# PUBLIC HEALTH ALERT

Vol. 1, Issue 5 Investigating Lyme Disease & Chronic Illnesses in the USA December 2006


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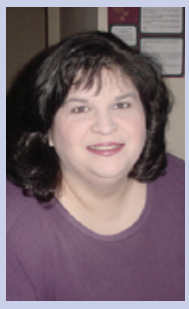

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November 16, 2006
The Hearing begins at 9:00 AM
At the Legislative Office Building located at
300 Capitol Avenue,
Hartford, CT.

# University of Texas San Antonio Studies Bio-Terroristic Agents

## Lyme Disease Among the Diseases Being Studied

***By Kris Rodriguez***
***UTSA Today***

U.S. Sen. John Cornyn, R-Texas, joined UTSA President Ricardo Romo and community members to celebrate the opening of the $10.6 million Margaret Batts Tobin Laboratory Building on the UTSA 1604 Campus.

The new lab is named for the local businesswoman who in 1947 became the third woman to serve on the UT System Board of Regents.

"I am encouraged to see the outstanding research taking place at UTSA and in my hometown of San Antonio," said Cornyn. "The work that is being done here has benefits for the entire country, and UTSA has shown great vision and foresight in biotechnology."

"This facility is key to UTSA's movement to become the state's next premier research university," said Romo. "Faculty and students working in these labs are crucial to the university's mission to improving the lives of all our citizens -- today and in the future."

*Photo by Mark McClendon, UTSA*

J. Bruce Bugg Jr., Tobin Endowment trustee; Sandy Cornyn, wife of the senator; Sen. John Cornyn; Leroy G. Denman Jr., Tobin Endowment trustee; and UTSA President Ricardo Romo at the opening of the bio-lab at UTSA.

The 22,000 square-foot facility, designed by FKP Architects and built by Vaughn Construction, will accommodate UTSA faculty and graduate stu

***"Bio-Lab" ....cont'd pg 10.***

# ILADS President Calls for Retraction, Peer Review of IDSA's Lyme Treatment Guidelines

The Infectious Disease Society of America (IDSA) recently released a new set of guidelines for the diagnosis and treatment of Lyme Disease. These guidelines were met with great shock and disdain by Lyme literate medical professionals who treat this disease on a daily basis. The following letter is from the President of the International Lyme and Associated Disease Society calling for the full retraction of the IDSA released guidelines.

October 25, 2006

Sherwood Gorbach, M.D., Editor
*Clinical Infectious Diseases*
Tufts Univ. School of Medicine
200 Harrison Avenue
Boston, Massachusetts 02111

Subject: Retraction of "The clinical assessment, treatment, and prevention of Lyme disease, human granulocytic anaplasmosis, and babesiosis: Clinical practice guidelines by the Infectious Diseases Society of America."

Dear Dr. Gorbach:

On behalf of the membership of the International Lyme and Associated Diseases Society (ILADS), I am submitting a formal request for retraction of the article, "The clinical assessment, treatment, and prevention of Lyme disease, human granulocytic anaplasmosis, and babesiosis: Clinical practice guidelines by the Infectious Diseases Society of America" (hereafter referred to as the "Lyme guidelines article"), which has been published electronically in your journal (1).

ILADS is requesting retraction of the Lyme guidelines article because the authors of the article employed exclusionary data selection that substantially biased the resulting diagnosis and treatment recommendations while ignoring opposing or dissenting views about these recommendations. As with research articles tainted by data selection, the Lyme guidelines article threatens to harm patients and patient care due to the biased methodology used by the authors, and this threat can only be avoided by formal retraction of the article.

The attached analysis of key points in the Lyme guidelines article demonstrates that the authors of the article made statements that either reflected significant selection bias of published data or ignored published evidence that conflicted with their opinions. Nowhere is this more apparent than in Dr. Klempner's analysis of the three NIH-funded Lyme treatment studies, which elevates and relies on the findings of his own study while dismissing the results of two other studies that conflict with his findings. Other statements about the erythema migrans (EM) rash,

***"Retraction"...cont'd pg 7***

# Editorials & Opinions

## When Truth is Stranger than Fiction

It is election time once again! It never ceases to amaze me... the political games and empty promises that are made during an election season. What I find particularly interesting in this election year is the absolute SILENCE of senators and representatives in Texas on the issue of the Lyme Disease legislation that has repeatedly been brought to their attention.

On one hand we have Representative Joe Barton from North Texas who has not yet acknowledged our many letters and faxes with so much as a form letter. Joe Barton sits as the chairman of the committee in which this Lyme legislation is currently held captive. At this rate, if it is not moved out of committee and on to the senate for a vote, it will die in his committee.

On the other hand we have Republican Senator John Cornyn (see cover story and photo) that is aware that Lyme Disease is being studied as a bio-terroristic agent at the University of Texas in San Antonio...all the while we still have doctors in Texas that say we do not have Lyme Disease in Texas! Cornyn has yet to sign on to the legislation as a supporter!

It truly makes one wonder why all the conflicting information. I would not consider myself to be a "conspiracy theorist"...but who needs conspiracies when you have cold hard facts that are stranger than fiction!

For instance, Texas A&M University has had research for over 10 years showing the Lyme Disease is in Texas. There is even a tick research lab at the University of North Texas. UT San Antonio has a bio-lab where Lyme is being studied as a bio-terroristic agent. The Army has been doing tick surveillance research in Texas and has found several areas to be "at risk" of Lyme infection.

So with all the mounting evidence that Lyme is here to stay, why is it that the medical community in Texas still says "there is no Lyme in Texas" and they will often even refuse to treat Lyme disease? The Texas Parks and Wildlife website says that the Lyme bacteria is not only found in ticks, but also in fleas, mites, mosquitoes, and biting flies.

Could it be that these government agencies, universities, military branches and state medical associations are just not communicating with each other? Forgive me for stating the obvious!!

I find it rather curious that the CDC does not list Lyme Disease as a bio-agent on their website, yet the bio-lab at UTSA, "which requires certification by the Centers for Disease Control and Prevention and government security clearances for researchers" is clearly studying it as such...with the knowledge of the CDC. Interesting.

Do you want to know what else I find strange and interesting? It is the fact that there have been several doctors from the east coast (Lyme endemic areas) write to me, here in Texas (where according the TX medical establishment Lyme does not exist) for 1000+ copies of the Public Health Alert to be passed on to their patients and colleagues to help get true Lyme awareness out to the masses. Now I don't know about you, but when the east coast comes to Texas for Lyme Disease information and education materials, there's just something strange about that situation!

It all sounds like a really messed up game of CLUE! The CDC did it, in the lab in San Antonio, for a bio-weapon in Iraq.

*Dawn Irons, Lyme Disease patient and Editor of PHA holds a BSW degree in social work from the University of Mary Hardin-Baylor and has been working with medically related social issues for almost 10 years.*

## Troubling Practices of the FDA

***by Susan Williams***

This August, the FDA approved a spray known as LM-102, which consists of six bacteria-killing viruses that will be used on ready-to-eat meat and poultry products.

These viruses, known as bacteriophages, can kill the Listeria monocytogenes bacteria which can cause a serious infection known as listeriosis. The Centers for Disease Control and Prevention (CDC) estimates that approximately 2,500 Americans become seriously ill with listeriosis each year, and 500 of those victims eventually die. Most of those who become ill are pregnant women, the elderly with compomised immunity, and small children.

This bacteriophage spray, marketed as a food additive, is designed to be sprayed on ready-to-eat meat products such as cold cuts, hot dogs, sausages, and chicken right before they are packaged. The FDA claims that the bacteriophages are prepared in such a way that they only attack strains of the Listeria bacterium, and do not harm human or plant cells.

In spite of these assurances, many consumers are understandably worried. Some feel that this will lead to poorer hygiene and quality control among meat vendors, who will depend on the spray to cover their errors. "Listeria is a small problem in the grand scale of things to be worried about when it comes to our food supply. The real problem is that they let slaughterhouses use infected, diseased animals. There's little oversight," asserts Mike N., a consumer and health activist from Weston, Wisconsin.

Others worry about resistant strains of Listeria developing, or mutations of the viruses contained in the spray which could then become harmful to humans.

Félix d'Herelle, a French-Canadian microbiologist and one of the first to discover bacteriophages, co-authored a 1924 book titled "Immunity in Natural Infectious Disease". The book specifically addresses "Adaptation and the Bacteriophage", explaining various studies by the authors that show the bacteriophage and the bacterium that is being attacked both undergo an adaptation process. d'Herelle comments, " The bacteriophage adapts itself to a more and more vigorous attack against the bacterium, and the bacterium accustoms itself to resist this attack."

He continues, "The proofs are then multiple: The bacteriophage possesses the power of adaptation... of assimilation. It possesses likewise the two corollaries of these powers; the faculties of multiplication and variability.... The bacterium does not remain passive before the attack of the bacteriophage. It is capable of resistance. It is even able, when the conditions for it are favorable, to acquire a complete immunity."

Lytic phages, like the ones that the FDA has determined are contained in the LM-102 spray, function basically in this manner: In short, the bacteriophage attaches to the surface of the much larger bacteria. Once attached, the bacteriophage injects DNA into the bacterium. This viral DNA instructs the bacterium to produce

***"FDA"...cont'd pg 7***


## Public Health Alert

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

PHA seeks to bring information and awareness about these illnesses to the public attention as well as a broad base of health and nutritional news. We seek to make sure that anyone struggling with these diseases has proper support emotionally, physically, spiritually and medically.

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We cannot accept credit card payments.

You may mail your donation to:
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**821 Sansome Drive**
**Arlington TX 76018**

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We are have distribution in Texas, California, Florida, Louisiana, Missouri, and Arizona. We look forward to more nation wide distribution as we further network with chronic illness support groups across the U.S..

We are a privately owned business and have the right to refuse publication of articles or advertising we deem inappropriate.

**Disclaimer:** This newspaper is for informational and educational purposes only. The owners, staff, writers and contributors of this group are not doctors (unless identified as such in their title). Articles in this newspaper are not intended to prevent, diagnose, treat or cure disease.


### Letters to the Editor

You may send letters to the editor:
**editor@publichealthalert.org**
or by postal mail to:
PHA
821 Sansome Drive
Arlington TX 76018

All letters to the editor must be signed, and include name, address, and phone number. Letters will be printed as space permits.

# Letter to the Editor

Dear Dawn;

As a result of reading the most recent IDSA guidelines please consider the following for publication if you see fit.

I do not propose this as a symmetrical rebuttal of the scholarly work by the Infectious Disease Society, but just some food for thought until an official rebuttal is made available.

***"Unless we put medical freedom into The Constitution, the time will come when medicine will organize into an undercover dictatorship"***

These are obviously the words of an out of control, conspiracy theory worshipping, JFK was shot by aliens, whacko...or are they?

A signer of the Declaration of Independence, personal Physician to George Washington, and namesake of Rush Medical School, Dr. Benjamin Rush wrote these words well over 200 years ago.

How much this has to do with the current state of Lyme disease controversy today I do not know.

What I do know is that there seems to be quite a common story among Lyme disease suffers and their treating professionals. The consensus within the International Lyme and Associated Disease Society (ILADS) and other Lyme literate medical doctors (LLMD) is remarkable. It is as if they have all read from the same book.

Likewise the consensus of the Infectious Disease Society is quite remarkable. Their recent 78 page document has over 300 references and more Ivy League graduates than Congress. They speak with one voice also.

How is it possible that these two groups have become so directly opposed that common ground does not exist?

One group has worked together for decades, and been able to hone their influences to an art and science.

•They truly are coordinated in their efforts, have nearly unlimited funding and intelligence, with impeccable academic backgrounds.

The other group was selected in a somewhat more random fashion.

•A small arachnid, closely related to a mite, roughly the size of a sesame seed on your Big Mac, lives in the dirt and feeds off the blood of animals. It randomly falls upon victims as they pass by, and has the IQ of a walnut.

Which group is more likely to be swayed by complex political and or economic, agendas? Which group would be more likely to put a spin on a complicated, multifactorial, worldwide health crisis? Which group meets regularly to exchange complex ideas and influence public opinion? Which group may have obscure and hidden financial ties to drug and vaccine companies?

Ticks are simple; they are only trying to survive. They don't have a position paper.

Questions arise in my mind about Lyme disease patients, particularly **"Chronic Lyme disease"** patients.

• What are the chances that this completely random group all conspired together to mislead the public about their remarkably similar conditions?

• What are the chances that the position taken by this group, and their treating physicians, could be stated in a simple document (see ILADS website) when the group is selected by the ticks themselves?

Is it possible that forces are at work here that requires a little more understanding than the average tick can manage?

Lyme disease is curable, but the diseases that it imitates generally are not.

Multiple Sclerosis, Psoriatic Arthritis, Rheumatoid Arthritis, Chronic Fatigue syndrome, Fibromyalgia Syndrome, ALS; all require lifetime care.

Perhaps more importantly the smaller the group of individuals that currently is diagnosed with Lyme disease, the larger the market for a vaccine. You can't sell a vaccine to someone already exposed to the disease. These parameters must be defined in advance.

Follow the big money, follow the big picture, ignore the individual patient and where are we led?

I have no good answers, but good questions may be the place to start.

Mike D. Maddox, DC

*pha*

# Reagan's Ramblings Rants & Raves

*by Donna Reagan*

# The 3 Ring Circus: Welcome to the Big Top!

## Part 1: The Big Picture

**Step Right Up, Ladies & Gentlemen!**

When I first heard about the "NEW" Lyme disease treatment guidelines produced by the Infectious Disease Society of America (IDSA) - I thought: "Hmm….can actor Ashton Kutcher actually 'PUNK' an entire nation? Can we somehow be on a really BIG hidden camera? Is that 'Candid Camera' fella still alive?"

Manufacturers of products come out with "NEW" stuff all the time; usually the products are either improved in some way, or at least presented in a bigger, better box. But the "NEW" IDSA guidelines are in all reality …worse!

The IDSA camp would claim this is BIG NEWS when, in fact, I think it should be more of a BIG SECRET that such a society would join together to simultaneously cram their BIG feet into their BIG mouths, while delivering a blow to American, and even international patients, that is equivalent to a disability or death sentence.

The big picture with these "NEW" guidelines seems to reveal more of the true agenda behind health care in these United States. That agenda is more complicated than choreographing a 3-ring circus. In one ring there are BIG business interests, the second ring holds the entertainment provided by BIG Pharma, and of course, smack dab in the center ring is none other than "BIG Brother".

Before delving into these "NEW" guidelines, I briefly scanned through the 70+-page document and realized I'd rather make cocktails out of Syrup of Ipecac than to read all the drivel which was clearly going to make me sick to my stomach anyway. Ipecac cocktails seemed, to me, to be more efficient. Unfortunately, our liquor cabinet contains neither Ipecac nor any liquor, so I forced myself to peruse the treatment guidelines set forth by this "professional" society, comprised of individuals who supposedly took the Hippocratic Oath to 'first do no harm'.

For those of you brave enough to have actually read that lengthy text, I know I don't have to tell you it is full of erroneous information, possibly fraudulent, which will certainly bring harm to thousands upon thousands of Lyme disease patients if unwitting physicians follow what amounts to be a set of instructions for the novice practitioner, unfamiliar with appropriate treatment of Lyme disease. In all fairness to the IDSA, they include a disclaimer indicating utilization of the guidelines is 'voluntary'. However, when the Centers for Disease Control (CDC) quickly adopt such guidelines and recommend them on their website as THE 'guidelines' I find the word ***'voluntary***' to be more insidious than comical …like a clown performing an overly violent sideshow of slapstick, smiling all the while.

It should also be noted, it did not take the health insurance industry much time at all to seize what "voluntary" content it desired to use as a means to deny coverage of important treatment options for patients, such as specific and necessary antibiotics. Some may argue the guidelines are not a legally binding document, therefore patients and their physicians can choose to follow whatever treatment options they desire. Ah, if this were only the case! While that may be true in the legal sense - we must not forget that perception makes reality, and the reality for patients and the physicians who treat them is the Infectious Disease Society of America carries a great deal of authority. Lest we forget -- these new guidelines also have the power and authority of the CDC behind them, although it is WE, the people, who have given away that power and authority with every patient who needlessly suffers with this atrocious disease.

**Get Your Popcorn & Peanuts Here!**

In a nutshell, which is where these guidelines belong because they are absolutely "nuts" -- the IDSA requires the physician to base his/her diagnosis of Lyme disease upon the observation of the erythema migrans (bullseye rash) if any blood test is negative.

***"Big Top"...cont'd pg 12***

# Do Polyunsaturated Oils Play a Role in Chronic Illness?

***By Marjorie Tietjen***

The incidence of chronic illness is rising exponentially in the industrialized nations. For certain there is more than one reason for this phenomenon. However, for this article I would like to concentrate on the fats in our diets, how their uses have evolved and the apparent effect they are currently having on our health.

We all know how diet and health fads change and go through cycles. How are we to know what to believe? I like to think that common sense plays a role... looking at what is the most natural form of the food (the least tampered with) and what diets indigenous societies have been thriving on for hundreds of years. Much of the modern dietary advice we receive has had it's origins in corporate technology and greed.

We need to understand some of the basic reasons for the transition from the use of saturated fats to the fairly new idea that polyunsaturated fats are "healthier". Before World War 2 most of our oil consumption was in the form of saturated fats, including coconut oil. When the Japanese occupied the South Pacific and the Philippines during World War 2, the importation of coconut oil was aborted for a few years. In the meantime our country had to substitute other oils which could be used for cooking purposes. This is when polyunsaturates began appearing on the horizon. Saturated fats, especially coconut oil, began to receive much negative press. For a more detailed history of the politics and financial aspects, check out the articles by Dr. Mary Enig, on www.coconutoil.com

As the consumption of natural saturated fats decreased and the use of polyunsaturated oils increased, the rate of heart disease rose exponentially. Much research now shows that cholesterol levels in food do not correlate with levels of this substance in the blood.

Many of us have heard by now that hydrogenated oils, such as margarine, are not all they have been cracked up to be. Science has recently demonstrated that hydrogenated vegetable oils form trans fatty acids. This type of artificially manipulated fat has been linked to heart disease…. the very disease it was supposed to help prevent.

I have recently been researching into the benefits of consuming saturated fats, especially coconut oil. The following is a quote from the book *Virgin Coconut Oil* by Brian and Marianita Jader Shilhavy. "Congress held hearings in 1988 to discuss the safety of tropical oils. Dr. George Blackburn, a Harvard medical researcher, testified that coconut oil has a neutral effect on blood cholesterol, even in situations where coconut oil is the sole source of fat. Surgeon General C. Everett Koop dismissed the entire attacks on coconut oil as "Foolishness" and continued to say "but to get the word to commercial interests terrorizing the public about nothing, is another matter."

The problem with polyunsaturated oils is that they are very unstable and turn rancid very easily, which is why the process of hydrogenation was implemented. Polyunsaturate oils, such as soy, safflower, corn, sunflower and canola, are the worst oils one can choose for cooking. Many toxic chemicals are formed by frying with these oils. Butter and extra virgin olive oil are somewhat better to fry with but are still damaged by heat. Olive oil is best used on salads. Of all the oils, coconut oil best resists damage from high heat. Coconut oil is so stable that in the tropics, where it is stored at very warm temperatures, it has been found to resist rancidity for 2 to 3 years.

New research is beginning to show that consumption of the polyunsaturated oils (omega 6 oils) puts us more at risk for heart disease than the much maligned saturated fats. Polyunsaturates promote an increase in platelet stickiness, which encourages blood clot formation. Coconut oil actually reduces platelet stickiness and the resulting risk of blood clots. Also, when fats turn rancid easily, which the polyunsaturates are notorious for, they form free radicals in the body which play a major role in accelerating aging and in the causation of degenerative disease. Some of the problems associated with free radical damage are: heart disease, cancer, stroke, diabetes, digestive problems, allergies, hypertension, poor memory, wrinkles, cataracts and more. We can't avoid all free radicals but we can eliminate as many of the sources as we can…such as cigarette smoke, sugar and other denatured and processed foods.

Now, for those of us with chronic illnesses, such as Lyme disease and other viral, bacterial and parasitical infections, coconut oil provides more added benefits. Coconut oil is the richest natural source of lauric acid, aside from mother's breast milk. Much research has been conducted on lauric acid and it has been found to have significant antiviral, antibacterial, antiyeast, mold, fungi and antiparasitical activity. This fact should be of vital interest to anyone who wants to sustain their good health or to those who need to restore a weakened immune system. Coconut oil contains anywhere from 42 % lauric acid to 57%.

Caprylic acid is also found in coconut oil. Some of you who have treated systemic yeast infections have used caprylic acid in capsules from the health food store. This isolated substance can be very helpful in keeping candida under control. However, many herbalists and researchers are finding that most often it is much more beneficial to our overall health to consume these natural substances as they occur in nature…in their whole food form.

Our chronic illnesses are often a collection of several or many different microbes. Coconut oil may be able to help keep some of these germs in check. The medium chain fatty acids (MCFAs) in coconut oil disrupt the lipid membranes of many of the following organisms: influenza, measles, HIV, herpes, cytomegalovirus, strep, gonorrhea, heliobacter pylori, salmonella, clostridium botulinum, yeasts and even ringworm.

Remember, I mentioned before that many times chronic illnesses are caused by a collection of different microbes. So, even if a microbe you know you are infected with isn't listed here, coconut oil may aid in reducing the total microbial load, which in turn helps restore the immune system.

Many chronic diseases, such as Chronic Fatigue Syndrome and Chronic Lyme Disease, involve thyroid issues, especially hypothyroidism. I often wonder which comes first…..the malfunctioning thyroid which then compromises the immune system or if a biological agent enters into the picture first and subsequently attacks the thyroid. Either way subnormal thyroid function can be a major source of fatigue and other immune system problems. Research has shown that the medium chain fatty acids in coconut oil are not easily stored as fat but are actually utilized for energy production. Coconut oil increases the body's metabolism, aiding the thyroid. This produces increased energy and encourages weight loss. One will begin hearing more of the dietary slogan to" eat fat to lose fat". Of course an all around sensible diet and exercise must also be followed. Too many refined carbohydrates is often the culprit which causes weight gain. Boosting our metabolic rate also aids cell regeneration, which accelerates the healing process.

Historically, coconut oil has also been used extensively in skin care, helping to prevent acne, dry skin, wrinkles and other damage caused by the sun.

Some people feel that virgin coconut oil is the best form to

***Oils...cont'd pg 5***

**May be useful for:**

- Heavy metals
- Liver detoxification
- Weight loss
- Cholesterol
- Lyme disease
- Arthritis
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- Crohn's disease
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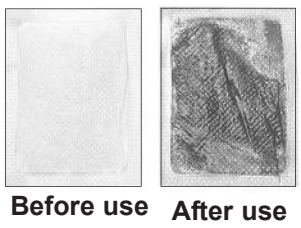

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## Polyunsaturated Oils...cont'd from pg 4

use over expeller pressed. More of the beneficial constituents are retained, due to its minimal processing. Despite the many benefits of virgin coconut oil, coconuts do not contain the omega 3 fatty acids, so to maintain a healthy balance; we still need to eat fish, fish oils or flaxseed. There is no one miracle food that cures all.

Natives of the tropics, who eat the traditional diet, consisting of more than 50% fat from fish and coconut products, are lean and strong, with healthy bone structure, no tooth decay and little or no heart disease. Dr. Weston A. Price says in his book "Nutrition and Physical Degeneration" that those in the tropical climates, who eat the traditional foods, did not acquire vector borne diseases such as malaria.

If you would like to learn more about coconut oil and the benefits of going back to traditional diets, I recommend two books….*The Coconut Oil Miracle* by Bruce Fife, C.N., N.D. and *Nourishing Traditions* by Sally Fallon. Most people think that virgin coconut oil is delicious, including me! The above 2 books include important factual information along with mouthwatering recipes.

We are meant to eat fat….yes, even saturated fats. The proper fats in the right balance are essential for a smooth functioning immune system. pha

# URGENT ACTION NEEDED

Sign the Petition at the LDA

**www.lymediseaseassociation.org**

**New IDSA Guidelines Effectively Stopping Treatment for Lyme**

The new IDSA guidelines published in October by the Infectious Diseases Society of America (IDSA) are already causing patients to be denied treatment for chronic Lyme disease. The guidelines have recommended against any long term treatments, listing numerous specific antibiotic classes not to be given, listing alternative treatments and even supplements not to be offered to Lyme patients. Clinical discretion has been removed from treating physicians. We ask that you, your families, and friends across the country sign this petition immediately.

**Lyme treatment is at stake.**

http://www.lymediseaseassociation.org/referral/Petitions/Petition.php?id=1

# URGENT!

Yes...we are taking the space, one more time to remind you of the URGENCY for

YOU
YOUR FAMILY
YOUR FRIENDS
ANYONE YOU KNOW OVER 18 YRS OLD

to go and sign the

# PETITION

at the National Lyme Disease Association Website:

www.lymediseaseassociation.org

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

**1. The correct diagnosis of this infection can be challenging in many patients.**

**2. Chronic antibiotic therapy alone is not the answer.**

**3. Many conditions such as Chronic Fatigue Syndrome, Fibromyalgia, Multiple Sclerosis, etc. have a Lyme Disease connection.**

**4. A comprehensive approach using a novel protocol holds the most promise of eradicating this infection and restoring health.**

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# One Tough Grandma

## (On Becoming a Grandmother in a Lyme-Endemic Family)

***By Ginger Savely, FNP-C***

The phone rang early the morning of October 4, 2006, and as I came out of my barely-conscious stupor, I heard the exhausted but exhilarated voice of my eldest daughter softly announce, "You're a grandma!" My first grandchild - a delicate little girl with lots of dark hair, looking just like her mom did when I first held her in my arms some 26 years earlier, marveling at her perfection and overwhelmed by my love for her.

Many feelings run joyfully, inquisitively, and apprehensively through the minds of new mothers and grandmothers - the same thoughts, questions, and concerns that have passed down through the ages as women relive the miracle and splendor of birth. As I soaked up the reality of my new role and the new life that had blessed us, I pondered: Will my new granddaughter have my daughter's clever wit and strength of mind? Her husband's ingenuity and athletic ability? Will she bear resemblance to me in any way or will she inherit the strong Irish genes of my daughter's father? Will she be calm or impatient? Serious or jovial? Disciplined or free-spirited?

However, for our family, and others like ours, a darker question looms forebodingly in the background. Did the spirochete that causes Lyme disease, the corkscrew-shaped bacteria that infects my daughter and many other members of our family, pass through my daughter's placenta and into this innocent little baby's body, threatening to catch her under-developed immune system off-guard and wreak havoc when least expected?

The Centers for Disease Control and Prevention (CDC) maintains that there is absolutely no risk of congenitally transferring the borrelia spirochete that causes Lyme disease. Intuitively, this is hard to believe, considering that a genetically much less sophisticated spirochete, *Treponema Pallidium*, the causative agent of syphilis, is well-known to pass from mother to child and cause potentially devastating consequences for the infant. Borrelia bacteria have been isolated in both sperm and breast milk, and those of us who treat chronic Lyme patients have suspected and clinically observed the congenital transfer of the disease, over and over again. The results of congenital Lyme can be mild to devastating: the bacteria may cause almost immediate, acute damage or hide sequestered in the joints, heart, brain or other organs, to appear later in life, when least expected, causing subtle and unsuspecting problems like learning, social or developmental delays, all easily attributable to other causes.

Two years ago, when precious little Payton was born to one of my Lyme patients in Austin, Texas, I witnessed the full potential fury of the bacteria's congenital transfer. Payton was delivered by cesarean section due to a breech (feet first) presentation. From all outward appearances he started life as a healthy little baby boy. But the baby's maternal grandmother picked up on subtle cues that something was not quite right. She alone noticed his unusual lethargy, decreased muscle tone, and unwillingness to focus on faces or track moving objects. On the nineteenth day of Payton's life, he developed a fever and became very fussy. Following the pediatrician's protocol, the young parents took their baby immediately to the emergency room. After blood tests and imaging studies, the perplexed doctors were unsure as to why the infant had begun to bleed into his brain, causing him to take a sudden turn for the worse.

Various possibilities were considered, including an arterial-venous malformation in the brain, a stroke, an aneurysm, or possibly even infection. Payton's grandmother suggested the possibility of a congenital transfer of Lyme disease, since the infant's mom had, by oversight, discontinued her Lyme treatment halfway through the pregnancy. The neurosurgeon, pediatric neurologist, hospitalist, and pediatrician scoffed at the idea, informing the baby's grandmother that this was unheard of and furthermore impossible. Apparently they were not familiar with the highly regarded textbook, *Infectious Diseases of the Fetus and Newborn Infant*, published by W.B. Saunders in 2001. An entire chapter of more than a hundred pages is devoted to congenital Lyme disease. Written by the pediatric infectious disease specialist, Tessa Gardner, MD, the chapter describes more than 250 such cases.

A temporary shunt was placed to drain the excess fluid from Payton's brain. The doctors had highly recommended a permanent shunt, by now convinced of an irreversible condition. But, with fierce tenacity, Payton's grandmother had pushed for the temporary shunt, unwilling to give up on the notion that a treatable infection, rather than a congenital anomaly, was the culprit for the baby's brain bleed. Her stubborn refusal to accept what the doctors were saying began to create tension between her and her daughter, who was wearily resigned to Payton's fate and annoyed by her mother's persistence.

Payton's prognosis was tenuous as the stressful weeks dragged on. The specialists did all they could to keep him alive, while debating the etiology of his condition and the prudent way to proceed. The odds that little Payton would pull through this nightmare were diminishing, and each night his young parents barely slept, fearful that the night would be their baby's last.

At the request of the grandmother, I consulted with Dr. Charles Ray Jones, the nation's leading authority on pediatric Lyme disease, and was assured that Payton's predicament was a possible presentation for congenital Lyme. Furthermore, he had seen two similar such cases himself, both having benefited from positive outcomes after intravenous antibiotics were administered. More determined than ever, Payton's grandmother insisted that the pediatric infectious disease doctor on the case (the one doctor who was not openly antagonistic about the congenital transfer idea) provide her with a test tube of spinal fluid drained from the baby's shunt. Under my orders, she mailed it, along with the baby's already-frozen cord blood, to IGeneX laboratories in Palo Alto, California, for PCR (Polymerase Chain Reaction) testing.

The PCR test, which looks for actual genetic material of the guilty spirochete, is highly specific (if it's positive, you KNOW it's positive) but not very sensitive (it misses many of the true positives). Dr. Jyotsna Shah, director of IGeneX Laboratories, called me herself with the amazing news that both the spinal fluid and cord blood were positive for borrelia by PCR. Meanwhile, as fate would have it, soon before the test results arrived, the baby developed a staph infection in the brain (a risk of the brain shunt) and was started on three powerful intravenous antibiotics.

Payton's grandmother informed the hospital doctors of the positive Lyme tests, but by now the baby's miraculous transformation spoke for itself. Within less than twelve hours of the administration of the IV antibiotics, it was evident that the antibiotics were treating more than the newly-acquired staph infection. The baby's initial neurological symptoms cleared. He became alert and responsive with good muscle tone and eye contact. He began to thrive, ready to get on with life as if the previous six weeks had been nothing more than a nightmare.

The doctors were bewildered and amazed, having never witnessed such a dramatic transformation in a severely ill newborn. Reluctantly, a few of the doctors admitted that the borrelia infection was probably the cause of Payton's near death experience, and that the presence of the bacteria in the cord blood and placenta could only have occurred due to congenital transfer. Apologetic that they had dismissed the grandmother's pleas, these doctors still maintained that this was a "one in a million" case, an event unlikely to be witnessed more than once in a physician's career. Little did they know that those of us who have treated hundreds of Lyme patients witness congenital transfer cases (although perhaps not as dramatic as this one) every day.

That was one tough grandma! Lucky for little Payton, now a healthy, happy two-year old, his grandma was intelligent and intuitive and wouldn't take no for an answer. It takes guts to stand up to an entourage of condescending specialists who represent the conservative doctrinism of the medical establishment!

Despite this one, almost-devastating outcome, I have seen many other "Lyme moms" deliver perfectly healthy babies who test negative by PCR at birth and are

***"Tough Grandma" cont'd pg 16***

# "Retraction"...from pg 1

Lyme testing methodology, antibiotic treatment of chronic Lyme disease, Lyme disease in pregnancy and Lyme disease in Southern states all reflect a biased view of Lyme disease that is either unsubstantiated or refuted by available peer-reviewed published literature. It is disturbing that ten of the cetral recommendations in the guidelines are supported by evidence ranked E-III—that is, "very strong" recommendations based on the weakest level of evidence—opinion. In light of the controversy surrounding Lyme disease diagnosis and treatment and our evolving understanding of the disease, it is inappropriate to dictate medical care based on such weak evidence. The panel of authors was selected to exclude divergent points of view from patients, from treating physicians in other medical societies, and even from physicians within IDSA itself. The failure of the authors to disclose dissenting views presents a false sense of consensus on an issue that is in fact highly controversial, misinforming patients and physicians alike about available treatment options and denying the exercise of clinical discretion and individualized medical decision-making that is central to any complex illness.

Although the Lyme guidelines article boasts 405 references, many of the dissenting references are either glossed over or ignored in the text. In addition, as of the date of publication of the Lyme guidelines article there were 18,537 articles about tick-borne diseases listed on Medline, so the referenced articles represent only 2% of the available literature. The remaining 98% of these articles often present opposing or conflicting views of Lyme disease, and thus the data selection by the authors is even more striking.

We are aware that retraction of medical publications is generally reserved for research articles that violate principles of scientific integrity (2). Scientific integrity has been defined as "commitment to truthfulness, to personal accountability and to vigorous adherence to standards of professional conduct (eg, accuracy, fairness, collegiality, transparency)" (3). Clinical guidelines from societies as powerful as IDSA are generally accepted as accurate, fair, collegial and transparent, and they rapidly become the standard of medical care in our country. It is wholly inappropriate and dangerous for guidelines to be formulated using exclusionary tactics, flagrant data selection, biased opinions and sweepingly "strong" recommendations based on the weakest category III evidence. We feel that the same principles of scientific integrity that apply to medical research should also apply to practice guidelines. In our opinion, the Lyme guidelines article does not reflect accuracy, fairness, collegiality or transparency and should be retracted.

**We propose the following:**

1. Immediate retraction of the published Lyme guidelines article.

2. Formal notification of the CDC and other medical societies that the guidelines article has been retracted.

3. Formation of a widely diversified Lyme guidelines committee that bases its recommendations on the strength of the underlying evidence.

4. Reformulation of the Lyme guidelines article to reflect a more balanced view of tick-borne diseases, taking into account the existing evidence-based ILADS guidelines article listed by the National Guidelines Clearinghouse (4).

5. Submission of the reformulated guidelines article for outside peer review to a medical journal that is independent of IDSA.

Sincerely,
**Raphael Stricker, MD**
**President, ILADS**

To see the comparison chart
of the IDSA and ILADS guidelines
go to the following website:
http://www.ilads.org/guidelines_compare.html

**References**

1. Wormser GP, Dattwyler RJ, Shapiro ED, Halperin JJ, Steere AC, Klempner MS, Krause PJ, Bakken JS, Strle F, Stanek G, Bockenstedt L, Fish D, Dumler JS,Nadelman RB. The clinical assessment, treatment, and prevention of Lyme disease, human granulocytic anaplasmosis, and babesiosis: clinical practice guidelines by theInfectious Diseases Society of America. Clin Infect Dis. 2006 Nov 1;43(9):1089-134. Epub 2006 Oct 2.

2. Warner TD, Roberts LW. Scientific integrity, fidelity and conflicts of interest in research. Curr Opin Psychiatry. 2004;17:381-5.

3. Institute of Medicine National Research Council of the National Academies. Integrity in scientific research. Washington, DC: The National Academies Press, 2002.

4. The ILADS Working Group. Evidence-based guidelines for the management of Lyme disease. Expert Rev Anti-Infect Ther 2004; 2:S1-S13. pha

Dr. Stricker, the President of the International Lyme and Associated Disease Society (ILADS) calls for retraction of IDSA's 2006 Lyme Guidelines.

# "FDA" ...cont'd from pg 2

masses of new viruses. When so many of these new viruses are produced that the bacterium cannot hold anymore, the bacterium bursts (lysis) and dies. This then requires the viruses to find new host cells.

Bacteria produce poisons known as "endotoxins" in an effort to defend themselves. When the bacteria rupture and die, these endotoxins are released.

The FDA ruling remarks that Listeriolysin O (LLO), one of the main endotoxins of L. monocytogenes, "may potentially be present as a residue in this food additive after the manufacturing process." Yet the agency speculates that any residual LLO "does not present a toxicological concern" for three reasons: that it is "likely to be inactivated by the cholesterol" in treated meat; is "likely to be inactivated by the low pH…within the human stomach."; and is "expected to be rapidly and irreversibly degraded by proteolytic enzymes that may be presented in the diet or in the stomach."

Neither the FDA nor Intralytix, the manufacturer, provided data which would support any of these conclusions. In fact, the FDA stated in Reference 1 of the Final Rule that "no studies were performed at lower pH levels that are more consistent with that of the gastric environment."

Another issue with bacteriophages is that they irritate the body's immune system. "They provoke allergy, asthma, autoimmune problems, and elevate cholesterol. They also interfere with the healthy function of cells lining the digestive tract. Researchers have demonstrated that the presence of bacterial endotoxins can start cancer in the colon," explained Byron J. Richards, the Founder and Director of Wellness Resources and a Board-Certified Clinical Nutritionist. "Additionally, the human immune system reacts directly to viral phages. Thus, a person who eats a lot of processed deli meat is certain to evoke an immune reaction to the viruses.... How can the FDA approve a food additive that it knows can induce a variety of human immune responses?"

The Food and Water Watch Organization (FWW) has filed a stay of action and a formal evidentiary public hearing on this matter, with the intent of revoking the FDA's approval of this substance.

"The regulatory change FDA has promulgated is based on numerous arbitrary and capricious analytical failures and should be revoked. Due to significant shortcomings and factual misrepresentations in the Final Rule, potential risks to public health posed by FDA's decision have not been sufficiently examined," said Wenonah Hauter, Executive Director of FWW. "USDA has failed to enact stringent hygiene and testing regulations for Listeria even after years of regulatory delay. FDA's quick fix virus 'treatment' at the end of the production line can't make up for failures in sanitation or inadequate testing at food processing plants." FWW has criticized the FDA for ignoring its own regulations requiring extensive safety screening and testing protocols before treatments like this new

*"FDA" ...cont'd pg 11*

# Tunnel Vision Can Be Dangerous To Your Health

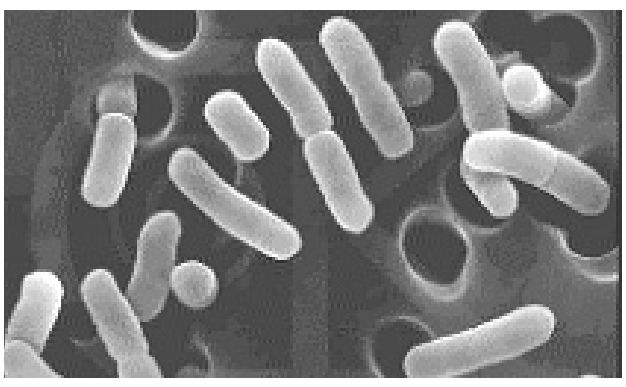
by Scott Forsgren

Many people view Lyme disease as an infection with the spirochetal bacteria known as Borrelia burgdorferi. They move through their healing process with a sole focus on eradication of this one organism, but often find that their healing process has become just a process and somewhere along the way the "healing" never happens.

Most LLMDs, and many of us that are struggling with Lyme, will recognize that Lyme disease is a multi-factorial illness that includes numerous co-infections that many will know.

These include Babesia, Bartonella, Ehrlichia, Mycoplasma, and a host of others. For more information on co-infections, refer to my article "Lyme Disease Co-Infections: Lottery Anyone?" in the August 2006 edition of the Public Health Alert.

Sadly, it has been my experience, however, that there are many other contributing factors to chronic illness. The stage has to be set over months and years for many of us to become significantly impaired if infected with Borrelia burgdorferi. It has been my experience that these are often overlooked by the



majority of those battling the disease as well as many of the doctors that are providing our care.

I think of "Lyme disease" like the see-saw that many of us used to play on when we were kids. It is about balance. On one side of the see-saw we have those things that are good for us, those things that help us to balance out the bad. On the other side, we have the bad things. Some of these bad things may include: heavy metals, viruses, parasites, mold, pathenogenic bacteria, mycoplasma, hypercoagulated blood, chemicals and other toxins, nutritional deficiencies, food allergies, emotional baggage, geopathic stress and energetic disturbances, dental infections and certainly Borrelia and Lyme co-infections.

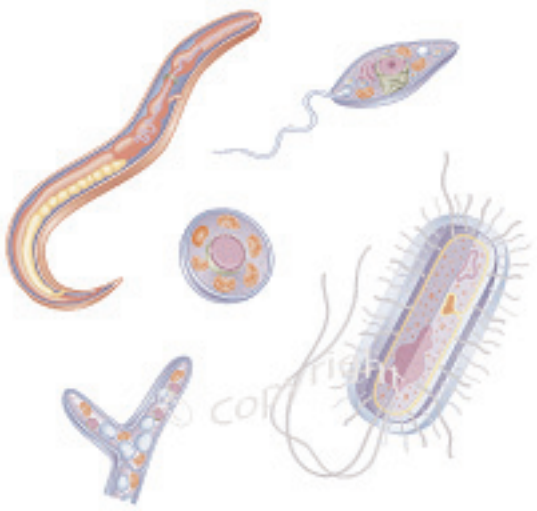
The more of these that sit on the bad side of the see-saw, the more that health shifts in that direction. Once it moves past an equal balance on both sides, it quickly shifts towards ill health. When we have ill health, it is important to evaluate all of the factors that can once again influence that state in an effort to shift the balance back to one that is favorable. For me, this means both removing some of the "bad" influences on my health and adding more of the "good". At some point, the balance can once again shift to a more favorable place.

Heavy metals may be one of the more complex areas of chronic illness based on my experience. Many doctors don't consider the true significance of these substances and what they do to our bodies. Many doctors also don't know how to effectively or properly address them. Though conventional tests showed no significant issue, I continued to test for metals using a testing technique which I place significant confidence in called Autonomic Response Testing, or ART. I recently started what appears to be just the right combination of heavy metal treatment agents, and aluminum is already pouring out. If I had not continued looking, I may never have known that this was also an issue that needed to be dealt with.

Parasites are another area that is often overlooked. I have heard countless stories of doctors that have sent known parasites, even tapeworms, to parasitology labs for a report only to find that the submitted sample was "negative". The parasite itself was pushed aside so that the sample could easily fit on a slide to be viewed under a microscope. In many other countries, parasites are seen as a more significant issue and testing and treatment more readily available. I personally have done several tests in the past two years from labs that are viewed as the best in the country and all came back "negative". I subsequently had been tested energetically using two very different methodologies and both found parasites were also an issue. An opportunity later arose to have testing performed by a visiting doctor from Nigeria and those results showed two types of parasites were present. With those now being addressed, the balance has an opportunity to shift, if even in a small way, once again in the desired direction.

Hypercoagulated blood can often be another important issue which requires investigation. It is not uncommon for Lyme and its co-infections, especially Babesia, to provide signals to the body to produce more fibrin which then thickens the blood. The fibrin acts as a protective layer behind which the microbes can hide and further avoid appropriate treatment. There are tests and treatments (Heparin and Rechts-Regulat are the two which I have used to date) which may help address the hypercoagulation issue. In many cases, these may be necessary to ensure that the treatments that are otherwise being used actually get to where they need to be in order to address the chronic infections.

Removal of various toxins (detoxification) is another key area that should be a part of any Lyme treatment program in my opinion. There is often a collection of toxins in the body which may not get appropriately shuttled out of the body without agents such as chlorella, cholestyramine, and others. Lyme itself produces neurotoxins which can circulate in the body for years in certain individuals even if the Lyme infection itself were entirely removed from the body. I have found that various detoxification supporting options can greatly



help reduce the bodies total load. Some of these include chlorella, FIR sauna therapy, coffee enemas, castor oil packs, detox foot pads, colonics, and numerous other interventions.

Beyond parasites, heavy metals, hypercoagulated blood, and the numerous toxins which may be present in those of us with Lyme disease, it is important to look at all of the areas mentioned earlier in this article. We must each find which ones may be part of those items which are pushing our state of health toward the bad. It takes time to work through all of the potential factors, and in my opinion, few doctors are capable of doing this on their own.

It may seem as though there are numerous areas that need to be investigated and dealt with, and in my opinion, that is often the reality of Lyme disease. Without addressing the various other issues, the Lyme component may be allowed to persist. It may be these numerous other factors that allows Lyme to entrench itself in our bodies in the first place and create a state of chronic ill health. There are likely an equal number or more people that are infected with Borrelia burdgorferi that are entirely asymptomatic. They likely have not had enough of these assaults to the body over time to allow it to shift the entire balance.

Just as important as getting rid of the bad are adding those things which can be good. These promote the healing process. Many of these are common sense and yet often overlooked. We must consider drinking enough pure water, getting exercise compatible with

*"Tunnel Vision" ...cont'd on pg 10*

# Blood Donation

# Can Save Lives...

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

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

**A general rule of thumb if you have ever had Lyme Disease:**

**Never donate blood or blood products**

**Never donate your organs**

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# Bio-Lab...cont'd from pg 1

dents researching emerging infectious diseases. The facility includes UTSA's second biosafety level three laboratory, which requires certification by the Centers for Disease Control and Prevention and government security clearances for researchers. Additionally, the facility houses six biology research laboratories, a multipurpose conference room and a computer media center.

The Tobin Endowment is providing $1 million to fund the Margaret Batts Tobin Distinguished Chair in Biotechnology in support of research in the new facility. Among the Tobin Laboratory researchers is Professor Garry Cole, an internationally known microbiologist specializing in fungal diseases. Cole has authored more than 170 publications. He recently joined UTSA from the Medical College of Ohio and will focus on coccidioimycosis or desert valley fever, endemic to West Texas.

Accompanying Cole will be Judy Teale, professor of microbiology and immunology; Jose Lopez-Ribot, associate professor of microbiology; and Floyd Wormley, assistant professor of microbiology.

Teale is an immunologist investigating neurocystercercosis, a parasitic disease of the brain found in Latin America. Additionally, Teale will study the immune response to Francisella tularensis, the bacterium that causes tularemia. The organism is highly virulent when inhaled and is considered to be a potential bioterrorism weapon by the CDC because of the ease with which it is aerosolized.

Lopez-Ribot will focus on Candida albicans, the leading cause of fungal disease in the world, and Wormley is working to develop novel immune therapies and vaccines to treat or prevent invasive fungal infections.

All four researchers are part of the 15 faculty comprising UTSA's new South Texas Center for Emerging Infectious Diseases. The center's researchers are focusing on critical areas of human health including anthrax, tularemia, cholera, Lyme disease, desert valley fever and other parasitic and fungal diseases. pha

# Special Moments...

*by Barbara Gerami*

Chronic illnesses come in many different forms. One form is seizures. Seizures can come in different varieties and forms. A seizure is an uncontrolled electrical activity in the brain, which produces a physical convulsion, minor physical signs, thought disturbances or a combination of symptoms. I have two sons that have a seizure disorder, however, their seizures are so totally different in every aspect possible.

My older son, Donny, has petit-mal seizures in which he says strange things, or just goes to sleep. He also has grand-mal seizures in which he will usually ask for his helmet to protect his head, and as he is on the floor, his body jerks with his extremities flailing. We give him a few minutes to respond to us and if need be, we sometimes have to call the ambulance.

My younger son with seizures is Gregory. He is now 13. We were blessed with Gregory when he was just10 days old, and 4.9 pounds. He has been diagnosed with Fetal Alcohol Syndrome, Cerebral Palsy, ADHD, Static Encephalopathy, and a seizure disorder. His biological mother was on many drugs while pregnant with him. The doctors called him a crack baby.

Gregory's seizures are entirely different than Donny's. His have been more controlled, however, when he was younger he was not learning. We did not know that he was having continuous small seizures, to the point where he couldn't remember his alphabet. His seizures came in the form of staring and they were very hard to detect. Then he began having more severe seizures, although, still not grand-mal. His right hand would come in towards his body and his left arm would extend out and then he would go to sleep. Once we figured this out, the doctor increased his medicine and Gregory was, for the first time, able to start learning. He was 9 years old when he began to learn to read. Although his IQ states that he is a slow learner, he is very intelligent in many ways. People that know him do not know or understand how difficult it is for him to read and learn. His attributes are that he loves to read, be read to, and learn, even when it is very difficult.

He has just turned 13 this summer, and between growing and puberty, we are starting to see more signs of seizures, as in staring, wandering off, not remembering, and suddenly going to sleep. Although grand-mal seizures are hard to take, in my opinion these other seizures are harder, because we do not clue into them as quickly. Lately, we have been noticing that Gregory has started to wander away more frequently than his usual wandering.

Gregory is very outgoing and sweet. He can strike up a conversation with anybody, even while being in the midst of a seizure. If you don't know him you would probably not even notice. His Neurologist has explained to me that the seizures might get worse during puberty. We have again increased his medicine and are very watchful, as to keep him safe, and for him to continue to learn. His favorite subject is History. We read together a lot, and he enjoys reading, although it is still difficult. He is a good son, loves the Lord and his family. He will give the shirt off his back to help some body, and is very empathic towards people in need. Gregory has great aspirations, and wants to be a golfer and President. Even though we may have a little bit more involvement in raising him, I enjoy watching Gregory grow into a fine young man and know that we are totally blessed to have him in our family. pha

# Tunnel Vision...

cont'd from pg 8

ones ability, supplying appropriate nutrition and supplementation, and possibly most important, getting the proper amount of restful sleep.

It can be overwhelming to consider all of the things which may need to be addressed, but the rewards are well worth the effort. It doesn't all have to be done today, or even tomorrow, but the more that one can move away from the pitfall of tunnel vision and begin to see the whole picture, the more opportunities one will find to help shift the balance back to where we all want it to be.

## More information:

For one of Scott's favorite overviews on Lyme disease which discusses many of the items mentioned in this article and much more, visit http://www.klinghart.org. Then select Articles and Protocols, Protocols, Lyme Disease Protocol.

**Note:** Scott Forsgren has battled Lyme disease for the past ten years. He shares his story on his web site at http://www.BetterHealthGuy.com.

**Scott can also be reached at**
Scott@BetterHealthGuy.com.

pha

Texas Lyme Disease Association

www.txlda.org

# "FDA" ...cont'd from pg 7

virus solution can be legalized. For example, the agency has not studied whether the viruses could cause genetic damage, organ malfunction, blood disorders or other problems in people who consume them. FWW also asserts that approval was based on woefully inadequate human testing, and that many key points were based purely on conjecture.

Food & Water Watch also criticized the agency for failing to provide the information it used to evaluate safety and efficacy in a timely manner. "It is outrageous that the agency was so slow in releasing key documents used to support its decision - some of which aren't available even as the comment period closes," charged Hauter.

Additionally, the only studies conducted using the approved substance, LM-102, were performed by the manufacturer, Intralytix, were not published in peer-reviewed journals, and therefore were not reviewed by independent scientists. Furthermore, Intralytix does not guarantee that the bacteriophage spray will completely eliminate the L. monocytogenes bacteria.

"There are other methods available which are more effective in reducing the amount of bacteria, and carry far fewer potential unintended consequences than bacteriophages," suggested Hauter. "A few examples include surface-treating hot dogs with a mixture of pressurized steam and hot water at 121° C, (Journal of Food Protection, March 2005) and dipping hot dogs in liquid smoke and heating them for 1 minute at 165° F (Institute of Food Technologists Annual Meeting, July 2004, Las Vegas)."

Consumers will not be informed as to which meat or poultry products have been treated with the LM-102 substance. However, organic products will not be treated with the spray.

Intralytix, the Baltimore-based manufacturer, is planning to seek FDA approval for another bacteriophage spray aimed at killing E. coli bacteria. *pha*

Susan Williams is a freelance writer for the PHA who lives in Kyle,Texas.


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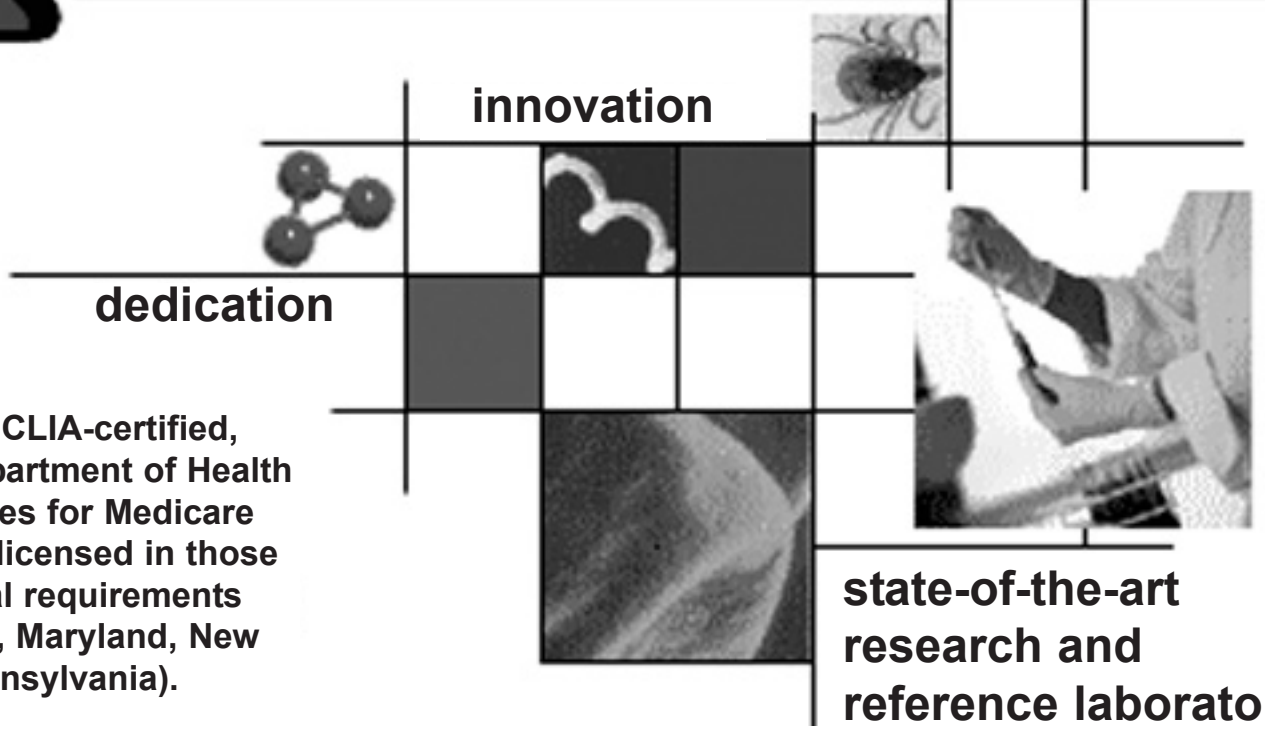


The laboratory is CLIA-certified, inspected by the Department of Health and Human Services for Medicare testing, and is also licensed in those states with special requirements (California, Florida, Maryland, New York, and Pennsylvania).

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# "Big Top"...cont'd from pg 3

I find this requirement quite curious since physicians who regularly diagnose and treat Lyme disease realize that greater than 35% of patients will initially test negative on a standard ELISA test, which as a screening test should have a 95% accuracy rating. Also, a Western Blot test performed by a traditional insurance approved lab will miss 20-30% on acute cases of Lyme disease, and even more on chronic cases, because they do not test for the bands that are critical for identification of specific Borrelia strains (bands 31 and 34).

The Western Blot test is looking for the antibodies to the Borrelia burgdorferi bacteria (Lyme bacteria) and some patients are either recently infected and have not had time to produce the antibodies; some patients' immune systems may be compromised because of additional illness or medication; and after time, the antibody titers have been shown to decline in individuals with chronic forms of the disease, therefore their Western Blot titers may actually appear to be more in the "normal" range.

Big NEWS: The Center for Disease Control already know this! For years their website has indicated that Lyme disease is essentially a clinical diagnosis, and should not be based on their surveillance criteria or the dependence upon a positive blood test. Now, perhaps out of convenience or maybe because the CDC prefers the IDSA guidelines as it more accurately agrees with an undisclosed agenda, the CDC proudly recommends these IDSA guidelines which indicate:

***"Clinical findings are sufficient for the diagnosis of erythema migrans, but clinical findings alone are not sufficient for diagnosis of extracutaneous manifestations of Lyme disease or for diagnosis of HGA or babesiosis. Diagnostic testing performed in laboratories with excellent quality-control procedures is required for confirmation of extracutaneous Lyme disease, HGA, and babesiosis."*** (from IDSA guildelines -Executive Summary, page 2: http://www.journals.uchicago.edu/CID/journal/issues/v43n9/40897/40897.html )

The directive to use "laboratories with excellent quality-control procedures" further complicates this picture because it creates a big hole for interpretation. Realizing it's not a sound financial decision for people to actually be cured, as healthy folks do not make the best healthcare consumers - can you imagine where morally debased physicians, other big business interests, and big Pharma will land on this issue? While one would certainly expect that any lab used for such important diagnostic validation would be those with "excellent quality-control procedures," the interests of those above mentioned groups would insist upon the utilization of laboratories that do not identify the specific Western Blot bands most likely to validate a diagnosis of Lyme disease.

Furthermore, the CDC is quite aware there are other guidelines which have proven to be more effective, and are in fact, clinically tested guidelines provided by the International Lyme & Associated Diseases Society (ILADS). Yet the CDC's own website fails to mention them. I find it intriguing that the CDC does not choose to recognize how the recommendation of these "NEW" and rigid IDSA guidelines, in lieu of the more effective ILADS guidelines, reflects poorly upon the attainment of their own mission statement:

*"To promote health and quality of life by preventing and controlling disease, injury, and disability."* (http://www.cdc.gov/about/mission.htm )

How can they be so blind to the contradiction these guidelines pose to their own pledge to the American people:

- "To base all public health decisions on the highest quality scientific data, openly and objectively derived.

- To place the benefits to society above the benefits to the institution."

Perhaps the biggest irony here is the IDSA guideline writers do not treat chronic forms of this spirochetal infection because they don't believe in it.

*"In many patients, post-treatment symptoms appear to be more related to the aches and pains of daily living rather than to either Lyme disease or a tickborne coinfection. Put simply, there is a relatively high frequency of the same kinds of symptoms in "healthy" people."*
(IDSA Guidelines - Post Lyme Disease Syndrome, pg. 33)

Keep in mind these physicians are more 'researchers' than actual 'healers', and many conclusions they assert are based on findings from the laboratory and the behavior of the bacteria isolated in a test tube or dish, rather than the findings derived from hands-on experience with patients, providing them with much needed clinical experience. After all, is the human body not more intricately designed and complicated than a Petri dish? Are we all the equivalent of walking test tubes?

Because these infectious disease physicians do not believe this spirochetal infection lasts after a very limited exposure to antibiotic therapy, they choose to include what seems much like a slur in these "voluntary" instructions - implying those of us with continuous symptoms are big whiners unable to cope with "daily living".

Yet a reasonable question to me is 'How can IDSA dictate the method and manner other physicians are to employ to treat or rather, NOT to treat, various forms of this chronic disease when they don't believe in it? To me, that's like an atheist dictating to Jews, Muslims, and Christians how they are to worship, or rather, NOT worship God. Isn't it?

The new stringent requirements provided by the IDSA guidelines and promoted by the CDC will actually punish that subset of patients who do not fit their new, erroneous criteria. If those patients do not produce the overly relied upon bullseye rash, or test positive on an inaccurate blood test - their future health may continue to decline until they are completely disabled; they begin manifesting so many symptoms they are misdiagnosed and treated for an entirely different disease with medications which may cause their health to further decline; and some may even die.

Yes, this is more complicated and choreographed than a 3-ring circus. Unfortunately, the ringmaster and the clowns involved in this circus are not the least bit delightful. They've got big money and big secrets riding on the outcome and they'll stop at nothing. Again, it's all about big business, big Pharma, and Big Brother!

## Animals on Parade

In that nutshell, we have big business interests where the health insurance companies are pacified by having the ammunition to deny what amounts to potentially expensive short-term treatment over the more expensive long-term, palliative pharmaceuticals which may be necessary for the duration of the patient's miserable life. At first look, we may assume the insurance industry is by far the dumbest animal in this scenario; but we know their true agenda is to make money which means they will attempt to deny claims until the patient tires of filing multiple appeals, dies from the disease process, or suffocates under the avalanche of the company's endless 'Explanation of Benefits'.

With these "NEW" guidelines, Big Pharma comes out smelling like a rose, although they are one of the more filthy animals in this analogy. Antibiotics are some of the cheapest medications they produce, thanks to the availability of generic brands; therefore life-long dependence on pharmaceuticals needed to alleviate a myriad of symptoms is best for their bottom line.

As for Big Brother - what I have to share may make me sound like a conspiracy-theorist nut job. So be it. But it all boils down to the fact that a few decades ago (post World War II), there were Nazi war criminals secretly transported to America so that we, the people, could gain the knowledge of that exciting new field of 'germ warfare'. In exchange for this knowledge, these criminal scientists would receive immunity for their horrendous war crimes. Don't believe me? It's called "Project Paperclip".

These scientists, along with their many secret successors (see front page story in this issue) have tinkered with a wide assortment of nasty microorganisms that can be delivered upon a population through various vectors (Vectors are "carriers" such as ticks and mosquitoes. See http://www.cdc.gov/ncidod/dvbid/)

Such laboratory achievement comes with risk, and it also requires experimentation. Some of us are victims of poorly enforced laboratory safety standards, and some of us are the unlucky subjects of said "experimentation" simply because of our weakened immune systems, and its inability to keep a host of unwelcome microorganisms at bay.

Again, I may sound like a conspiracy nut - which would be the precise impression many of the players in this scenario would prefer. But sometimes the ugly truth must be exposed. To borrow a phrase from a friend- Lyme is a weapon of mass infection. Focus on the facts; follow the story. There's a seedy undercurrent in

# Public Health Medical Briefs

*by Susan Williams*

## U.S. To Allow Small Imports of Drugs From Canada

The federal government has agreed to stop seizing some medications mailed from Canada.

The new policy will allow Americans to import small amounts of prescription drugs, generally about a 90-day supply. Previously, U.S. Customs officials had seized an estimated 40,000 shipments, and the Americans who had ordered the drugs received letters informing them that it was illegal and unsafe to purchase prescription drugs from outside of the U.S.

The new policy, which was announced by the Department of Homeland Security, went into effect in October.

## Best Time To Schedule Surgery

If you have to undergo surgery anytime soon, you may want to consider scheduling your procedure during morning hours.

A recent study by researchers at Duke University found that patients who have surgery in the late afternoon are more likely to experience problems than those who have surgery in the morning.

The team of researchers analyzed the outcomes of over 90,000 operations which were performed at Duke University Medical Center since the year 2000.

The scientists identified instances of "error", such as improper doses of anesthesia, and instances of "harm", such as prolonged sedation, wound infection, and post-operative nausea and vomiting. The scientists also identified instances of "other adverse effects", which included potentially dangerous changes in blood pressure and problems with operating room equipment. Many of these events were related to pain management, both during and after surgery.

The scientists also identified nearly 9,500 instances of "administrative delays" during the late afternoon which might have contributed to the increase in surgical problems that occurred during this time period. These delays included waiting for laboratory test results, doctors running behind schedule, and rooms not being ready on time.

The researchers found that adverse events were most common during operations that began between 3pm and 4pm, and least common during 9am to noon operations. The researchers speculated that this might be attributed to a number of factors, including end-of-day fatigue among health care workers, personnel shift changes, and work schedules.

The team published its findings in the August 2006 edition of the journal 'Quality and Safety in Health Care'.

## Meningitis Vaccine Concerns

Many incoming college students across the United States are told to receive the meningococcal vaccine or risk not being admitted. However, new risks about this vaccine are now coming to light.

Adverse reactions to the vaccine seem to be fairly common. 41% of the vaccine's recipients reported headaches, 35% reported fatigue, 24% reported malaise, and 20% reported joint pain. Even more alarming, the FDA announced last fall that 5 recipients of this vaccine, all aged 17 to 18 years old, developed Guillain Barre Syndrome, a condition somewhat similar to Multiple Sclerosis, shortly after receiving the vaccine. Furthermore, the vaccine has not been tested to determine its effects in relation to causing cancer, infertility, or any other long-term effects.

The benefits provided by this vaccine do not seem to be overwhelming in evidence. According to the vaccine's own package insert, it does not protect against one-third of the strains of meningitis, and does not guarantee immunity against any of the strains.

Meningitis typically infects fewer than 1 in 100,000 people annually in the U.S., approximately half of whom are infants. Most people who do contract the disease recover fully. "Only 5-15 college students nationwide die from this disease and contributing factors, which is far less than other risks faced by college students," summarized Andy Schlafly, General Counsel for the American Association of Physicians and Surgeons. "When long-term harm from the vaccine is combined with the short-term harm indicated above, it is quite possible that the vaccine is causing more harm than it is preventing. For a disease that can be largely avoided by not mixing saliva with an infected person, or receiving prompt treatment if one is infected, the insistence on vaccination rather than education is unfortunate."

Parents and students should be aware of the risks, and that all states have available exemptions to decline this and other vaccines.

## Childhood Asthma Linked To Traffic Pollution

The next time you are house-hunting, you may want to consider a home's proximity to major roads.

A recent study of more than 5,000 children in 13 California cities concluded that young children who live near a major road are significantly more likely to have asthma than children who live only blocks away.

The study found that children living within 75 meters (about 82 yards) of a major road had a 50% greater risk of having had asthma symptoms in the past year than were children who lived more than 300 meters (about 328 yards) away. Higher traffic volumes were also related to increased rates of asthma.

"These results suggest that living in residential areas with high traffic-related pollution significantly increases the risk of childhood asthma," says David A. Schwartz, M.D., director of the National Institute of Environmental Health Sciences (NIEHS), the primary agency that funded the study. "Children with no parental history of asthma who had long-term exposure or early-life exposure to these pollutants were among the most susceptible."

The results of the study appeared in the May 1 issue of Environmental Health Perspectives. *pha*

Susan Williams is a freelance writer for the Public Health Alert from Kyle, Texas.

# "Big Top"...cont'd from pg 12

some of our health bureaucracies (the CDC) because some of the

***"Big Top"...Cont'd pg 13***

primary agendas are to maintain secrets which would surely cause severe backlash if the American people were finally to know.

There's enough mystery, lies, and intrigue in this story that I often feel trapped in a Tom Clancy or Robert Ludlum novel. Unfortunately this is not fiction. Just consider - that to mandate a standard of care which will surely result in the suffering and subsequent death of thousands is not conducive to fulfilling the CDC's professed mission statement *"To promote health and quality of life by preventing and controlling disease, injury, and disability,"* rather it is to squelch or quiet a nation of patients exhibiting the bad sense to actually complain about their health and lack of adequate healthcare afforded them. After all, we are ultimately suffering at the hands of our own government; and that is much too distasteful to reveal or discuss.

Let's face it - with the conflicts of interests for the writers of the IDSA guidelines, their history and connection with these other BIG players - it becomes obvious to the average American patient that there's far too much cross breeding going on and these players would be more at home in a cheap carnival freak show than any Barnum & Bailey event.

Recently I was reminded of the old adage about the blind men and the elephant; how each of the blind men described different parts of the elephant and each were quite certain their own description was the 'right' one. If that axiom can be applied to this particular situation, may I humbly suggest which part of said elephant (standing prominently in the middle of the room) the alleged medical "professionals" from the IDSA & CDC are describing? Although comparatively BIG - I assure you nothing of much use comes out of that end, unless of course you need it for your compost bin.
(Stay Tuned for next month's installment in this multi-part series. Now if you'll excuse me, I must go find a convenient underground bunker in which to 'vaca-

# IDSA's 2006 Lyme Guidelines Ignite the Skirmish to a Battle

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

The face of Lyme has changed again dramatically with the publication of the Infectious Disease Society of America's (IDSA) 2006 Guidelines for Treatment of Lyme Disease. Lyme's face is now writhing in pain that is only surpassed by that caused by the disease itself. The new guidelines can be linked from the Center for Disease Control and Preventions's (CDC's) website at www.cdc.gov/ncidod/dvbid/lyme/index.htm.

The Guidelines were electronically published on October 2, by *Clinical Infectious Diseases* [2006;43:1089-1134]. They were submitted and accepted on the same day, August 21, 2006. There is no indication of manuscript revision, suggesting that there was no review by a peer review committee of the publisher.

The lead and corresponding author is Dr. Gary P. Wormser, Rm. 245, Munger Pavilion, New York Medical College, Valhalla, NY 10595 (Gary_Wormser@nymc.edu). The following disclaimer precedes the Executive Summary:
*"These guidelines were developed and issued on behalf of the Infectious Diseases Society of America. It is important to realize that guidelines cannot always account for individual variation among patients. They are not intended to supplant physician judgment with respect to particular patients or special clinical situations. The Infectious Diseases Society of America considers adherence to these guidelines to be voluntary, with the ultimate determination regarding their application to be made by the physician in the light of each patient's individual circumstances."*

Unfortunately, only a small number of physicians and medical professionals have taken the time to educate themselves and become Lyme Specialists so that they can make the responsible determination of a Lyme patient's needs. The vast majority of physicians are simply not inclined to invest the time to learn, or worse yet, lack the intellectual curiosity to look beyond the several guidelines covering all treatment areas. I'm inclined to refer to them as technicians, except that demeans my mechanic for whom I have more respect.

The new Guidelines were at once identified as targeted, and designed to undermine the now long established clinical practices shown to produce best patient outcome. The Guideline authors amassed a weighty 405 references carefully selected to support their opinions and conclusions while diminishing anything in the literature from an opposing position.

> [The Guidelines] were submitted and accepted on the same day, August 21, 2006. There is no indication of manuscript revision, suggesting that there was ***no review by a peer review committee*** of the publisher.

Disclaimer aside (or ignored), the Guidelines have within weeks of their release caused insurance denials for prescribed medication, and even a pharmacist's refusal to fill a prescription because the medication was listed by IDSA as ineffective for Lyme treatment. Medical politics that toy with people's lives - what can be more horrific?

IDSA's panel of expert authors are well known to those who have studied Lyme politics. We are left to wonder if there must be something more valuable than their reputations to protect. I have come to describe the relationship between the CDC and IDSA as a consortium when it comes to Lyme disease.

The CDC has reflected IDSA position and deferred to IDSA Guidelines on the CDC website. A current inquiry to CDC will return, in effect, a sales brochure statement of the 2006 Guidelines. The CDC had long ago taken on sponsorship of the IDSA system of belief and promotes it even more with the new Guidelines.

The CDC website information on Lyme disease is sadly misinformed, in fact is dismissive of the seriousness of the disease and its prevalence. This isn't new. It's always been that way. To bolster my assertion of a consortium, you have only to review the well-known names in the Guideline author's list and check their continuing funding sources. The CDC and IDSA are joined at the hip. Inbreeding leads to the death of any organization, but that's too kind a description.

The CDC/IDSA Consortium is incestuous and it's causing harm. Complaining to IDSA is pointless in my view. They have always ignored criticism on the subject. However, the CDC has vision, mission, core values, and a pledge under which it operates, http://www.cdc.gov/about/mission.htm. The reader is well advised to review these statements with scrutiny to determine if the CDC has met its own standards in explicitly claiming ownership of the 2006 Lyme Guidelines. I believe it has failed substantially.

The CDC answers to the public directly and through legislative channels. CDC's Director is Dr. Julie L. Gerberding, M.D., M.P.H. The Director's office can be reached at (404) 639-7000, and letters can be sent via FAX to (404) 639-7111. Electronic mail is discouraged and the address in fact not disclosed. You can read Dr. Gerberding's welcome message at http://www.cdc.gov/about/director.htm.

The CDC's Chief Science Officer is Tanja Popovic, M.D., Ph.D., available at (404) 639-3311. The CSO is in charge of CDC's Information Quality Peer Review, http://www.cdc.gov/od/ophr/infoqualpeerreview.htm. Did the Guidelines undergo a formal CDC review before endorsement and release through CDC's website, or were they blindly accepted from a "family member"?

As part of Public Law 107-116, signed by President Bush on January 10, 2002, the Congress expressed to the CDC a number of significant concerns regarding Lyme and made a number of strong recommendations, the last of which is, *"The CDC is encouraged to include a broad range of scientific viewpoints in the process of planning and executing their efforts. This means including community-based clinicians with extensive experience in treating these patients, voluntary agencies who have advocacy in their mission, and patient advocates in planning committees, meetings, and outreach efforts."*
None of the Congress' year 2002 recommendations have been implemented to date.

Julie Gerberding took over the CDC's directorship in 2002. The responsibility is hers. There needs to be an accounting. An effort in the current Congress to reform the health care agencies is being made. HR 6164, National Institutes of Health Reform Act of 2006, passed the House on September 26, and is now in the hands of the Senate. Perhaps, the CDC needs another critical review. The principal sponsor of HR 6164 is Rep. Joe Barton [TX-6] who chairs the Energy and Commerce Committee. His stated goal is to get the politics out of the health care agencies so that grants and contracts are awarded purely on merit. This is the same committee where H.R. 3427 (House Companion Lyme Bill) is waiting action. Constituents, especially, need to lobby their U.S. Legislators to push all of these issues.

The Lyme community is receiving a number of calls to arms on the new guideline challenge, and also old issues that dog this disease. At the time you will be reading these words, important discussions will have been held at conferences, and those thoughts will be making their way through the various channels that we depend on for information. There is much to consider and weigh, plans to coordinate and then the important work of individual effort. Everyone has a high-risk stake in the outcome. Everyone is needed to make whatever contribution of effort that they can muster to achieve a breakthrough. *pha*

# National Support Groups

## National Multiple Sclerosis Association:

www.nmss.org

**Alabama**
3840 Ridgeway Drive
Birmingham, AL 35209
Phone: (205) 879-8881
Phone: 1-800-FIGHT-MS
Email: alc@nmss.org
www.nationalmssociety.org/alc

**Northern California**
150 Grand, Oakland, CA 94612
Phone: 510-268-0572
toll-free: 1-800-FIGHT MS
Email: info@msconnection.org
http://www.msconnection.org

**Colorado**
700 Broadway, Suite 808
Denver, CO 80203-3442
Phone: 303.831.0700
1.800.FIGHT.MS

**Georgia**
455 Abernathy Rd. NE,
Suite 210
Atlanta , GA 30328
Phone: 404-256-9700
Phone: 1-800-FIGHT-MS
mailbox@nmssga.org

**Florida**
2701 Maitland Center Pkwy,
Suite100
Maitland, FL 32751
Phone: (407) 478-8880
Email: info@flc.nmss.org
www.nationalmssociety.org/flc

**Texas**
8111 N. Stadium Drive,
Suite 100
Houston , TX 77054
Phone: 713-526-8967
www.nationalmssociety.org/txh

## ALS Association DC / MD / VA

http://www.alsinfo.org/
7507 Standish Place
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
Phone: 215-643-5434
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
1231 Greenway Dr., Ste.385
Irving, TX 75038
s.melson@alsanorthtexas.org
972-714-0088
877-714-0088

**The ALS Association Upstate New York Chapter**
323 Route 5 West
P.O. Box 127
Elbridge, NY 13060
315-689-3380
Toll Free for PALS:
1-866-499-PALS
info@alsaupstateny.org

## Lyme Disease Association

lymediseaseassociation.org/
Pat Smith 888.366.6611

**Arizona**
10440 N. Via Linda
Scottsdale, 85259
Group facilitators :
Karen Genest 480-632-6444
Larry Levy
Larry@valuepro.netbox.com
**Northern Arizona** - Tina Caskey:
tcaskey@safeaccess.com
928-779-2759
**Southern Arizona** - Donna Hoch:
nanandbo@cox.net 520-393-1452
L.E.A.P.
Tina J. Garcia
L.E.A.P. Arizona
Lyme Education Awareness Program
http://www.leaparizona.com
480-219-6869 Phone

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

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

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

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

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

## Lyme Disease Support Groups cont'd

**Kansas**
913-438-LYME
Lymefight@aol.com

**Montana**
bepickthorn@earthlink.com

**Nevada**
Rene Rothstein 702-256-9776
reeen@earthlink.net

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

**Oklahoma**
Janet Segraves 405-359-9401
Janet@LDSG.org
www.LDSG.org

**Portland, Oregon**
Meets 2nd Sunday of each month
2010 NW 22nd Street
Second Floor from 1 PM to 3 PM.
503-590-2528

**Dallas/Ft Worth**
www.dfwlyme.com
donna@dfwlyme.com
817-455-8520

**Houston**
Contact: Teresa Lucher
lucher@sbcglobal.net

**Washington State**
Alexis Benkowski
WA-Lyme-owner@yahoogroups.com

**Lyme Coalition of N. Wisconsin**
Pat Jackson (715) 356-3364
www.pattyknack.com
pattyknack@charter.net
**WI * IL * MN**
Contact P.J. Langhoff
www.lymeleague.com (US & Can)
www.sewill.org

## DFW Lyme Disease Support

**www.dfwlyme.com**

**Meetings held the 3rd Saturday of each month**

**Baylor Regional Medical Center at Grapevine**
**1650 West College**
**Grapevine, TX 76051**

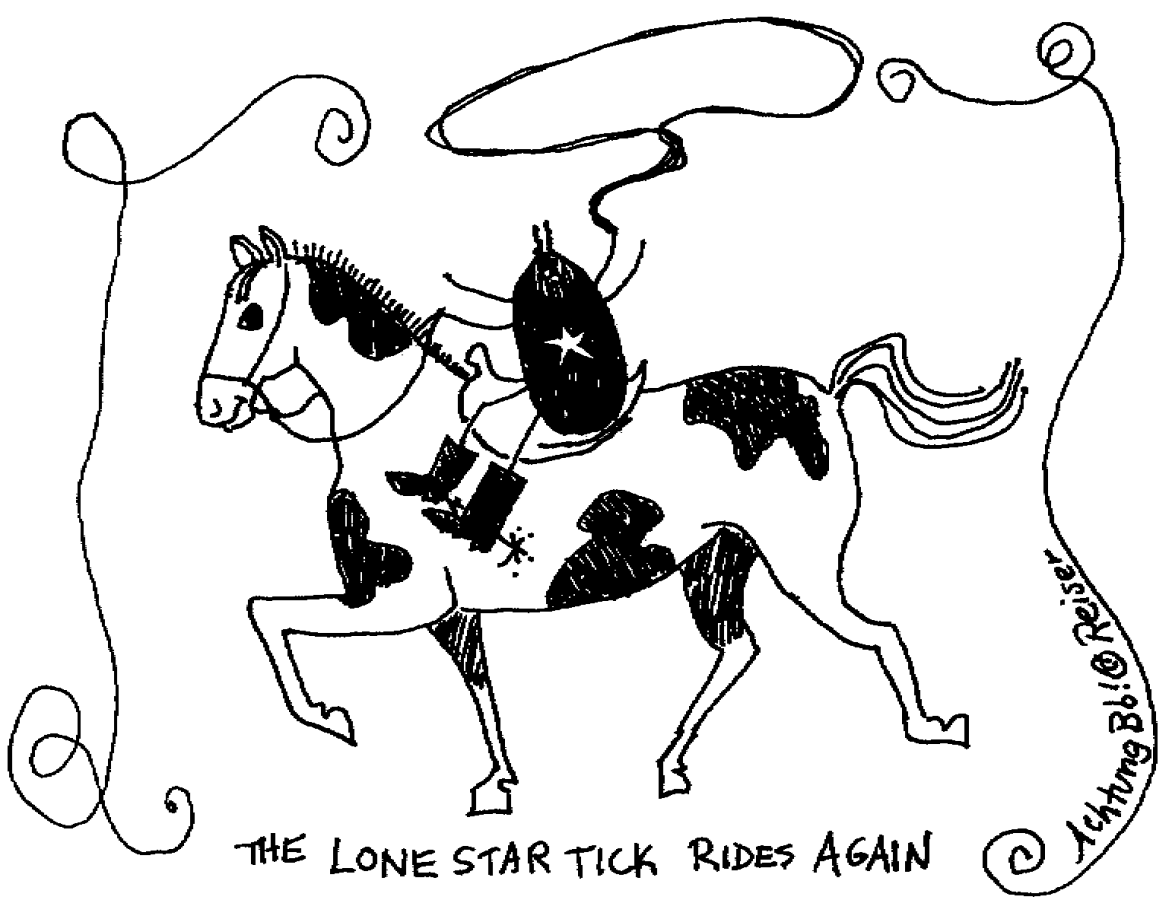
**(817) 481-1588**

**in the continuing education room**

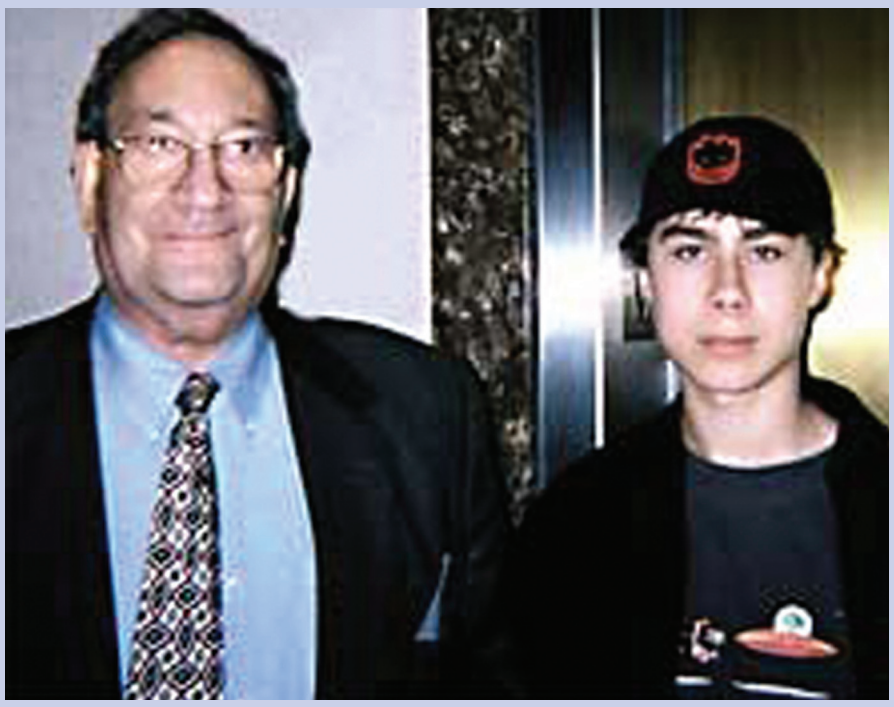
For more information:

**Donna Reagan**
**Group Leader**
donnareagan@sbcglobal.net

## Ticktoons




by Terri Reiser



# You are Cordially Invited...

You and your family's attendance is requested, and considered necessary at the

November 16, 2006
Connecticut Medical Board Hearing against Dr. Charles Ray Jones.
The Hearing will begin at 9:00 AM
At the Legislative Office Building located at
300 Capitol Avenue, Hartford, Ct.

Your presence, if only for an hour or two, will convey a strong message of support for Dr. Jones, for the care and treatment he bestows to his most precious patients: our children. It is Time that all Lyme Disease patients take a Stand for Dr. Jones, our children and all LLMD's. Please plan to attend this hearing, as difficult as this might be. Dr. Jones needs our support, and our kids need Dr. Jones. Your sacrifice will not go unnoticed; it is greatly appreciated!

**Wolcott Lyme Disease Network (collinsfam@yahoo.com) and Newtown Lyme Disease Network (203) 270-3301**

It's not enough to have a dream,
Unless you're willing to pursue it,
It's not enough to know what's right,
Unless you're strong enough to do it,
It's not enough to learn the truth,
Unless you also learn to live it,
It's not enough to reach for love,
Unless you care enough to give it"
-Samuel Smiles

Help Support Dr. Charles Ray Jones Legal Defense Fund
to donate via credit card go to: www.DefendLymeDoctors.com
to donate by check, make donation payable to

**"The Dr. Charles Ray Jones Legal Defense Fund"**
**Mail in care of:**
**George Heath, III (CPA)**
**26 Fairlawn Drive,Wallingford, CT 06492**
**Note "gift" in the memo field.**
Don't Delay Do it today!

# Tough Grandma...*cont'd from pg 6*

thriving and developing normally. These moms stayed on antibiotics throughout the pregnancy and were able to tolerate the pregnancy and childbirth remarkably well. Many Lyme moms, in fact, report feeling better than ever during pregnancy, a phenomenon probably related to the high level of natural killer cells and suppression of inflammation necessary for the body not to reject the pregnancy. The stress of the birth itself, lack of sleep, and rapid hormone decline after the birth can, however, cause Lyme symptoms to flare. Therefore, keeping the mom from "crashing" after childbirth is the main challenge with the childbearing experience for the Lyme mom.

Pregnant women who harbor the Lyme spirochete should consider doing what my daughter did and take baby-friendly antibiotics throughout the pregnancy, arrive at the hospital with IGeneX laboratory test kit in tow, and

request collection of cord blood and placental tissue immediately following the birth, to send for PCR testing. Although the test often yields a false negative result, a positive test allows for immediate treatment of the infection (providing, of course, a willing collaborating pediatrician can be found).

We do not yet know the results of my new granddaughter's Lyme tests. Even if they are positive, she will be in good company in our family, as many of us deal with some degree of the illness every day. But she is a beautiful little girl, perfect in every way, and we will cherish her and love her and, if it comes down to it, teach her to cope with the aches and pains and inconveniences of the family "curse". Because even if she tests positive for the Lyme bacteria, things could be so much worse. She has all of her fingers and all of her toes. She has her mama's beautiful dark hair and her daddy's intense blue eyes. She has dozens of doting family members surrounding her with their love. And she's got one tough grandma who will stand up for her and take care of her no matter what challenges may come her way.

***Post note: Payton's grandma happens to be one of my dearest friends, Laura Barton. She is not only one tough grandma, but an amazingly warm and generous woman and an irreplaceable friend.*** pha