to appreciate just how important family and friends are. When my mom is going through one of her bad spells, it is family and friends that get us through.

They visit, bring meals, and offer prayers and support. My mother's illness has brought our whole family so much closer together.

Second, I have become very comfortable around people with disabilities. Growing up, my mom was always using different devices from canes, to a walker, to a wheelchair. This has taught me to have a servant's heart, and I take great pleasure in helping others. My mom has always encouraged me to help others, so we have spent a lot of time at nursing homes and senior centers.

Finally, I have the opportunity to share about Lyme disease as Miss Cumberland County. During my year so far I have given presentations to over 500 people about Lyme disease prevention. Because of my mother's experience with Lyme, I am able to speak passionately about my pageant platform.



## The Faith Factor...

by *Joan Vetter*



Have you seen those inkblot pictures where you are supposed to find the face of Jesus?

Depending on where your eyes focus, suddenly He becomes clear. And then you wonder why you didn't see Him at first because now you can't see anything but Jesus!

The beginning of "faith" is always to SEE Jesus. How do we begin? First, ask yourself if you have truly encountered Him? Sometimes the road to real faith is to ask real questions. For instance when Jesus said to Nicodemus, "You must be born again." Nicodemus gave an honest answer: "How can a man be born when he is old? Can he enter a second time into his mother's womb and be born?"

As Jesus converses with Nicodemus, His words are now one of the most-quoted Bible verses: "For God so loved the world that He gave His only begotten Son, that whoever believes in Him should not perish but have everlasting life." (John 3:16)

We aren't told if Nicodemus truly understood what Jesus spoke, but somehow I believe He did. My question to you is, "Have you been born

again?" Is your faith picture coming into focus? Have you gotten to the place where you can say, "Yes, I see Him"?

A friend of mine wrote the following poem that describes what it's like to meet Jesus.

### The Man Above All Men by P. A. Oltrogge, 2005

Have you met up with Jesus?  
He's your kind of Man...  
Came down here from heaven,

Carrying out  
God's mighty plan.  
He's still here today,  
Capturing hearts,  
lives and souls,

Giving all whom He touches  
much worthier goals.

He doesn't actually show up  
in visible form,

But you're aware of His  
presence

When prayer becomes norm.

And some have had visions  
Or have seen Him in dreams,  
And what they remember is the  
love that He beams...

That's also reflected in the  
Words of His book,  
The renowned Holy Bible is the  
right place to look.

You might think you know  
What could give you life's best,  
But those who follow His lead  
are on a sure quest.

He wants to increase your every  
potential,

But living for Him and others is  
essential.

Dedicating all that you have to  
Him is not loss -

The best in mind for you is why  
He died on the cross.

I remember so clearly  
the day I met Jesus. It was  
Easter. We had four children  
under 5 years old. My husband  
traveled all week, and I truly

needed an Easter resurrection in  
my life. I thought I believed in  
Jesus, but I needed something  
more - something viable to give  
me strength and direction.

I went to hear my neighbor's son-in-law speak at a local church. There I saw people praying for one another. I felt love in that place, and I heard the speaker's compelling message about leaving his wealthy family's brick business to go into the inner city and work with poor kids.

The next day I called my Methodist pastor, asking him to come see me. As we talked in my living room, I found myself spilling out my doubts about the Bible and asking my pastor how we can really know that Jesus rose from the dead. I remember thinking I shouldn't be saying this to a pastor! He just smiled at me and said, "I'll pray for you and the Holy Spirit will show you." He said a quick prayer and left.

Immediately I picked up my Bible, and when I read the words about Jesus in the Book of John, suddenly I knew they were true. There was a light present at that moment and the feeling of love like I have never experienced. For two weeks the trees were greener, the sky brighter, and the whole world was bathed in love.

After we are reconciled to the Father's love through Jesus, we begin to focus on loving Him and loving others, thereby beginning to bear fruit. At this point it is the Word we focus on - still asking honest questions because God's Word tells us in James 1:5, If any of you lacks wisdom, let him ask of God, who gives to all liberally and without reproach, and it will be given to him.

## FOCUS: Eye Opening Faith

Often the very question you've asked will suddenly be answered as you are focusing on the Word. Remember it is the Holy Spirit who illuminates the Word, or words people speak, to bring into focus something you are asking for. For instance, when we were planning to move to Arlington, Texas, I felt like the Lord prompted me to sell our Florida home, using the By Owner format. As the time got closer to our move I began to get anxious, so I asked the Lord for a confirmation that we really were suppose to sell By Owner. Then Hebrews 10:37 came to me - "For yet a little while, and he who is coming will come and will not tarry."

Now the true meaning of that verse is that Jesus is coming back, but the Holy Spirit used it to speak to me to stay the course - that the buyer for our home would come in a little while. After that I had peace until the day a Real Estate Agent came and put in an offer for himself. The contract he brought was perfect, with a closing date that was right after we closed on our home in Arlington!

If we focus on circumstances or ourselves, we can get so discouraged. We're pretty good at pointing out all our inadequacies and problems, and the devil loves to come into agreement with us. I love to pray often "Thy Kingdom come, Thy will be done".

Of course there are those times when our circumstances seem insurmountable - we can't see the end, and have no clue how God will change things or intervene in the situation. That is a time to focus on hope. In Hebrews 6:19 the Bible says "This hope we have as an

anchor of the soul, both sure and steadfast, and which enters the Presence behind the veil, where the forerunner has entered for us, even Jesus." It is our soul (mind, will and emotions) that needs to be stabilized. Just think about it - by faith we can cast an anchor to where Jesus dwells, and then our soul doesn't drift, but remains steady. We can pray like the psalmist, "Why are you cast down, O my soul? And why are you disquieted within me? Hope in God; for I shall yet praise Him, the help of my countenance and my God." (Ps. 42:11)

Sometimes when we should focus on Jesus Christ, our vision becomes blurred-as though we had spiritual cataracts. Our future looks fuzzy and unclear. In those moments of blurry vision, it's time to praise God and go back to the "map" - the Word of God.

Sometimes I wish God was more like a GPS system - where we could just type in our day and watch and listen to His directions step-by-step. I remember a shopping trip to K-Mart when we lived in Ohio.

As I stepped into the area where the automatic doors opened, I had this impression from the Lord, "You could have just been a step away and prayed for the doors to open, but they wouldn't have opened because you needed to get in the right position." Suddenly I realized prayer is not demanding my own way - but stepping into the presence of God and co-operating with Him.

Have you seen Him? Are you focusing on Him? If so, then others will see Him in You.

*pha*

## South Texas Doctors Report More Severe Cases of Community Staph 'Super Bug' Hospitalizing Children

by Driscoll Children's Hospital

**CORPUS CHRISTI, Texas** -- A lesser known antibiotic-resistant bacteria is a growing danger to otherwise healthy kids across the nation. Doctors are seeing the potentially deadly staph infection known as Community Acquired-Methicillin-Resistant Staphylococcus aureus (CA-MRSA) emerging in epidemic proportions. South Texas was one of the first regions of the country to experience CA-MRSA and has since

become a hot bed for the infection.

"We've seen that MRSA working in the community is much more virulent," says Jaime Fergie, MD, Director of Pediatric Infectious Diseases at Driscoll Children's Hospital in Corpus Christi, Texas.

In the past, MRSA was well known as an infection acquired in health care facilities or nursing homes. Today, the contagious "superbug" is stronger and it's in the community.

Some severely infected children are requiring multiple surgeries

including orthopedic, cardiothoracic, and drainage procedures to get rid of the infection.

Fortunately, most infections are easy to treat with a simple incision and drainage, and use of stronger antibiotics. The New England Journal of Medicine states MRSA is the most common identifiable cause of skin and soft-tissue infections in emergency rooms nationwide. Commonly referred to as "community staph," the infection's bacterium enters the body through skin wounds and appears as a boil or abscess

sometimes mimicking a spider bite. It can also invade the blood stream infecting bones, joints, muscles, and lungs. Most children present with skin and soft tissue infections, but some develop life-threatening conditions, and a few have died. Fergie, a leading international expert on CA-MRSA, has been studying MRSA and CA-MRSA comprehensively for 13 years. Based on his research conducted at Driscoll, he has seen a significant spike in the number of patients with community staph and its severity.

Fergie, and Kevin Purcell, MD, co-authored a 2004 study which indicated the rate of patients with CA-MRSA increased from five per 10,000 patients in 1999 to 360 per 10,000 in 2004.

Additionally, 628 cases were identified in 2006 and, to date, 281 cases in 2007.

"Although potentially deadly, CA-MRSA can easily be prevented by diligent hand washing and good hygiene," says Fergie. "Parents need to know what the symptoms are so it can be caught and treated early." *pha*

## "Anthrax" ... Cont'd from pg. 4

tives such as "harmless" parts of anthrax bacteria, aluminum, benzethonium chloride, formaldehyde, and squalene? The military's AVIP (anthrax vaccine immunization program) describes ingredients in the anthrax vaccine which it says are all FDA-approved. The site lists the PA protein (protective antigen) as the vaccine's main ingredient. It states with regard to the aluminum adjuvant, that "many other vaccines contain aluminum" but this does not mean it is safe. It also says that benzethonium chloride is a preservative (also used in medications, injections, eardrops and creams). Formaldehyde is a stabilizer to increase shelf-life, and that "trace amounts" of squalene have been "detected in some lots of anthrax vaccine." It claims that squalene is "an oil found naturally in the human bloodstream that is essential for life." [4]

The Vaccination Liberation information website discusses the composition of vaccines and has this to say about some of these ingredients. Aluminum is listed on at least 2 federal regulatory lists, is more hazardous than most chemicals, and is a cardiovascular or blood toxicant, and is a neuro- and respiratory toxicant. It is an EDF-suspected carcinogen. Formaldehyde is an EDF-recognized carcinogen, and is immuno-, neuro-, reproductive, skin, organ, gastro and liver toxicant. It is on at least 8 federal regulatory lists, and one of the most hazardous compounds

in human health (and worst 10% to ecosystems). See [www.vaclib.org/basic/vacingredient.htm](http://www.vaclib.org/basic/vacingredient.htm). Benzethonium chloride is an anti-infective used in cosmetics, and personal care products like anti-itch creams, towelettes and wipes. It is orally toxic and is a neuromuscular toxicant. Squalene occurs naturally in humans, plants and marine animals, and is a biochemical precursor to the whole family of steroids. It is also an important anti-oxidant and anti-cancer tool. The FDA found squalene at 10 to 83 parts per billion within 3 vaccines; anthrax, tetanus and diphtheria. [4]

The National Vaccine information center (Vienna, VA, [www.nvic.org](http://www.nvic.org)) says that the vaccine adjuvant "MF59" which contains squalene, and which can cause autoimmunity, is something the NIH (National Institutes of Health), is proposing for flu vaccines. It says that Gulf War veterans were given anthrax vaccines and tested positive for squalene antibodies, despite the U.S. Department of Defense's denial that MF59 appeared in their vaccines. The site warns of mandatory vaccines containing squalene that could one day be declared mandatory during epidemics. The site also says that the vaccine adjuvant, MF59 is not licensed in the U.S. as safe for human use. Some ill Gulf War veterans who were given anthrax and other experimental vaccines, have tested positive for squalene antibodies. [5]

A letter from Dr. Galo Grijalva dated February 7, 2005 to the FDA alleged that the squalene-containing anthrax vaccine was "illegally given to our soldiers" and was "not the same vaccine that was originally licensed, nor was it used for what it was licensed for." Dr. Grijalva calls the anthrax vaccine "a monumental travesty, and a raping of an unsuspecting and patriotic force." Dr. Grijalva urges the FDA to stop the Dept. of Defense's "illegal" use of the adjuvant. Dr. Grijalva mentions the recent study by Russian scientist Ken Allibeck which acknowledged that bioengineered anthrax would be resistant to any vaccine or antibiotics. [6]

Some audience members walked out in obvious anger and upset during the middle of the Montel show, and of whom Montel pointed out consisted mainly of active duty service members. Perhaps the audience members were angered by the mere mention that there could be a causal relationship between what the military was injecting into voluntarily enlisted men and women, and the possibility that the injections might be causing irreparable harm. Montel was undeterred however by the interruption. The adage "the truth hurts" may certainly apply to this situation. No one wants to believe that in return for voluntarily serving our country, that the U.S. military might entertain the utilization of its soldiers as experimental guinea

pigs in its vaccination research programs (and I am not saying that they are), or that they might inadvertently be harming our children instead of protecting them while they heroically and unselfishly protect and serve the American people.

Those watching the Montel show are nevertheless left with many questions unanswered, among which is, "are vaccines of any kind effective, or even safe?" Whatever your position on the anthrax and other vaccines, before deciding if vaccination is right for you, you must do the research and consider all options, including ingredients, risks, your overall health, disease history, genetics, side-effects and benefits. It would seem that making the decision to vaccinate (or not) is becoming nearly as complex as the vaccines themselves. In this day and age, we can no longer rely on anyone's advice or government recommendations alone. Vaccines are not fool-proof and long-term studies have yet to determine safety and efficacy. The bottom line with the anthrax vaccine at least at this time, is as stated within its patent application, that it is complex and poorly understood. Isn't that enough to make you stop and think before you agree to be vaccinated? It does for me. *pha*



PJ Langhoff is an author and freelance writer for PHA and has published several books and articles, including scientific articles with multiple physicians.

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# Columbia University Medical Center Leads First Placebo-Controlled Study of Cognitive Impairment Due to Chronic Lyme Disease

## Findings Show Severe Physical Dysfunction Among Patients & Benefit of Repeated IV Antibiotic Therapy to Provide Long-Term Symptom Relief



**Dr. Brian Fallon, lead researcher from Columbia Univ. on Chronic Lyme Study**

**NEW YORK-** Findings from the first placebo-controlled study of chronic cognitive impairment after treated Lyme disease (also known as chronic Lyme encephalopathy) demonstrate that patients report moderate cognitive impairment, physical dysfunction comparable to patients with congestive heart failure, and fatigue comparable to patients with multiple sclerosis. In the study, repeated intravenous (IV) antibiotic therapy was shown to be effective in treating cognitive dysfunction and the debilitating pain, fatigue and physical dysfunction associated with this disease.

The study, titled "*A Randomized, Placebo-Controlled Trial of Repeated IV Antibiotic Therapy for Lyme Encephalopathy*," will be published on-line by the journal *Neurology* on Oct. 10, 2007. The study was led by Principal Investigator Brian Fallon, M.D., M.P.H., director of the recently established Lyme and Tick-borne Disease Research Center at Columbia University Medical Center ([www.cumc.columbia.edu/news/press\\_releases/fallon\\_lyme\\_center.html](http://www.cumc.columbia.edu/news/press_releases/fallon_lyme_center.html).) The research was conducted jointly at the Columbia University Medical Center and New York State Psychiatric Institute and was funded by the National Institute of Neurological Disorders and Stroke (NINDS).

"These findings replicate results from a prior placebo-controlled trial of post-Lyme fatigue, which found positive treatment results from repeated antibiotic therapy. They also replicate the degree of physical impairment results demonstrated in another prior study of chronic Lyme disease," said Dr. Fallon (\*see citations below). "The door should be left open for physicians to prescribe medications as warranted, after a careful discussion with the patient of the potential risks and benefits."

Dr. Fallon and his research team identified patients with cognitive problems that developed after being diagnosed with Lyme disease and which persisted or relapsed despite prior treatment, in order to determine whether patients who have already received the "standard" course of antibiotic

treatment (three weeks of IV antibiotic therapy), would benefit from an additional 10 weeks of antibiotic therapy. They also set out to determine whether patients relapse when taken off antibiotics or whether the alleviation of symptoms is sustained or enhanced with time.

Study participants (57 subjects: 37 patients with a history of Lyme disease and 20 controls) were divided into three subject groups: patients with a history of treated Lyme disease who were randomized to IV treatment with an antibiotic called ceftriaxone for 10 weeks; patients with a history of treated Lyme disease who were randomized to IV placebo for 10 weeks; and, healthy controls who were tested at the same time points as the patients to help to control for the practice effect on neuropsychological testing. All patients had to meet criteria for memory impairment at the start of the study and they were also required to have a positive IgG Western blot for Lyme disease at study entry.

**Key findings from the Neurology paper are as follows:**

**Cognition**

\* There was significantly greater improvement in cognition in the antibiotic treated sample at the primary end point for efficacy (week 12).

\* When patients were retested three months after antibiotic treatment, the initial gains in cognition for the ceftriaxone-randomized sample were no longer present.

\* Patients lose their cognitive improvement when IV antibiotic therapy is stopped.

**Pain, Fatigue and Physical Dysfunction**

\* Among patients with greater severity at the start of the study, those randomized to ceftriaxone had more significant symptom relief of pain, fatigue, and physical dysfunction at week 12, as compared to those patients who did not receive ceftriaxone.

\* Patients initially randomized to IV ceftriaxone who had greater severity of symptoms at baseline continued to show reduced pain and improved physical functioning at week 24. Improvement in fatigue continued, but was no longer statistically different from placebo at week 24.

\* Repeated IV antibiotic therapy is effective in improving cognition, and among the more impaired, in improving pain, fatigue, and physical dysfunction.

**Safety**

\* 18.9 percent of the 37 patients had serious adverse effects associated with either the IV line or a reaction to the antibiotic itself. Although all

fully recovered, IV antibiotic therapy has the potential for serious risks, such as systemic infection, thrombus formation, or allergic reactions.

**Clinical Recommendations**

\* Repeated IV antibiotic therapy should be considered a valuable option with long-term benefit for managing the disabling symptoms associated with chronic Lyme disease.

\* Given the risks and benefits associated with IV antibiotic therapy, physicians and patients need to have a thoughtful discussion prior to initiating treatment.

**Citations from Recently Published Research**

\* The percentage of patients with meaningful improvement in fatigue noted at six months in this *Neurology* study (66.7 percent for patients treated with ceftriaxone vs. 25 percent for placebo) was comparable to the improvement in fatigue noted after repeated IV ceftriaxone therapy in a prior placebo controlled study (64

percent for drug vs. 18.5 percent for placebo) (Krupp et al., *Neurology*, 2003).

\* The degree of physical impairment (comparable to congestive heart failure) was comparable to the impairment noted in another chronic Lyme study (Klempner et al., *NEJM*, 2001).

"Future research needs to focus on identifying a treatment approach that either allows not only for acute efficacy, but also long-term cognitive improvement; or, a treatment that could be given after the IV antibiotic therapy that would allow for sustained or enhanced cognitive improvement over time. Our Lyme and Tick-borne Disease Research Center continues to work towards finding these solutions," said Dr. Fallon. "The most important lesson of this study is that physicians and patients need to collaborate openly to design an individual treatment plan to manage the long-term and complex suffering from symptoms of chronic Lyme disease."

Columbia University Medical Center provides inter-

national leadership in basic, pre-clinical and clinical research, in medical and health sciences education, and in patient care. The medical center trains future leaders and includes the dedicated work of many physicians, public health professionals, dentists, nurses, and scientists at the College of Physicians & Surgeons, the Mailman School of Public Health, the College of Dental Medicine, the School of Nursing, the biomedical departments of the Graduate School of Arts and Sciences, and allied research centers and institutions. [www.cumc.columbia.edu](http://www.cumc.columbia.edu)

**PATIENT QUERIES:**


To schedule a clinical evaluation for patients with neurocognitive or neuropsychiatric problems from Lyme disease, please call 212-543-6508.

To schedule a research evaluation for possible participation in a diagnostic study, please call 212-543-6510.

Please note: As of June 4, 2007, the center is not currently conducting any active treatment trials. *pha*

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# Responding to a New England Journal of Medicine Critical Appraisal of "Chronic Lyme Disease"

by Dr. Joseph Jemsek

Read The Full NEJM Article Online at <http://content.nejm.org/cgi/content/full/357/14/1422>

This is an opinion piece by Dr. Joseph Jemsek, in consulting collaboration with other experienced colleagues. It is not intended to reflect an exhaustive critique of the many shortcomings of the "Feder" paper, but rather an attempt to highlight the most glaring incongruities and perplexing logic flows contained within what is considered a shameful and politically-motivated article. The purpose of this critique is to place disparaging opinion about persistent disease associated with Lyme Borreliosis on full exhibit.

The subject of "Chronic Lyme Disease" was once again presented in a prominent journal setting in a recently published "review" in the October 4 NEJM article by Feder et al. As seen in several previously published reviews, opinions, and guidelines, the tenor of the publication is dismissive to physicians who feel that *Borrelia burgdorferi*, the causative agent of Lyme disease, may be responsible for persistent illness which requires long-term antibiotics and a myriad of other treatment considerations and measures. It seems to patronize the opinions

of these physicians, opinions which are backed by hundreds of scientific publications and galvanized by countless clinical encounters with desperate and marginalized patients.

Published "reviews" on Lyme disease, similar to the Feder article, seldom offer any new or credible insight into clinical or scientific issues, and therefore their purpose and timing must be questioned. This article clearly echoes the stilted logic and highly suspect content promoted by the portion of the 2006 IDSA Guidelines which dealt with this subject matter and whose authors may come under anti-trust investigation. The repetitive arguments promoted by a select group of researchers and/or self-proclaimed "ad hoc" committee members - "the Lyme Cabal", as we will refer to them, includes the high-ranking members of the CDC's Vector Borne Branch, Johnson and Mead, and do nothing to further our understanding of what is making our population chronically ill.

In the absence of new

ideas and with a history of rejecting meaningful dialogue with those who may disagree with them, Feder and associates appear to simply reshuffle authors and rearrange their tem-

facts. Many of the authors cited are known to have ties to patented business ventures dealing with, among other things, future testing and vaccine development in

Borreliosis-related ventures. We have serious concerns about propriety and integrity issues for both the Lyme Cabal constituents and for the NEJM, which has a heretofore irreproachable standard of excellence in publishing medical science. We also express serious concerns about the health of our population in terms of the continuing scientific "ambiguity" surrounding this disease complex, which we term Lyme Borreliosis Complex (LBC).

The review begins by indicating an important fact - that Lyme disease is a serious public health problem which is "complex", but the tone of the article

immediately thereafter becomes and remains, dismissive. LBC is trivialized through consistent application of journalistic phrasing techniques designed to give the reader a sense that the authors are annoyed that there

is a fuss about this issue, and that their views have not been accepted without reservation.

Examples of these methods of literary intimidation and the abusive misuse of factual material are scattered throughout the text and are briefly portrayed as follows:

a) This "serious public health threat" which is "complex" will "usually respond well to conventional antibiotic therapy." The committee fails to provide evidence of what response is measured and by what methods.

b) They further state that a "minority of patients" have symptoms which remain after "resolution...after antibiotic treatment." Again, this assumes that all patients are diagnosed and treated, which is simply not fact, and again this statement defaults to the committee's inflexible criteria for diagnosis and treatment.

c) The committee further considers symptomatic illness as "usually mild and self-limiting", and defines these patients as having "post-Lyme disease syndrome", an arbitrary term adopted by the Feder camp years ago and thoroughly associated with ill-defined, non-organic illness through repetitive indoctrination with this brand of pseudo-scientific jargon on the unsuspecting medical community. "Mild and self-limited" is counter to the char-

*"Critique"...cont'd on pg 14*

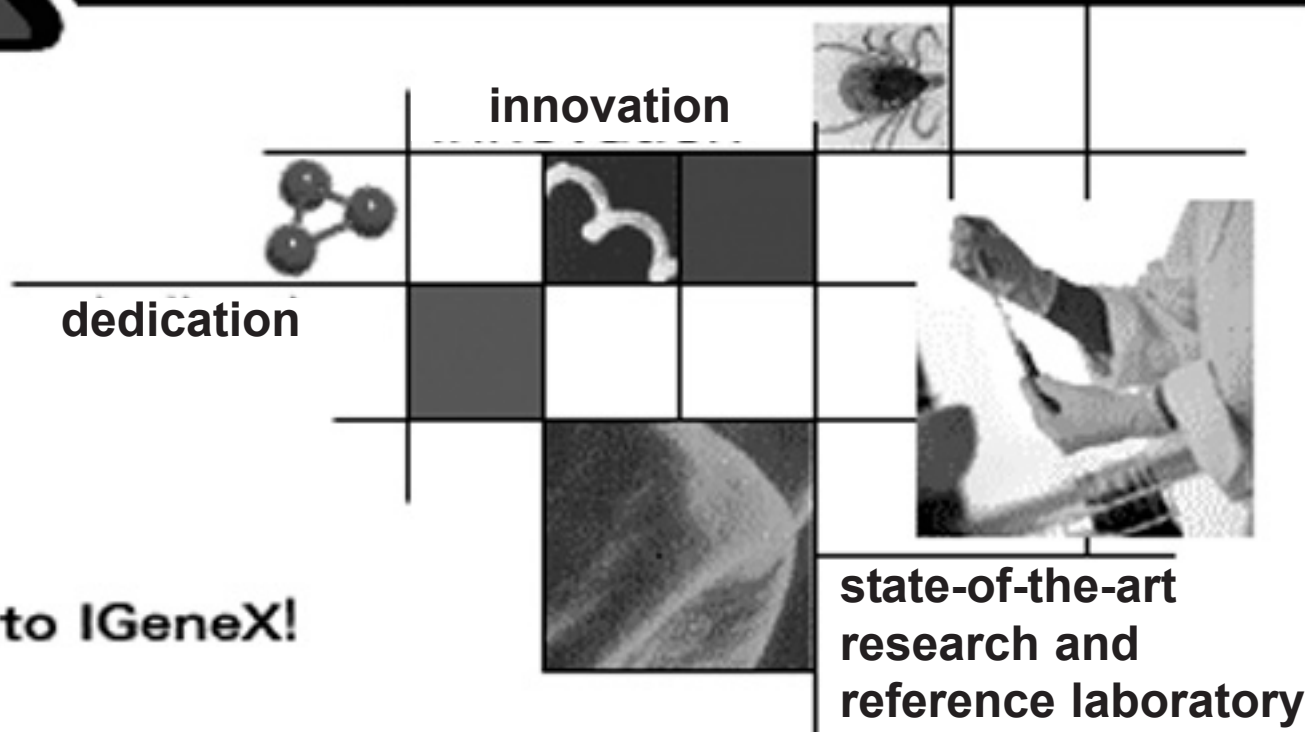


*Dr. Joseph Jemsek exposes the many fallacies of the NEJM's presentation of Chronic Lyme Disease which he calls shameful and politically motivated.*

plate of imperial arguments for this most recent article. Again they employ the same indecipherable, distorted, and circular logic which they have displayed in the past, and appear to play favorites with their

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# The Lyme and Associated Diseases Registry™

## -Is Your Physician Participating in the Program that Could Lead to Identifying the Cure for Lyme Disease?

by *Turn the Corner Foundation*

Imagine a world where all Lyme-literate physicians' intricate and unique knowledge on what works best for them when treating Lyme disease is collected and filtered into a single system. This system then assesses the best overall approaches to diagnosing and treating Lyme disease on an international level. If you can envision what this type of consolidation of knowledge would do for the Lyme disease community, you would find world-renowned Lyme disease physician and International Lyme and Associated Diseases Society member, Dr. Joseph J. Burrascano, of Watermill, NY at the helm of such a project.

In fact, for the first time in history, a registry designed to gather important clinical and scientific information regarding tick-borne diseases in humans has been created by Dr. Burrascano. The Lyme and Associated Diseases Registry™ is copyrighted and is the intellectual property of Turn the Corner Foundation. A novel design makes this Registry user-friendly and extremely powerful, allowing it to be adopted by an unlimited number of interested clinicians and patients. With hard data from a large sample of patients spread across the USA, and eventually internationally, groundbreaking discoveries and useful clinical information will result. The format of this Registry allows this data to be critically analyzed and published for the benefit of medical care worldwide.

The Registry is an integral tool for the medical community to use in properly diagnosing and treating Lyme disease. Often in Lyme disease there are many unanswered questions regarding the best clinical approach that physicians may take to properly diagnose and treat this com-

plex, dreadful epidemic. Only through large scale, multi-center studies of literally thousands of patients will we be able to, for the first time in history, scientifically validate the best ways to make the diagnosis, best antibiotics to use, and the most effective and safe doses of antibiotics to administer. The role of the many supportive measures currently being employed by physicians will also be able to be evaluated. This Registry will ultimately allow researchers to identify and publicize the most commonly used and effective measures for the diagnosis and treatment of Lyme disease and is a critical component to finding a cure.

Now that this innovative program has been developed, it's time for physicians to begin to register their wisdom. Is your physician participating? It has been surprisingly difficult to find cooperating physicians willing to take the time to contribute their wisdom to this program across the country. It is the hope of Turn the Corner Foundation and Dr. Burrascano that you, as someone touched by Lyme disease, will find this program important enough to insist that your local Lyme-literate physician participates. Visit or call your physician's office today to request that they begin sending in the forms necessary to share their knowledge through the Lyme Disease Registry Program. You can also request that your physician participate in the sample letter included in this article, by filling in your physician's name, signing the letter and sending to your physician. To have materials sent to your physician on the Lyme Disease and Associated Diseases Registry™, please contact [info@turnthecorner.org](mailto:info@turnthecorner.org). To learn more about this program, please visit [www.turnthecorner.org](http://www.turnthecorner.org).

Date: \_\_\_\_\_

Dear \_\_\_\_\_

I am one of your current patients coping with Lyme disease. I appreciate your efforts to become Lyme-literate and treat my illness with the most cutting-edge procedures available to me. I am writing you today to request that you participate in the Lyme and Associated Diseases Registry™ in order to continue to promise the most innovative medical care possible is available to your Lyme disease patients.

The Lyme Disease Registry Program was created by Dr. Joseph J. Burrascano, of Water Mill, NY and is designed to gather important clinical and scientific information regarding tick-borne diseases in humans. Moreover, a novel design makes this Registry user-friendly and extremely powerful, allowing it to be adopted by an unlimited number of interested clinicians and patients. With hard data from a large sample of patients spread across the USA, and eventually internationally, groundbreaking discoveries and useful clinical information will result. The format of this Registry allows this data to be critically analyzed and published for the benefit of medical care worldwide. This Registry will ultimately allow researchers to identify and publicize the most commonly used and effective measures for the diagnosis and treatment of Lyme disease and is a critical component to finding a cure.

If you are not currently participating in the Lyme Disease Registry Program, I request that you begin collaboration as soon as you are able. Contact [info@turnthecorner.org](mailto:info@turnthecorner.org) to learn more about how you can register your valued knowledge today. Please visit [www.turnthecorner.org](http://www.turnthecorner.org) to learn more about this innovative program.

Sincerely,

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## Grace and "Muriel"

### Pilot's Passion to Raise Lyme Disease Awareness Takes Flight

by *Di Freeze*

As a little girl growing up in Holy Loch, a small village in Scotland, Grace McGuire knew she would one day be a pilot. When she entered her teen years, she found work at a local airport, during summer months, as a ground hostess.

"I used to go to the flight school and chat with the pilots but they didn't have much time for me," said McGuire, at her home in Rumson, N.J. "I loved to talk to the old-timers."

In the 1960s, McGuire visited the United States. While there, her passion for vintage aircraft led her to New Jersey airports, and, shortly before she turned 18, to her first flying lesson at the now defunct Red Bank Airport in New Jersey.

"I went with an English friend of mine who was here babysitting for the summer," she said. "We had enough money for about a half hour each."

Soon, McGuire began hearing the same comment: "You look just like Amelia Earhart!"

"Who is that?" McGuire asked --once.

"Listen kid," one old-timer said. "In aviation circles, you don't ask, 'Amelia who?'"

Over the years, the resemblance--down to the short, tousled hair--continued to be noticed.

"We had the same contour and we were both tall and skinny," McGuire said.

Curious about her look-alike, McGuire would later get her hands on every book about Earhart she could. She read with excitement about her life, including her plans to fly around the world, in 1937, in a twin-engine 1936 Lockheed Electra L-10E.

She was dismayed to discover that Earhart and her navigator had disappeared off the coast of New Guinea, while looking for Howland Island, and that neither they nor the

aircraft had ever been found.

It might have been the resemblance to Earhart, or it might have been her apparent passion for aviation, but McGuire was soon accepted into the "inner circle." She remembers a particular day, after taking a few lessons, when, as she was leaving the airport, she was stopped by a couple of those "old-timers."

"Look, don't keep running off," she heard. "Hang around after your lesson and do a little hangar bumming; we'll take you for rides."

But soon, McGuire headed home to Scotland. However, she returned to New Jersey in the late 1960s, and reestablished her friendships. In the early 1970s, when she could afford it, she began working towards getting her private pilot license at Preston Airport (now Marlboro Airport).

"I babysat and tended gardens to pay for the lessons," McGuire said. Forty-three hours of flight time later, in

1972, McGuire flew to the Bahamas, through the Devil's Triangle, in a Cessna 150. She found the flight exhilarating.

She was soon working towards getting her other licenses and ratings, which would eventually include instructor and commercial ratings, as well as multi-engine land and sea and instrument ratings.

After earning her instructor rating, Dorothy Fenwick, co-owner of Preston Airport, offered McGuire a job as an instructor. Although she was later offered a job with a major airline as a co-pilot, she turned it down.

"I loved only vintage aircraft," she said. "I was born too late; I should have been a barnstormer."

But McGuire would do her fair share of barnstorming, as well as flying air taxis between New Jersey and South Carolina, seaplanes and helicopters, and even the occasional fighter aircraft.

Her involvement in New Jersey aviation would extend to being a captain in the Civil Air Patrol and a member of a local 99 chapter.

It was at an air show in North Jersey, in 1979, that the aviatrix was "discovered." As she stepped from the plane, a photographer asked if he could take her picture.

"I was very shy," McGuire said. "I said no and started to walk away, then a friend of mine told me to do it. I didn't know it at the time but the organizers of the air show had asked him to look for an Amelia-look-alike." McGuire's picture appeared in the local newspaper, with the caption, "Amelia is back."

An idea had begun to form in her mind. It was at another air show that McGuire revealed it to friends.

"I opened my big mouth and said I was going to finish her flight for her," she said. "I thought it would be a nice trib

"Grace" ...cont'd pg 12



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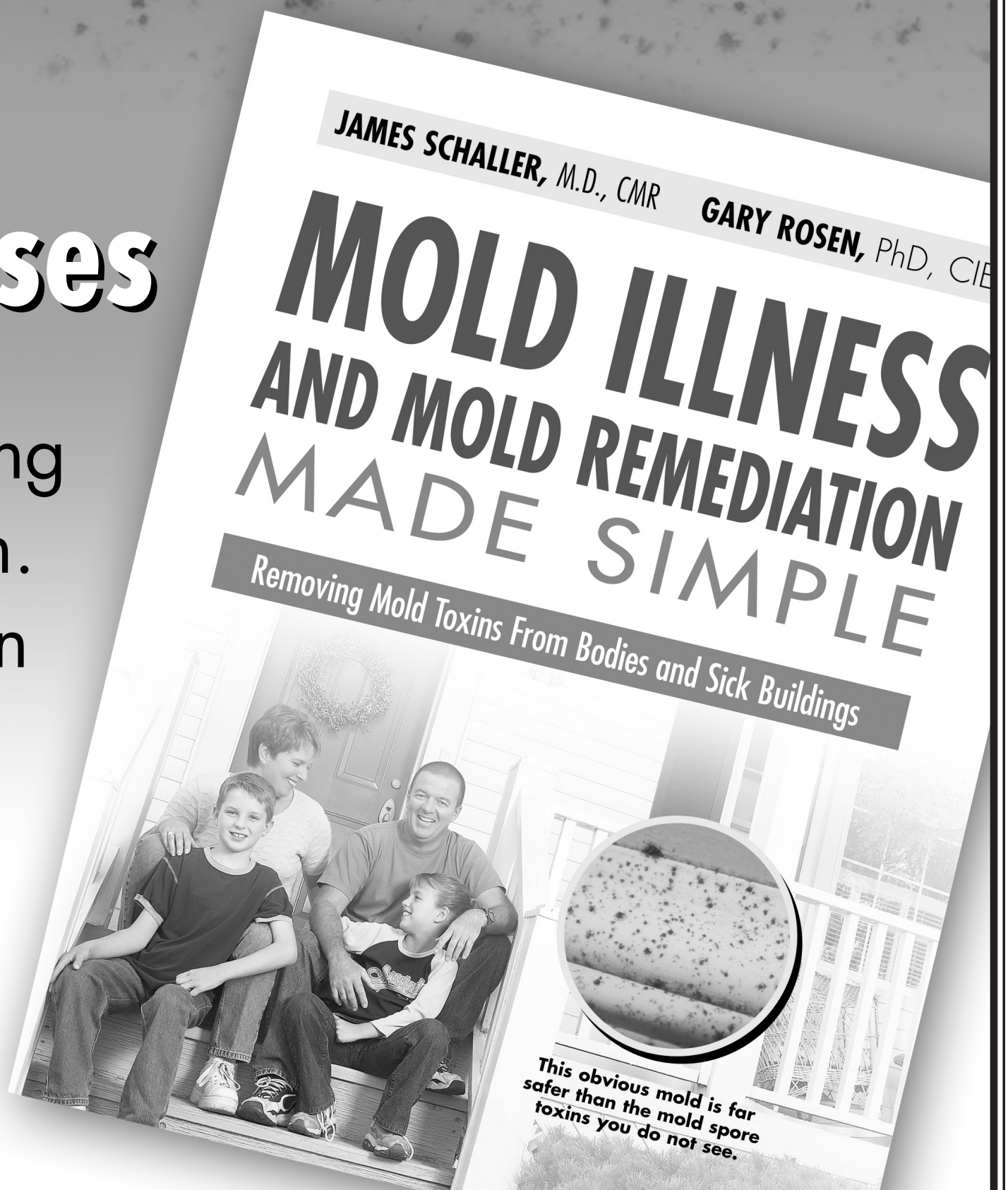
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Email: alc@nmss.org  
www.nationalmssociety.org/alc

### Northern California

150 Grand, Oakland, CA 94612  
Phone: 510-268-0572  
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Email: info@msconnection.org  
http://www.msconnection.org

### Colorado

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### Georgia

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Phone: 404-256-9700  
Phone: 1-800-FIGHT-MS  
mailbox@nmssga.org

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Email: info@flc.nmss.org  
www.nationalmssociety.org/flc

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Rockville, MD 20855  
(301) 978-9855  
toll free: (866) 348-3257  
fax: (301) 978-9854

### Great Philadelphia ALS Chapter

321 Norristown Road, Suite 260  
Ambler, PA 19002  
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Toll Free: 1-877-GEHRIG-1 (1-877-434-7441)  
Fax: 215-643-9307  
alsassoc@alsphiladelphia.org

### South Texas Chapter

http://www.alsa-south-tx.org/  
(210) 733-5204  
toll free at (877) 257-4673

### North Texas

http://walk.alsanorthtexas.org/site/PageServer  
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s.melson@alsanorthtexas.org  
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### The ALS Association Upstate New York Chapter

323 Route 5 West  
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info@alsaupstateny.org

## Lyme Disease Association

lymediseaseassociation.org/  
Pat Smith 888.366.6611

### Arizona

Scottsdale, AZ 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. Arizona

Tina J. Garcia  
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1057 R St.  
Fresno, CA 93721  
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Membership@Calda.org

### Colorado

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

### Alabama

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

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Mary Alice Beer  
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### National Support:

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## Lyme Disease Support

### Kansas

913-438-LYME  
Lymefight@aol.com

### Montana

bepickthorn@earthlink.com  
**North Carolina**  
Stephanie Tyndall  
sdyndall@yahoo.com  
Lenoir County Hospital,  
Kinston, NC

### New Mexico

Veronica Medina  
(505)459-9858  
vrmedina@comcast.net

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### Greater Austin Area Lyme Council.

Teresa Jones  
tmomintexas2@yahoo.com

### Houston

Contact: Teresa Lucher  
lucher@sbcglobal.net

### Washington State

Alexis Benkowski  
WA-Lyme-owner@yahoogroups.com

### WI / IL / MN Regional areas

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

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

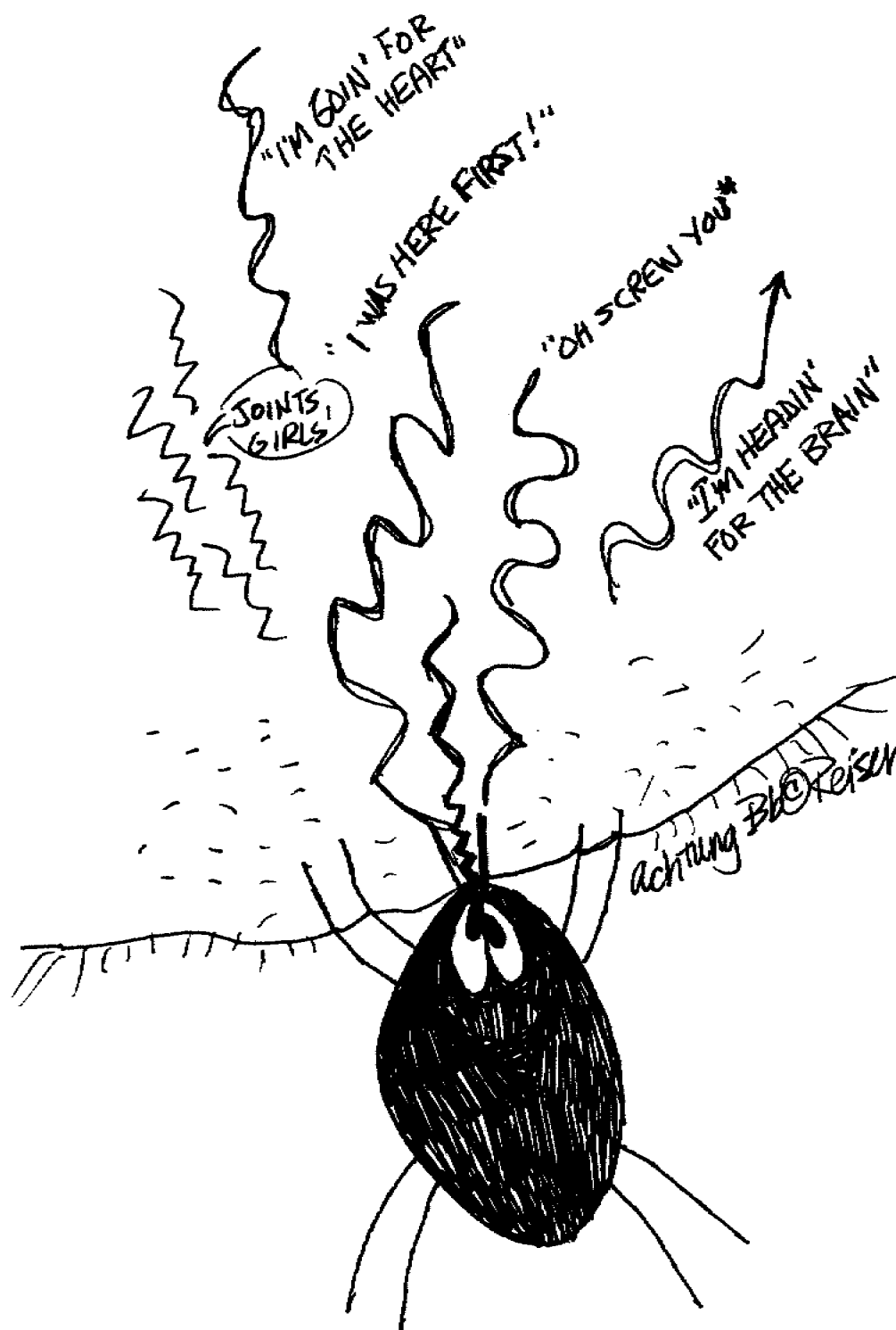
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## Ticktoons



THROUGHOUT THE COURSE OF HISTORY - BORRELIA HAS FOUGHT AMONG THEMSELVES. HENCE THE QUICK DISPERSION IN THE BODY.

by Terri Reiser

## “Grace” ... cont'd from pg 9

ute."

At first, McGuire talked about just "finishing" the flight. Later, she decided she wanted the same challenges Earhart had. She wanted to make the entire trip. And, she wanted to do it Earhart's way--the "old-fashioned way."

This meant circumnavigating the globe in the exact aircraft model, with the same equipment, and taking three and a half months, with 32 stops along the way.

She believed she had the determination and skills to make the trip, but she was minus a few needed ingredients, including the aircraft, a Lockheed Electra L-10E, of which only 15 were built.

When McGuire began searching for one, she was told that all had been scrapped, and that she might have to convert a 10A. But, she kept looking. And, she kept researching.

She wanted to make sure her flight didn't end like Earhart's.

In the book, "Amelia Earhart: The Mystery Solved," published in 1999, authors Elgin M. Long and Marie K. Long revealed their findings that Howland Island was actually six miles east of the position shown on Earhart's chart.

Over a decade before the book was published, McGuire, after studying Earhart's navigational charts and flight plan, and charting the coordinates navigator Fred Noonan had for the trip, came up with the same conclusion.

"She was using 100-year old British admiralty charts with the wrong coordinates," she said.

In the midst of her search for an aircraft, McGuire attended a function at the Wing's Club in New York, where she met Muriel Earhart Morrissey, Earhart's sister.

"I hadn't said anything to the media about my plans but my friends knew and told Muriel," she said. "She asked if I would come over to her table. I thought she was going to think I was a quack, but it was instant love. We hit it off right away."

The meeting led to a friendship that would last for years.

"She thought I reminded her of Amelia, but she said that wasn't the only reason she liked me," said McGuire, of the woman who became one of her staunchest project supporters.

After searching for an L-10E for more than two years, McGuire was about to give up, when she received a call from Christie's Auction House.

"They called to tell me they were auctioning off the contents of the Wings and Wheels Museum in Orlando, and they had a restored Lockheed 10 there," McGuire said. "But I was down to about \$200 and couldn't even afford to fly to the auction, let alone buy the aircraft. Then, after the auction, they called again and said they wanted to help me. They said there was a heap of junk lying in the yard and if it wasn't sold, it would have to go to the scrap yard."

Since no one knew of any 10Es in existence, McGuire

assumed the aircraft was a 10A. She flew to Orlando International, where, in a back lot, she was shown the "sorriest looking thing" she'd ever seen. But, urged to do so, she scraped together the money and bought the badly corroded plane that

was very naive about what it would take to get the plane ready.

"I thought I could hire a couple of mechanics and just fix it up," she said. "Then I found out that it was impossible to get parts. Everything has to

to leave."

With the help of a friend in Washington D.C., McGuire was given the use of a small hangar at Old Bridge Airport.

When the news of the project got out, "Time Magazine" called and offered to

celebrate their sponsorship. The Electra was returned to McGuire piecemeal. Nothing was labeled and pieces were missing.

With determination, McGuire and her volunteers set about piecing it together.

With the chaos and long hours of work, it didn't surprise McGuire when she started noticing that her health was suffering.

"I got sick but I thought it was from all the excitement," she said. Although she continued to notice the problems with her health, and that she was getting thinner and thinner, she continued the work on the project--in between trips to various doctors.

"I had excruciating pain everywhere and I was being stuffed with all kinds of junk," she said. "No one could figure out what was wrong with me. I thought I had multiple sclerosis. It progressively got worse."

Still, in 1986, when a chance came up to fly to uninhabitable Howland Island--the 1.5-mile-by-.5-mile coral atoll near which Earhart disappeared--McGuire jumped at it.

"I wanted to see what kind of shape the old runway was in," McGuire said. "The U.S. Army Corps of Engineers was going to the islands to clean up debris."

McGuire went with them in exchange for mapping both Howland and Baker islands. After flying to the Gilbert Islands, the party sailed to Howland, where McGuire set up camp at the foot of a lighthouse built by the U.S. Coast Guard as a memorial to Earhart. Along with mapping, during her weeklong stay, she located live ammo from the war.

"I was very busy and the heat was just incredible," she said. The old runway, made of "well-packed crushed coral and bird droppings," she found taken over by ground covering a few inches high, but most of it was still visible.

"While I was there, I discovered two bomb craters that were made after Pearl Harbor was hit," McGuire said. "The Japanese also hit the radio shack where the Coast Guard kept equipment they used to call Amelia in 1937. I dug it all up out of the bomb crater and brought it back in my backpack."

McGuire carried home mementos she hand-delivered to a friend who was the president of a museum, and was assured they would be put on display.

"I thought for years that they were," she said.

But McGuire would soon be too ill to worry about her findings, which due to funding, were placed in a backroom and never displayed.

Little by little, McGuire's life was turning upside down. Her health problems included temporary blindness, paralysis, muscle spasms, severe head pain, and tremendous fatigue and weakness.

Without insurance, her finances dwindled rapidly, as she continued to search for the cause. Even worse, friends, unsure what was wrong, began

"Grace" ... cont on pg 18



had previously been owned by Pan American Airways.

"When I got the bill of sale, I found out it was the only original L-10E left," she said of S/N 1042, built in 1935, which she promptly named "Muriel." "I was ecstatic. But, what did I know about rebuilding planes?"

But McGuire, a member of the Long Island Chapter of the 99s, would soon have assistance.

"A few of the 99s would fly into Orlando and help me," she said. "We stripped the plane. Amelia had a polished aluminum plane so I had to get rid of all that stuff."

McGuire said that she

be fabricated; even some of the tools."

With help from various people that included two mechanics who had worked with Earhart and a sheet metal expert, the work inched along. McGuire soon became a "grease monkey," usually working seven days a week.

After a while, "Muriel" found a home at the Lakehurst Naval Air Engineering Center, where military aircraft mechanics volunteered to work on the plane in their spare time.

"I was in the corner of the Hindenburg hangar," McGuire said. "But the big hangar was leased and we had

do a story. Shortly after that, other publications called for interviews, as did ABC's "Good Morning America."

After McGuire appeared on the show, several international companies offered to sponsor the flight. McGuire, adamant about starting the flight in America, turned down many sponsors whose conditions were to begin the flight elsewhere, be in control, or install modern equipment. Eventually, she found just the right sponsor.

However, before the Electra could be fully restored, a management change occurred within the company, which can-

# Your Doctor Said What? Exposing the Communication Gap

Sue Vogan Interviews Dr. Terrie Wurzbacher, MD

Catching up with Dr. Terrie Wurzbacher is no easy task. Her work as an emergency room physician keeps her busy, her new book (*Your Doctor Said What? Exposing the Communication Gap* - available at Barnes & Noble, Amazon and other fine bookstores) keeps her hot on the interview trail, and of course, she co-hosts once a month on *In Short Order* at [www.highway2health.net](http://www.highway2health.net). I thought the readers would like to know what makes this physician so special.

Terrie understands what it's like to be a family member of a patient -- her mother had cancer. She knows what it's like to be a patient after just having a stint in the hospital. And, she knows what it's like to be the physician -- having been in the profession over 30-years - with over 25-years in the U.S. Navy. She has seen medicine from every angle of the gurney and finds problems that exist.

Communication seems to be a major problem for both patients and physicians. The doctor speaks what often seems like a foreign language -- terms and conditions right out of the medical books. The patient often would like to speak about everything BUT the real reason for the appointment or they are not prepared for the 6-8 minute office visit and therefore have unanswered questions as they leave.

To understand the difference between patient and doctor, one must first understand where each is coming from. The physician is tackling the visit from an "objective" perspective, where the patient is coming at the issues from a "subjective" stand point. "Until each side recognizes that they are the exact opposites, trouble will prevail." If you know this and how the system works and what everyone's role is, you may stand a better chance of navigating your way through the land of the doctor's office -- you know, the place where "you feel like processed meat."

There are the "gatekeepers." Now, not only are you sick and frightened, you must call for an appointment, a referral for a specialist, or worse yet, approval from your insurance carrier. From the begin-

ning, it's frustration (and remember, you're sick). "You not only have to ask your insurance company to be sick, you have to also ask their permission to do something about it." And, as if we aren't smart enough to know we need a spe-

"In some parts of the country the patient can't explain their symptoms in TEN MINUTES." Wurzbacher suggests that there must be a change "in how you prepare for your visit, how you interact with and what you expect from your primary care

ask the question that way? This isn't how the doctor learned to ask questions. The doctor doesn't have time to explain because he has a schedule.

Dr. Wurzbacher likens the relationship like marriage -- they "think or believe different-

ing what to do with your stuff and no shoes on your feet. You are following the nurse as a goose bump follows a naked body on a cold, wintry night. The nurse parks you in line for the tests the doctor ordered. Your butt is hanging out, your knees are knocking, and you wait...and wait...and wait. It's your turn and someone shoves a container and a wipe into your hand. Next, a needle and a jab to extract some warm blood -- ouch! It's on to x-rays -- "invert" your foot," the technician orders. What? She explains and you turn your foot inwards so she can get the picture. All done! Now, it's on to get an EKG -- another cold and embarrassing moment. Then, it's off to the exam room from whence this nightmare began -- and you wait. The doctor arrives, "hmm" is his new word and you ask what that response means. He/she tells you there's nothing on the tests. Is this good or bad news? It's good news, so says the doctor. If there's nothing on the tests, there must not be anything wrong with you.

"Ding! Ding! Ding!"

Bells and whistles go off and now you think the doctor thinks you're a "nitwit" and "it's all in your head." You have a sinking feeling -- you don't know any more now than when you came through the door -- all because your symptoms (square peg) did not fit the doctor's list of treatable maladies (round hole). Everyone knows you can't fit a square peg in a round hole! So, your symptoms don't fit the list and there's nothing on the tests -- you must be good to go? Not! You're sick and it's not all in your head -- now what? If your doctor is like most, it's more tests and more co-pays -- or, "the path of least resistance: pills."

Terrie Wurzbacher is one funny lady who currently resides in San Antonio, Texas . And if you haven't guessed what makes this physician so special, it's her humor in understanding the problems from all sides of the gurney. But if you happen to run into Dr. Terrie Wurzbacher and find yourself in the position as her patient, be kind...she can order embarrassing exams at will!

pha



cialist, we are forced to see a primary care physician to have him/her say, "Yep, you need a specialist!" I didn't realize there were so many rules for getting well!

"The insurance company isn't the only gatekeeper. The doctor's office staff can be as bad or worse (of course, they can be excellent too). Often they seem compelled to protect the doctor: protect him from you. That makes you feel worse." Your office visit may take longer because of any complications, questions, or delays -- it's a tough field to play. "Make no bones about it though; the staff consists of the people who help the patients more than anyone!" I suppose we start making nice at the front desk.

At the doctor's office, did you ever feel you were being pushed and herded? You aren't alone! Dr. Wurzbacher calls it "the cattle factory syndrome." Everyone has to hurry in and out -- the physician has only minutes to find the answer.

physician." Writing down questions and bringing a list of symptoms and drugs you are currently taking is a big time-saver. And, get on familiar ground -- ask questions and keep that tone out of your voice. Familiar ground is where the communication flows as on a one-lane alley -- and everyone is going the same way!

Then the common complaint: the doctor doesn't really listen to us. Who's at fault? Wurzbacher says both may be responsible. Communication is the key and sometimes no one knows where the keyhole is...or for that matter, the door. Some patients with more than one complaint don't talk about them in order of importance -- go figure! But, this is what the physician expects and gets impatient when the unspoken rule is broken. When the doctor asks what kind of pain it is, it is customary for us to point out the painful area. What the doctor may be trying to get as an answer is: sharp, stabbing, mild, etc. Then why didn't he

ly, with dissimilar upbringings. Unless a conscience effort is made to discuss the variation in the language and innuendos, there will be problems. Ask any married couple." Let the physician know that you are not understanding or that there are still concerns he/she has not addressed satisfactorily -- in a nice manner.

There are many different types of patients, too. Some are of the "denial/minimizing/embellishing" group, while some are from the "shame and embarrassment" sector. Can we imagine how difficult a time the doctor has now? And what about those gowns? How much would it cost to add a couple of ties?!

The real office exam begins. You in the gown that looks like a paper-doll dress and the doctor and nurse as busy as if they were on a game show and the buzzer is about to go off. The doctor pokes and prods, orders the nurse to order tests and everyone is "gone in a flash." Out you go -- not know-



The Poison Plum is a gripping, chilling novel exposing the rampaging epidemic of Lyme disease now sweeping across America and the disease's connection, if any, to the government's top-secret biological research laboratory at Plum Island, New York.

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## “Critique” ... cont'd from pg 8

acterization of numerous other reports, and contradicts the authors' opening remarks of a "serious and complex" illness. The terms "mild and self-limited" are subjective, and craftily inserted to prejudice the biased opinions which follow.

d) After the initial paragraph, the word "complex" is no longer mentioned, as if the authors feel readers will forget the reference as it is plowed under by subsequent disparaging remarks.

e) The committee stated that their review is "not the objective manifestations of late Lyme disease but rather the imprecisely defined condition referred to as 'chronic Lyme disease.'"

i. 'Objectivity is in the eye of the beholder. The more skilled and experienced the observer becomes, the better the tools available with which to measure; the better the understanding of the elements which comprise the universe of the subject matter at hand, the more "objective" the manifestations of the illness complex will become.

ii. The committee is derelict in not being more forthright about issues of objectivity; if objective measures are wanting, why not make efforts to improve them? The practice of medicine is suffering mightily as our practitioners increasingly rely upon guidelines and "cookbook" medicine, and not on what the patient communicates. We physicians are becoming more robotic, and why is that so? The physician must constantly listen to, and learn from the patient, especially when "testing" fails both provider and patient.

iii. The committee stumbles over the precise definition of an illness they initially state is "complex" and proceeds to wantonly blur the debate further by talking about, "not the objective manifestations of Lyme disease", but rather "chronic Lyme disease". This is classic double-speak on their part.

f) The committee targets a "small number of practitioners", not a subtle reference, the terminology of which is assuredly designed to reduce the number and significance of those with opposing viewpoints. The committee appears to mock physicians who "suggest" that persistent B. burgdorferi may require long-term antibiotic treatment, or that it may be "incurable". They do so in such manner that suggests a whimsical allusion to futility, and implies in parallel analogy that patients who embrace this view are equally futile in their thinking.

g) Declarative and unsubstantiated statements dominate the "review" as in "the opinion of the committee is that Lyme disease includes a broad array of illnesses or symptom complexes for which there is no reproducible or convincing scientific evidence of any relationship to B. burgdorferi infection". First, note that this is an opinion but, in the setting of the Lyme Cabal publishing in the NEJM, this opinion equates to dictum and also, in our collective opinion, equates to an abuse of power

by those who hold power in this setting. The lack of "evidence" reference, which glides so easily on the NEJM page, is easily countered by well-documented literature references indicating that the world at large is held hostage to unreliable and stifled testing which severely limits the ability of the practitioner to provide laboratory data in support of this aforementioned "complex illness".

h) In the very near future, we predict that many of the Lyme Cabal will find it hard to explain the more than 200 patents they hold for better testing, vaccine development, and other business interests in the expanding universe of Borreliosis-related disease.

Further, it may prove exceedingly difficult for the Cabal to explain why their involvement with these patents have been largely undisclosed, when the science at hand could have benefited the untold thousands whose lives have been unalterably changed by this chronic illness.

i) Late in the publication, the committee uses the political and inflammatory term "Chronic Lyme Disease" as the heading of a new section, instead of their preferred term, "late Lyme disease". We ask the obvious question of why the choice to begin a section with something the committee says does not exist.

j) The committee further makes vague and imperial comments about those diagnosed and treated for Lyme disease, as somehow being "substantively" different than those with other "recognized" infectious diseases. We are disturbed that a NEJM editorially-approved

article would accede to a reference which equates to "intellectual cement" in academic medicine. At what point did the US academic universe decide that they had a handle on the mysteries of medicine? Over 90% of the most prominent chronic illnesses, e.g. MS, RA, Crohn's, etc., have no known cause. This is hardly a position from which to exude scientific arrogance. Diagnoses are, and always will be, integrally associated with varying clinical criteria, test interpretations, and physician judgment. Testing was designed to serve the will of the clinician and now it seems that the tail wags the dog. Generational change in medicine historically shows that 50% of what we hold as fact today will change, but which 50%?

k) A disclaimer by an organization is an attempt by the rule makers to absolve all recriminations in perpetuity. To wit, as our authors and their alter egos at the IDSA suggest, (and as some of the committee's authors who took part in the 2006 Lyme Guidelines stated): "It is important to realize that

guidelines cannot always account for individual variations among patients. They are not intended to supplant physician judgment with respect to particular patients or special clinical situations". Why then would these committee members attempt to minimize the role of physician judgment in the diagnosis of any illness, especially a disease with the devastating impact of persistent Lyme disease? Clearly the committee is deemphasizing clinical judgment and experience because they don't fully appreciate the roots of their discipline - the patient. This is a highly disturbing and dangerous thought for the profession of medicine and for the population which it serves.

l) The committee criticizes the "lines of reasoning" to

**As if not satisfied with yet another highly creative and biased interpretation of the data, the authors then turn to criticize "specialty labs" as not "FDA approved". The FDA, which by the way, acknowledges that current testing is unreliable, has nothing to do with credentialing labs unless a product is marketed, a convenient oversight by the authors.**

support a diagnosis of Lyme disease in those who do not show antibodies against B. burgdorferi in serum, particularly given the "the well-known immunogenicity of lipoproteins". They claim these "theories" of antibody negativity with LBC are not well-supported by scientific data. They fail to acknowledge that the testing reagents used in traditional labs are limited to only one strain (B31) in a disease in which multiple Borrelia burgdorferi strains may play a role. They ignore the well documented altered life forms of Borrelia species, (e.g. CWD forms, cysts, and blebs), none of which manifest lipoproteins. They fail to acknowledge the intracellular habitat of both helical and cyst forms, and the disturbing ability of the B31 spirochete to penetrate a series of neuronal and glial cell lines, as described in the 2006 Livengood CDC paper published in the summer of 2006. They fail to hypothesize or consider the notion that patients with LBC may have highly dysfunctional innate and adop-

tive immunologic effects.

As if not satisfied with yet another highly creative and biased interpretation of the data, the authors then turn to criticize "specialty labs" as not "FDA approved". The FDA, which by the way acknowledges that current testing is unreliable, has nothing to do with credentialing labs unless a product is marketed, a convenient oversight by the authors. This "shoot the messenger" approach ignores the highly suspect and arbitrary manipulation of data and policy which took place at the 1994

Dearborn meeting and left the world without Osp A and B bands as qualifying criteria for diagnosis. This is a particularly mystifying situation since the ill-fated and ill-conceived LYMERix vaccine promoted by several of the Lyme Cabal was based on the Osp A, or kda band 31, lipoprotein antigen.

Most significantly, the authors fail to mention that much of the research done by several of the authors of their own committee, (when closely examined), supports the opposite view of what they express. Perhaps they should go back and re-study their own, earlier research. As stated previously, many in the Lyme Cabal are involved in various side-interests which include, but are not limited to, the patenting of diagnostic tests and/or components thereof, which we have referred herein. Therefore, we and others are concerned that these individuals might have a vested interest in dismissing any diagnostic or treatment modalities contrary to their "recommendations".

m) The committee uses "shock value" terminology to describe a minority group who treat Lyme disease - a handful of practitioners utilizing "unconventional" or "dangerous" methods to treat Lyme, as if they are the collective majority. The mainstream of providers does not fit their characterization, so these inferences are wholly unsubstantiated, unwarranted and malicious. To this end, the committee has a history of promoting the term "medical quackery" at every opportunity because its use resonates loudly as an alarm to the public. The authors know that libelous remarks directed against specific physicians or groups are very difficult to prosecute and that their public indignation makes for good journalistic copy without fear of reprisal.

n) Further, the committee states that "no other spirochetal illness including... tertiary syphilis is managed in an analogous fashion." Syphilis, caused by treponema pallidum, has a formidable and sinister history for causing human illness in past centuries, and in

recent times has experienced a renaissance associated with the HIV/AIDS pandemic. Unlike Borrelia burgdorferi, treponema pallidum has only one host, the human, whereas Borrelia burgdorferi has many hosts. For the record, we use a "tongue in cheek" byword when referring to treponema pallidum, which we refer to as "Lyme's DUMB Cousin." We use this droll term based on comparative genomic profiling among spirochetal and other bacterial species, which makes Borrelia burgdorferi the clear winner in the microbial genetic lottery.

o) The authors compare the duration of treatment for Lyme disease to that of tuberculosis, another predominantly intracellular infection. We are amused at the implications by the authors that tuberculosis is treated successfully for a relatively limited period of 6 months, compared to LBC which "may go on for years". However, in the not so distant past, tuberculosis used to require 18 months or more of antibiotics. When better drugs became available and pulsed antimicrobial programs were employed, therapy was made more efficient and shorter in duration. Of interest, pulsed therapy is precisely the treatment methodology employed by the Jemsek Specialty Clinic and other Lyme-literate physicians in treating "chronic Lyme disease". Furthermore, as experience is gained, treatment programs using combination antimicrobials, as is the case for tuberculosis and HIV/AIDS among many other complex infections, is also allowing for more efficient therapy of shorter duration in LBC.

p) In terms of persistence, dozens of articles support this notion, including some of the authors' earlier works. From a purely observational basis, if Borrelia burgdorferi is so easily dealt with in the infectious state, why does it proliferatively persist in hard-shelled ticks, various small and large mammals, and humans (not the end host). Why is it revered by microbiologists as the most uniquely and lavishly genetically-endowed bacterium on the planet, and why is it being so heavily patented by Universities, researchers and others, including the majority of the members of the committee who performed the NEJM review?

q) Approaching the stratosphere of arrogance, the committee goes on to summarize Lyme disease into 4 convenient categories, like shoeboxes lined up in a row for shoeless and illiterate providers, without vote or consensus via any authorized committee or organization which would consummately arrive at these "categories"; and yet these were blithely published by the NEJM. So, because they must be addressed, we will do so.

i. They do not accurately encompass the majority of Lyme disease patients.

ii. They choose to ignore patients who present to their physicians with clear erythema migrans rashes and other clinical symptoms of

**“Critique”... cont'd on pg 16**

# Similarities & Paradoxes In Chronic Illnesses

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#### What I have learned in the past 20 years

Leslie Fein, MD Private Practice, Internal Medicine, Rheumatology and Lyme Disease.

#### The Positive Side of Lyme Disease

Kenneth Friedman, Ph.D. Associate Professor College of Pharmacology and Physiology

#### The Three Phases of Lyme Borrelia burgdorferi, Treatment and Evaluation

Joseph Jemsek, MD Infectious Disease & Internal Medicine, Founder of the Jemsek Clinic for Lyme Disease and HIV/AIDS.

*This activity has been planned and implemented in accordance with the Essential Areas and Policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint sponsorship of the University of South Florida College of Medicine, Morton Plant Mease Hospital and The Lanford Foundation Lifelyme, Inc. The University of South Florida College of Medicine is accredited by the ACCME to provide continuing medical education for physicians.*

#### Biomarkers of Lyme Disease and Controlled Treatment Trials

Brian Fallon, MD, M.P.H., Associate Professor of Clinical Psychiatry at the Columbia University College of Physicians and Surgeons

#### Current CFIDS Research

Nancy Klimas, MD Professor of Medicine, Psychology, Microbiology and Immunology at the University of Miami School of Medicine.

#### An Overview of Tick Borne Disease in Children & the Autism Connection

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# Eight-month Old Held Hostage by Hospital

by Parental Rights . Org

When Doug and Sally Stansfield took their eight-month old son Gabriel to Morristown Memorial Hospital, they thought their son was only being treated for a bowel obstruction. Instead, they found themselves under an intense investigation by social services.

Little Gabriel was born with spina bifida, a birth defect that results in an incomplete closure of the spinal column. According to the Spina Bifida Association, spina bifida is the most frequently occurring permanently disabling birth defect, affecting approximately one out of every 1,000 newborns in the United States. There are more than 70,000 people in the United States who are living with this birth defect.

Gabriel had been previously evaluated and treated for spina bifida by a doctor at Morristown Memorial Hospital. The family also continued treatment as prescribed by their family pediatrician, with no complications. But in the midst of their most recent visit to the

hospital with Gabriel, Doug and Sally were shocked to learn that an allegation of child abuse or neglect had been filed against them.

## A Frightful Home Visit

Hospital officials informed the parents of the complaint as a way of explaining why they were refusing to release Gabriel to his parents after his visit. Shortly thereafter, a social worker and uniformed police officers appeared on the family's doorstep, demanding admittance to interview Gabriel's six siblings about the condition of their baby brother--without the presence of their parents.

The Stansfields refused, pointing out Gabriel had been treated for his bowel obstruction, was in good health, and was ready to be discharged from the hospital. When the social worker persisted, the parents agreed to allow their children to be interviewed, as long as their lawyer could be present and would have the authority to stop the interview. The social

workers eventually backed down from this heavy-handed demand.

## Prisoner Of The State

After the social worker and police had left, the Stansfields called the hospital and were told that the staff had been informed of the situation. Hospital officials warned the couple that social services was planning to stop them from bringing Gabriel home, even though he was being discharged.

The Stansfields immediately directed the hospital to prevent the physician they suspected of generating the complaint from giving Gabriel any further treatment. Instead, they were informed that their parental rights had been terminated. The Stansfields went straight to the hospital, accompanied by their attorney, and asked to see the court order terminating their parental rights. The hospital had no court order, but did have a state social services form that allows children to be evaluated for three days.

Even though they did not have the proper court order, the hospital consistently refused to release Gabriel to his parents.

## Homecoming

Last Thursday, the Stansfields finally brought eight-month old Gabriel home, after a four-hour conference with social workers. The father, Doug, was overjoyed at the return of his son, but also expressed anger and frustration at the actions of social services in this case. "A doctor that doesn't know my family at all and has never met them or been to my house can make one phone call which will cause this much harassment," he told WorldNetDaily. Such a case "is outrageous and shouldn't be allowed to happen."

## Who Decides?

While the information and opinions expressed by physicians certainly help parents decide how best to treat their child, the role of primary decision-maker should be

lodged first and foremost in the parent. Unfortunately, the Stansfields' situation highlights a growing tendency among government and social service officials to second-guess the decisions that parents make for their children, and even to substitute their own judgments for those of the parents.

Action is needed if we are to protect the right of parents to make decisions concerning the upbringing and medical treatment of their children. Join with us by encouraging your friends to get involved in the battle to protect parental rights. Forward this email to your friends, and encourage them to join the campaign today and sign the petition at [www.parentalrights.org](http://www.parentalrights.org).

## SOURCES:

Baby Ordered Held by Social Services Returned to Family [www.worldnetdaily.com/news/article.asp?ARTICLE\\_ID=58197](http://www.worldnetdaily.com/news/article.asp?ARTICLE_ID=58197)

Spina Bifida Association [www.sbaa.org](http://www.sbaa.org)

## “Critique”... cont'd from pg 14

Lyme disease, but who are told they "do not have Lyme", because the physicians do not recognize its clinical manifestations, or are relying on surveillance criteria definitions, and inaccurate laboratory testing.

iii. These individuals are then not treated, and go on to develop Lyme disease in a chronic form.

iv. They also do not address patients who are misdiagnosed with other illnesses such as MS, ALS, RA and CFS.

v. The committee assumes at all points that patients are treated appropriately for their illness, and yet in fact, most patients receive little or no treatment, which is why they remain chronic.

vi. In patients with positive serology and no objective symptoms, the Bb-associated illness may be sub-clinical, as research proves that Bb remains dormant within the body for extended periods of time, from months to years after infection. Some of the committee members' own research clearly states this.

vii. Category 4 disease, as newly crafted and defined by the Lyme Cabal, has had an embarrassingly small number of treatment trials upon which to draw these conclusions. Further, in eschewing the study and expansion of the scientific and clinical horizons for the innumerable issues which remain to be addressed in this illness complex, the authors make it clear that they are content to remain entrenched in their existing dogma perhaps until it is "time to announce the Lyme epidemic" and bring out the new tests and vaccines. The most prominent of the studies mentioned above was performed by

Dr. Mark Klempner, a committee member who also happens to be on the editorial board of the New England Journal of Medicine. If the NEJM is an objective medical journal, we ask why this fact was not made prominently apparent for its

readership.

r) The committee is disdainful about antibiotic therapy causing "considerable harm" to patients, but fails to mention that all medical treatments have inherent risks. This allowance by the editor of the NEJM is in and of itself, unpardonable. Further, the authors fail to present a balanced representation of the patient populations in question. They fail for example, to mention that untreated and dismissed chronic Lyme patients commit suicide at alarming rates due to the hopelessness and agony associated with this illness.

s) The committee members claim those running clinical studies have had "difficulty" securing patients who meet the criteria of their obviously biased studies - such as the elimination of 500 people who were excluded because they lacked a "substantiated history of Lyme disease." Substantiated by what account? Most Lyme patients have no substantiated history of Lyme disease because doctors are missing the diagnosis and failing to treat these patients...more circular logic. Again, the committee is myopic in arriving at its conclusions about the scarcity of patients, either those "well-documented" or who develop "clinically significant problems" after "conventional treatment." We would like to provide the benefit of the doubt to the Lyme Cabal and pray that their glossing over and misinterpreting/ignoring or trivializing consistent and debilitating patient issues are not intentional.

t) There are untold thousands of individuals in our country and around the world who live unfulfilled and tortuous lives due to the political situation surrounding LBC and consequent access to quality care issues. A symptom of the

rudimentary state in which we find ourselves is made evident by the authors suggesting that eligibility criteria for controlled trials require symptoms be "severe enough to interfere with the patient's ability to function". This line of reasoning is simply astounding in its unsophistication and insensitivity. The committee's statements about controlled trials and documented disease history is admirable and would be more so if the medical community was fully engaged in an environment in which, as in HIV research, the best minds were involved and funded in the pursuit of the

## IN SUMMARY

Open attempts to intimidate the Connecticut Attorney General, physicians, and patients are not lending credibility to those who are perpetrating this behavior. Nevertheless, the politicization of an illness for which many people are tragically suffering, and who are afforded very little credence by the scientific community when evidence shows their illness is real, and who are subjected to increasingly narrow treatment options, may indeed be approaching not only anti-trust violations, but scientific fraud on a grand scale.

The public confusion comes not just from the myriad of symptoms or the restrictive definition of the illness itself, but also from physicians and patients who are well aware of the illness within their own bodies, and who are confounded by the unwillingness of the scientific community to embrace a medical illness of such major significance. Rather, many perceive an increasing plaintive and obvious disregard for the welfare of thousands of patients by a small number of individuals entrenched in power and trapped within their logic loops, whether these loops are genuinely

believed, or contrived. Inaction is somehow justified on the basis of a lack of double-blind, randomized studies. Regrettably, there also appears to be a barrier to publication of dissenting views by the editors and reviewers of established journals. The public, including some physicians, do know how to read, after all, and patents and a pattern of interpretative reversal in research opinions

speaking volumes about the truth of LBC. So does successful resolution of symptoms through open-ended, long-term antibiotic treatment of Lyme disease.

In this complex illness, therapy is most often successful, i.e. life restoring, when it is patterned on an increasingly sophisticated understanding of the many interwoven issues involved in the illness, and in the successful integration of therapies which address the immunosuppressive, multi-systemic, polymicrobial disease complex which is LBC. Most of us deeply involved in patient care don't care who takes credit for change, and realize that traditional powers must engage for this to happen. We encourage this at every opportunity. Physicians and patients are earnestly waiting for the truth to be revealed, and we hope that this truth will arise from the medical community in a proactive and vigorously engaged manner. LBC is just part of what is driving an epidemic of unwellness and chronic illness in this country. The paradigm of medicine and chronic illness must change over time.....too many of us are sick and getting sicker.

[1] Feder HM Jr, Johnson BJB, O'Connell S, Shapiro ED, Steere AC, Wormser GP, and the Ad Hoc International Lyme Disease Group\*. NEJM. 2007 Oct 4;357(14):1422-1430. A review article

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...the authors fail to present a balanced representation of the patient populations in question. They fail for example, to mention that untreated and dismissed chronic Lyme patients commit suicide at alarming rates due to the hopelessness and agony associated with this illness.

study of this illness complex. Patients know what has made them better and it is highly insulting to patients who are denied care or who had irreversible adverse health consequences to themselves or their loved ones because of suspect motivations by those who now hold power.....almost certainly the patient's interest is not the primary concern in this story.



# You Can Do Anything...TOGETHER!

## An Interview with Linda Lobes, President of the Michigan LDA

by Sue Vogan

It was my distinct pleasure to speak with another Lyme disease sufferer-teacher-advocate who has found the strength, determination and fortitude to reach out to others. Linda's schedule proves just how far she can reach. She's a whirlwind when it comes to advocacy and a scholar with regards to teaching - the passerby would never suspect Linda is ill with this often debilitating and deadly disease known as Lyme disease.

Just this past September 22nd, the Michigan Lyme Disease Association (MLDA) put on a fundraiser (Walk-Run-Sit-athon) that raised more than \$15,000.00 (donations are still coming in). The event was a 3-hour good time at Garden City Park, the weather was great, and the turnout was wonderful. The event was well organized by the board members and sponsors were more than willing to donate. There were golf gift baskets, DVDs, water bottles, books, furniture - no one went away empty handed. The food included 400 donuts, 100 deli sandwiches, pizza, fruit, cookies, drinks and more. Entertainment was even donated! A 50/50 raffle and the pair of Detroit Lions tickets were a hit! It all took planning and action, but you can do anything...together!

What will the money be

used for - education, of course! Like many of us, Linda Lobes shares the belief that education is the weapon against ignorance and the tool to better healthcare. The Lyme Disease Awareness Talks which have attracted thousands and the nearly 350 calls per month seeking answers are enough to let Lobes know that education is still very much needed.

Linda is a phenomenal human being -- employed by General Motors before she came down with Lyme disease, her last day was November 1991. That was where some would have given up. Not Linda! She claims she believes everything happens for a reason and this was no different. She almost immediately became involved with Lyme disease support and advocacy and in 1994 she became a Lyme disease support group leader. A short three years later, Linda became (and still is) the President of the Michigan Lyme Disease Association (MLDA).

During her tenure as President, Linda has led the statewide groups to great heights. In 1997, MLDA presented their first Lyme disease conference (a total of 4 conferences to date); fundraised enough money to erect billboards; raised awareness through radio, television, and newspapers; and has 14 support groups who work together

around Michigan. Linda has been instrumental in getting physicians educated and onboard with regards to Lyme disease and a new color tri-fold brochure that is passed out at various places - including the local health departments. The MLDA has set up booths at horse shows, dog fairs, and county fairs, just to name a few, to raise more awareness. And, if this were all not enough, the MLDA has recently purchased "Lyme in Rhyme," by Geri Rodda, RN, to donate to local libraries and doctors' offices. "Lyme in Rhyme" is an illustrated book for children that will teach them about the detection, prevention, and treatment of Lyme disease.

Michigan does not have Lyme disease legislation and, in Lobes's opinion, Michigan residents are better off without it. Education is the key to diagnosis and treatment - and it seems to be working. Linda travels around the state giving Lyme disease talks on an average of six per month. The travel expenses come out of her own pocket. The State of Michigan House of Representatives recognized the MLDA for their educational efforts and in 2007, The Governor Jennifer Granholm, established May as Lyme Disease Awareness month.

Everything that is done through the MLDA appears to be concentrated teamwork -



**MLDA Board Members:** Chris Senia Trustee, Linda Labadie Trustee, Ted Lobes Trustee, Linda Lobes President, Connie Siese Secretary, Jaylee Mayor of Garden City, Amy Holloway Trustee, Not shown, Bev Grunheid Vice President, Valerie Black Trustee, Mary Fairweather Trustee, Carolyn Gerhard Trustee, Gary Smith Trustee, Sally Lurvey Trustee, Nancy Sauvage Trustee, Chris Emery Trustee.

extensively researched, thoroughly planned, and carefully orchestrated. They are not associated with any national organization and plan to keep their efforts statewide. However, if anyone needs information about making their group or state functionally independent, Lobes is ready to explain how it's done. The success of the MLDA makes them a solid model for the remaining 49 states.

As I interviewed Lobes, she was packing for another Lyme disease talk about an hour away from her home. There would be brochures, tick-

removal kits, handouts, and plenty of eager people who desperately want information. Before we ended the interview, Linda received a request from the local health department - they were out of brochures and needed them right away. Linda would have to make a detour on her way to spread the educational word about Lyme disease - but this was just another day in the life of Linda Lobes.

For more information about how you can get Lyme disease education in your state, please call 1-888-784-5963.

## Low Maternal Cholesterol Tied to Premature Birth

### Researchers Also Uncover Link Between Mothers' Cholesterol, Infant Birth Weight

by NIH News

Pregnant women who have very low cholesterol may face a greater risk of delivering their babies prematurely than women with more moderate cholesterol levels, a team led by the National Human Genome Research Institute (NHGRI), part of the National Institutes of Health (NIH), reported today.

In a study published in the October issue of the journal "Pediatrics", NHGRI's Max Muenke, M.D.; Robin J. Edison, M.D., M.P.H.; Kate Berg, Ph.D.; and colleagues from the NIH Clinical Center; Kennedy Krieger Institute, Baltimore; Howard University, Washington; and Greenwood Genetic Center, Greenwood, S.C., confirm previous findings by other groups that very high levels of maternal cholesterol can increase the risk of premature birth. However, in a surprising new twist, the researchers found that low maternal cholesterol levels, which may be related to a woman's genetic makeup, diet or other health factors, also may lead to adverse birth outcomes, including premature birth and low birth weight.

"Based on our initial findings, it appears that too little cholesterol may be as bad as too much cholesterol during pregnancy, but it is too early to extrapolate these results to the general population. More research is needed to replicate this outcome and to extend it to other groups," said Dr. Muenke, the study's senior author and

chief of the Medical Genetics Branch in NHGRI's Division of Intramural Research. "For now, the best advice for pregnant women is to follow the guidance of their health care providers when it comes to diet and exercise."

Premature birth is a major cause of infant death and raises the risk of many potentially disabling conditions, including cerebral palsy, cognitive impairment, blindness, deafness and respiratory illness. Factors contributing to premature birth include maternal genetics, fetal genetics and environmental components, such as nutrition, stress, and infection.

In their study of 1,058 South Carolina women and their newborns, researchers found about 5 percent of the women with cholesterol levels in the moderate range of 159-261 milligrams per deciliter (mg/dl) gave birth prematurely. In contrast, white women with the lowest cholesterol levels -- less than 159 mg/dl -- had a 21 percent incidence of premature births. Interestingly, no increase in premature births was observed among African American women in the low-cholesterol category. However, full-term babies born to both white and African Americans with low cholesterol weighed 5 ounces less on average than full-term babies born to women with moderate cholesterol.

"The right amount of cholesterol is fundamental for good health, both before and after birth," explained Dr.

Muenke. "During pregnancy, cholesterol is critical for both the placenta and the developing baby, including the brain."

As in past studies, the new research showed very high cholesterol levels (more than 261 mg/dl) to be a major risk factor for premature birth. About 12 percent of white and African American women with very high cholesterol levels gave birth prematurely.

The study involved pregnant women between the ages of 21 and 34 who were referred to South Carolina clinics for routine prenatal care between 1996 and 2001. According to their medical records, they were all nonsmokers without diabetes who were carrying just one child. It looked at cholesterol levels from their second trimester of pregnancy. Premature birth was defined as delivery before 37 weeks of gestation.

Taking into account the natural rise in maternal cholesterol during pregnancy, researchers examined the effects of maternal cholesterol levels on rates of premature delivery, impaired fetal growth and birth defects. In addition, they analyzed measurements of newborn weight, length and head circumference. No differences were seen in the rate of birth defects, but researchers did detect a trend towards smaller head sizes among babies born to women with very low cholesterol.

"This study sheds important light on the intricate biological mechanisms at work

during human gestation," said NHGRI Scientific Director Eric Green, M.D., Ph.D. "In light of these findings, researchers have a renewed impetus to establish the genetic and environmental causes of low cholesterol levels because of its relevance to pregnancy."

In the "Pediatrics" paper, the NHGRI-led research team called for more studies to

refine our understanding of cholesterol levels in pregnant women, and to explore the genetic, nutritional and other factors that influence maternal cholesterol. They also pointed out the need for further investigation into the differing impact of low cholesterol levels on the rates of premature delivery in white and African American mothers.

pha



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## “Grace” ...cont’s from pg 12

to stay away, instead of offering support.

"It was a bad time," she said. She was eventually hospitalized.

"I thought I had multiple sclerosis and that I was finished," she said. "It was horrible. Only the thought of losing my plane kept me fighting."

After seeing several specialists, a German doctor and friend finally diagnosed her with Lyme disease, a tick-borne disease that wasn't named as such until an outbreak in Lyme, Conn., in 1977.

A Scottish doctor and his mother provided funding to pay for McGuire's first year of treatment, which included wearing a pump that dripped medication into her heart 24 hours a day. Following were "six and a half years of hell," and numerous high doses of intravenous antibiotics for years.

Finally, the disease was wrestled into partial remission. But it would be years before McGuire could again seriously think about making that trip.

In the meantime, interest in Earhart's flight and the mysterious disappearance has continued to hold people's attention, as it has continued to hold McGuire's.

The International Group for Historic Aircraft Recovery began the "Earhart Project" in 1988, to solve the mystery of Earhart's disappearance. The organization has conducted vast research and embarked on exhibitions to locate Earhart's L-10E.

They recently solved another mystery. In 1997, Linda Finch, sponsored by Pratt & Whitney, made a commemorative flight, roughly following Earhart's route. McGuire was surprised to recently hear that the flight was made in an L-10E, now owned by Mike Kammerer and based at Santa Fe Airport.

"I'm sure that 'Muriel' is the only existing L-10E," she said.

According to Ric Gillespie, executive director of TIGHAR, who has researched the history of the Electra series, Finch's aircraft, Model 10, construction number 1015, was "born" in 1935, as a Model 10A, and nearly six decades later, was rebuilt as a replica of Earhart's 10E.

"If you say that a true 10E has to have been born that way, the only survivor is McGuire's c/n 1042," said Gillespie.

Gillespie also said that the Electra has made three successful around-the-world flights. In April 1937, c/n 1091, a 10A, was delivered to the Bata Shoe Company of Zlin, Czechoslovakia, and was flown around the world as a promotional stunt. Dr. James Almand, of Denton, Texas, now owns the aircraft, which is still air-worthy.

In 1967, to commemorate the 30th anniversary of the Earhart disappearance, Model 10A, c/n 1112, owned and maintained by Lee Koepke, flown by Col. Donald Payne USAF and Ann Pellegrino, and navigated by William Polhemus, flew around the world approximating Earhart's



Grace McGuire and friends pose with Muriel



Muriel is the last existing L-10E. Grace McGuire flies around the country with names of Lyme Disease patients on her plane who have passed away from the disease to help raise awareness.



Grace also attaches photos of Lyme patients on her plane. This helps put a face to the disease hundreds of thousands battle each year.

equatorial route. The airplane has since been restored to its original configuration as an airliner for Trans Canada Airways.

Gillespie's research showed that Lockheed built 15 Model 10Es, including McGuire's, Earhart's (c/n 1055) and one built for newspaper tycoon Harold Vanderbilt 9c/n 1065)).

If McGuire succeeds in making her flight, she will still be the first to make a commemorative round-the-world flight in a 10E. But, years after the project began, there are still several hurdles.

The fuselage is original, but a lot of interior repairs were made. The cockpit has been

refurbished. It has also been equipped with two auxiliary gas tanks. The propellers are presently being worked on.

At one point, an engine company in Florida overhauled the Pratt & Whitney engines. Now, McGuire says there are just a lot of "little things" that need to be done.

"We're just tidying up," she says.

But McGuire is looking for "one good engine mechanic who is familiar with the Pratt & Whitney 13-40 engines."

"He'd just need to give me a hand finishing hooking everything up," she said.

Another problem is that the plane, once the wings and

tail section are secured, won't fit in the small hangar. The aircraft has a 56-foot wingspan and is about 39 feet long. McGuire says the remaining work could be done on the ramp, but the aircraft would need to remain outside, in danger of weather and souvenir hunters.

She was offered hangar space at Newark International, from a major airline that also offered use of their shop. But, said McGuire, if she took the space, she might lose her volunteers due to the drive and heavy traffic to the busy airport.

Allaire Airport, near Rumson, would be a perfect

solution, but McGuire doesn't have the available resources to rent one of the large hangars.

Then, McGuire needs a navigator/co-pilot. She wants "the best"--a Pan Am co-pilot.

"Pan Am found out that the plane had once belonged to them, and they were so good to me," McGuire said. "They used to send a crew from Kennedy Airport to the hangar. We would remove the part that needed to be replaced and they would fabricate new parts for us. They were wonderful. If they hadn't gone out of business, I think they would have helped me finish the work on the plane."

In honor of Pan Am, McGuire plans to place their logo on the plane. But she has another reason for wanting a Pan Am co-pilot.

"Amelia's navigator worked for Pan Am for a while," she said. "I had one but he passed away a few months after I collapsed. I'm looking for one, but they're all getting up there." And, she would like to find a co-pilot that is familiar with the South Pacific and has a little "over-water experience."

McGuire admits to being a bit "rusty" where flying is concerned, but she says getting back in shape is the least of her problems. Finding a sponsor is the last hurdle she needs to clear. She is still hoping to find an American company to sponsor the flight.

McGuire describes her "journey" to this point as "a long, hard road." But, she continues to keep her chin up. And she is justly proud of that fact that, through financial, physical, and emotional setbacks, she has managed to hold on to "Muriel."

Along the way, many would have gladly taken the aircraft off her hands.

"The Air & Space asked for her a couple of times but I said no," she said. "The museum is too big. They'd probably just put her on display for a little while, and then send her over to their storage facility. Too much work has gone into it. It has to be a permanent display."

McGuire has bigger plans for "Muriel."

"She has to be taken care of," McGuire says adamantly. "She's a very special little plane. There were times I crawled on hands and knees into the hangar to keep the project going. When I retire her, she'll go to Atchison, Kansas--Amelia's birthplace. That's where she belongs."

As for McGuire, it's disappointing that she hasn't yet been able to make her hoped-for trip, but she has gained from her trials.

"It's given me humility and compassion for others who might suffer from Lyme disease, until a cure can be found," she says. "The battle also gave me a renewed appreciation of life, a stronger will to succeed."

McGuire laughs and says there is one more thing that her battle has done.

"I'm not as arrogant as I used to be," she said. "It's injected a bit of humility into my personality." *pha*

## I recommend Researched Nutritionals® for my patients ...Joseph Burrascano, M.D.



Joseph Burrascano, M.D.

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