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## Tennessee Gov Hospitalized with Illness from a Suspected Tick Bite

by Dawn Irons

The wheels of government in the state of Tennessee came to a drastic slowdown as their Chief Executive, Governor Phil Bredesen, and avid outdoorsman, was admitted to the hospital for 4 days. Press Secretary Lydia Lenker, in her statement concerning the Governor said he, "was admitted to Centennial Medical Center in Nashville for observation late Monday night after experiencing flu-like symptoms, including a severe headache and high fever. Medical staff indicated the Governor's symptoms could be the result of a tick bite. The Governor is receiving antibiotics and feeling better. Physicians advised him to remain at the hospital overnight Tuesday for additional observation."

Blood tests are still out concerning the nature of Bredesen's illness. According to the Center for Disease Control and Prevention (CDC) the two most common blood tests for Lyme dis-

ease are the Lyme ELISA screening test followed by the Western Blot test. Recognizing that these tests are highly insensitive, the CDC states clearly that the diagnosis of Lyme disease and other tick borne illnesses must be a clinical diagnosis based on the symptoms alone.

There is much controversy surrounding the Western Blot test. This blood test is supposed to screen for extreme Lyme specific bands that would indicate infection by the borrelia bacteria that is transmitted by the bite of an infected tick. Unfortunately, the FDA approved Western Blot does not include the testing bands that were so specific to Lyme disease that they were used to create a Lyme disease vaccine. Therefore, the results of the most common tests available are basically useless in helping diagnose tick borne illnesses.



Tennessee Governor Phil Bredesen and his wife Andrea Conte.

Governor Bredesen is described as an avid hunter and outdoorsman. This gives much opportunity for tick exposure. The Governor presented at the hospital  
"Governor" Cont'd pg 16

## Early Treatment May Prevent Breathing Problems in Premies

### EARLY TREATMENT PREVENTS LASTING BREATHING PROBLEMS IN SOME PREMATURE BABIES -- BRAIN DAMAGE ALSO LESS LIKELY WHEN GIVEN WITHIN 48 HOURS OF LIFE

NIH News :National Heart, Lung, and Blood Institute

For the first time in large, multicenter clinical studies, a therapy has been shown to significantly lower the risk of lung and brain damage in some very low birthweight premature infants. Results from two randomized clinical trials demonstrate that when given within the first few weeks of life, inhaled nitric oxide helps prevent chronic lung disease in some low birthweight premature infants. In addition, when used within 48 hours after birth, treatment appears to protect some premature newborns from brain injury.

Combined, the two new, independent studies involved nearly 1,400 very low birthweight premature infants treated at 37 medical centers. The studies represent

the largest clinical research effort of inhaled nitric oxide therapy in premature infants, and they offer promising advances in the care of very small premature babies, who are at high risk for delayed growth, lasting problems with their breathing and brain development, and other complications. Other studies of therapies to prevent these potentially debilitating long-term complications have yielded conflicting results. Supported by the National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health (NIH), the studies' results are published in the July 27, 2006, issue of the "New England Journal of Medicine" in conjunction with a related editorial.

"Medical science has dramatically improved our ability to help very small and premature babies survive. But as the rate of

premature births continues to rise, it is even more critical that we develop ways to prevent many of the complications related to prematurity so that these children can lead healthy, robust lives," NIH Director Elias A. Zerhouni, M.D., says.

In 2004, more than one-half million babies in the United States (about 12.5 percent) were born prematurely (less than 37 weeks of pregnancy) -- the highest number reported since comparable national data have been available, according to the Centers for Disease Control and Prevention (CDC). Last year, costs associated with premature births in the United States totaled approximately \$26.2 billion, or \$51,600 per infant, according to a report released July 13 by an independent panel con-

"Premies" cont'd pg 14

## Oops! They Did It Again ...And So it Goes



by Dawn Irons

Nothing makes me more angry than preventable mistakes repeating themselves

because no one paid attention to the past mistake. My theory is a mistake can be a good thing if you learn something from the situation!

It was three years ago this month that after going through a whole battery of tests, and racking up diagnoses left and right that I finally had a meltdown in my doctor's office and DEMANDED that they run a Lyme disease test on me. They finally agreed to run the test. It came back positive! The doctor told me it was a false positive because "we don't have Lyme in Texas." So all the previous diagnoses would have to do.

Several hospital visits later, and a second opinion, we did another Lyme test. It was still positive. Imagine that! What is the likelihood of two doctors performing 2 different tests, at 2 different labs and both getting "false positives". Now, my daddy didn't raise no fool! If it looks like a duck,

waddles like a duck, quacks like a duck, and the LAB TEST says it is a duck, then of course we should assume it is a zebra! Any Infectious Disease Society of America (IDSA) doctor should know that!

I was reading a news article today about a 63 year old man who was found collapsed on the floor of his home. He was rushed to the hospital. While there, the nurses found an embedded (dead) tick on the man and a live one crawling on him during examination. They ran tick borne disease panels (TBDs) and it came back positive for Rocky Mountain Spotted Fever (RMSF). The doctors said that did not mean anything because it could just be an indication of a previous infection.

Twenty-five days after being admitted to the hospital with a "suspected" tick borne illness the man died. His medical records indicated that the doctors were still considering a TBD as a "possible" cause of his infection. Lab results in his records showed a positive result for both Rocky Mountain Spotted Fever and Erlichiosis, both KNOWN TBDs! But neither was considered a conclusive

diagnosis. No other potential cause for his underlying infection was given. A full review of his medical records showed NO evidence of prior RMSF in his files. His death certificate listed the cause of death as "multiple system organ failure, sepsis, hypertension, and irreversible brain damage." All symptoms of a TBD...the very symptoms that the CDC *claims* should be able to make for a conclusive CLINICAL diagnosis! Good grief, the poor man had positive serology tests in his file from THAT visit at the hospital...and 25 days after being admitted, he died.

And so it goes...because all IDSA induced logical reasoning demands that if it looks like a TBD, it MUST be something else!

One more TBD death... how many more will it take before the facts speak for themselves? TBDs are life threatening if they are not treated properly and immediately. Oh, that us "average citizens" could get the same treatment that the TN governor received! *pha*

*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.*

## The Faith Factor by Marjorie Tietjen

### Death & Resurrection

My life had never been particularly difficult. In fact I often felt guilty that others appeared to be struggling so, while for the most part, I seemed to sail smoothly along. Of course I had my little ups and downs but never really experienced the tragic in life.

About 17 years ago, as I was driving to work one day, I vividly remember a conversation I had with God. Dear God, I said, I am truly grateful for all the good in my life but I feel as if I am spiritually stagnant, not growing, learning and helping others the way I feel I should be. So...if I need an experience to help me evolve and grow, please...just don't make it too difficult to bear. Looking back, I can't believe I was saying this! Little did I know what I was about to experience.

As the year progressed, I gradually began to acquire odd unexplainable symptoms, such as tingling and numbness in various parts of my body, lower back pain, headaches, stiff and painful finger

joints and fluctuating anxiety. I remember visiting our general practitioner for tingling and numbness in my arms and hands. Without testing of any sort I was handed valium. Of course, the valium did not help.

During this time I was working in the cafeteria where my small children attended school. This worked out well as I had the same schedule as my children. When school let out for the summer that year, we looked forward to our traditional activities...camping and boating. I will never forget the camping trip where my life was changed forever. One morning I woke up in our camper and felt extremely ill. It seemed as if I had the flu but the symptoms were in some ways atypical. I was very weakened and sick but yet I could not sleep. What was the most unbearable to me however, was the free floating anxiety or panic...for no discernable reason. I would find myself pacing the floor, desperately trying to get away from it. I remember

saying to myself that I would not wish this experience on anyone...not even my worst enemy.

In the weeks and months to follow, I would plead with my dear family, who was so supportive and understanding ( even though they couldn't really understand ), to just put me away in a mental institution because I felt as if I was losing my mind and I did not want to be a burden. I made an appointment with our family doctor and was given three weeks of antibiotics...just to be sure....in case I had Lyme Disease. This was around 1989. They did not test me for Lyme at this point. I was told that it would be too early to show accurate results. It was assumed that if I did have Lyme that it must be from a recent bite. However, I feel the illness had been simmering in my body for quite some time. The treatment did not seem to touch my symptoms at all and in fact, I felt worse. The panic/anxiety became so intense

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

# Medical Revisionists Threaten Effective Lyme Treatment

by Dr. Raphael B. Stricker



A small group of scientists is turning the world of Lyme disease on its head. They deny the existence of

chronic Lyme disease.

They insist there is no "credible scientific evidence" for persistent infection after a short course of antibiotic treatment because the corkscrew-shaped bacteria that causes Lyme disease, *Borrelia burgdorferi*, cannot survive this treatment.

Fearing "over-diagnosis," they publish guidelines endorsing an insensitive testing program that misses half the patients with the tick-borne illness.

Fearing "over-treatment," they recommend antibiotic therapy barely adequate for acute infection and wholly inadequate for chronic Lyme disease.

Soon they will publish the latest version of an already restrictive set of guidelines that will further pressure the Centers for Disease Control and Prevention

and academic institutions to ignore chronic Lyme disease. The guidelines will encourage insurance companies to embrace up-front cost savings inherent in shorter treatment and deny payment for longer treatment, even if the Lyme patient is still sick but showing signs of improvement.

Although the Lyme denialists claim support from mainstream medical groups, the reality is that the handful of them have managed to dictate policy to larger health care organizations through a closed process that rejects dissenting views. Unaware of this one-sided process, the rest of the medical industry blindly follows their lead while patients suffer.

Lyme disease is the most common tick-borne illness in the world. Named after the town where it was discovered in 1975, the disease is transmitted by the bite of an infected tick. Research has demonstrated that the Lyme bacteria is one of the most invasive and elusive pathogens known to man. After causing a telltale "bull's-eye" rash, the bacteria screws its way into multiple organs and tissues to produce

often-debilitating muscle, joint, nerve, brain and heart ailments.

Although New England remains the epicenter of the disease, with up to 20 percent of new cases reported in Connecticut alone, Lyme disease and associated infections are popping up in new locations around the globe. Where you live doesn't accurately reflect your risk of catching Lyme disease because people travel on planes, trains and automobiles, while ticks travel on deer, birds and household pets. As a result, the risk of acquiring the disease is increasing unpredictably.

We know treatment is effective when instituted early, but fewer than half the people with Lyme disease even remember getting a tick bite or seeing a rash. The resulting infection may spread and become chronic before the victim has a chance to seek treatment.

Research over the past two decades suggests the key to eliminating chronic Lyme disease is prolonged antibiotic therapy. Lyme-treating physicians recognize this fact and studies support it.

The Lyme denialists refuse to accept this point of view.

Imagine if "AIDS denialists" had won out in the early 1990s. Doctors would have refused to prescribe antiviral medications and insurance companies would have refused to pay for them. How many millions of patients would have gone undiagnosed and untreated?

Sound scary? Welcome to the world of Lyme disease run by Lyme denialists.

Today many Lyme patients are going undiagnosed and untreated because of the Lyme denialist agenda. Although Lyme disease is usually not fatal, the disability associated with a chronic case is equivalent to congestive heart failure.

Health care providers, government agencies and Lyme patients must confront the Lyme denialists and fight for better recognition and treatment of Lyme disease. *pha*

## Reagan's Ramblings Rants & Raves

by Donna Reagan

### The Proof is in the Pudding

Hey - have you heard the news? The Infectious Disease Society of America (IDSA) will soon be updating their treatment guidelines for the treatment of Lyme disease! This is so exciting. I wait the unveiling of these new improved guidelines with much anticipation - much like the anticipation that comes from having a root canal, a colonoscopy, or a friend digging out my ingrown toenail with a flathead screwdriver.

Dr. Raphael Stricker, president of the International Lyme & Associated Diseases Society (ILADS) shared his (and his peers') opinion about the upcoming new guidelines in the July 31st issue of the Hartford Courant News (Hartford, Connecticut - [www.courant.com](http://www.courant.com)). Dr. Stricker's comments must have really caused some apprehension within the IDSA ranks, because shortly after Dr. Stricker's editorial was printed in the Courant, a rebuttal letter was printed by the president of the IDSA, Dr. Martin Blaser.

For your reading enjoy-

ment and edification, Dr. Stricker's article has been reprinted elsewhere in this issue of the PHA. Dr. Blaser's article will not be reprinted here as the Public Health Alert is a FREE publication and doesn't want to waste ink; however, I would like to share some of my thoughts with regards to Dr. Blaser's rebuttal.

In short, I shall now rebut the rebuttal.

With all due respect to Dr. Blaser, his rebuttal is absurd, and rather meaningless to someone suffering with chronic Lyme. I suffer from chronic Lyme so I feel I can freely say this, and just to be clear: Blaser's rebuttal is absurd and rather meaningless.

Blaser began his rebuttal with the assertion that Dr. Stricker's article is "filled with inaccuracies and misleading information" and that such would only add to the "public's misunderstanding and unfounded fears about Lyme disease."

Pardon me for a moment as I must take a second to contend

with this irony. Hahahahahaha! Heeheeheehee!

It is Blaser's rebuttal that adds to the confusion and fear about Lyme disease. Blaser belittles the general public with his claims, assuming the general public can not see through his illogical debate tactics. Meanwhile, Blaser manages to send just the tiniest ripple of fear through the Lyme community because we know it is Blaser's Goliath organization that stands between us and appropriate medical care.

In fact, it is Blaser's affiliation with this Goliath organization that is his first criticism against ILADS president, Dr. Stricker. Blaser contends that the IDSA, touting a membership of 8,000 infectious disease physicians versus ILADS, with its membership of 200 Lyme specialists, is the justification for their 'rightness'. In other words, right or wrong, Goliath insists upon making the rules, and we must all close our eyes and go with the status quo. Blaser would do well to recognize

that power does not equal "right". Truth equals right.

This logic may work on the uneducated, but I believe that the uneducated most likely do not read editorial opinions. The uneducated may fall for this kind of so-called reasoning of Blaser's, however, the truly educated realize that history is full of stories of many "Davids" facing off with the "Goliaths" of their time.

History demonstrates several scientists had to battle commonly held beliefs that were inaccurate. At one time hundreds upon hundreds of scientists believed the earth was flat; they believed that the earth was the center of the universe; they believed there was no such thing as chronic syphilis - another spirochetal disease, just like Lyme disease. And guess what? Those thousands of learned men and women were wrong.

Just because IDSA is the Goliath in this situation does not and should not imply that their collective opinion about one of

"Reagan"...cont'd pg 12

# But You Don't LOOK Sick...

## 10 Commandments for Interacting with the Chronically Ill



by Susan Williams

In the realm of chronic illness, one of our more challenging tasks can be gaining support from others. As if finding a knowledgeable and caring doctor wasn't difficult enough, finding caring and supportive friends to surround ourselves with can be even more difficult. Most people are simply not capable of understanding, unless they have the misfortune of a chronic illness of their own.

How many of us have heard something along the lines of "But you don't LOOK sick...?" It makes one wonder how a sick person is "supposed" to look. If one were to hobble around on crutches, would their illness suddenly become more believable? Our society understands the visible, physical manifestations of illness, such as a broken bone in a cast or hair loss from chemotherapy. What many fail to grasp is the subtle, invisible manifestations of chronic illness. Symptoms such as pain, severe fatigue, and cognitive impairments are not easily visible to the average observer, which means that sufferers of chronic illness often look "just fine".

Our society is all about instant results - the mindset that we can just pop a magic pill and all our troubles will go away. When sufferers of a chronic illness do not quickly "get better", we are often treated as if it were somehow our own fault. We may even be told that we are "hypochondriacs" or that "it's all in our head".

Remember when you had the flu? You were exhausted, achy all over, and could hardly get out of bed. But, fortunately, the illness passed and you were back to your old self and usual activities.

Now, imagine if you had never recovered from that flu. Every day, you wake up achingly sore and as tired as if you had not slept at all. Imagine trying to go through your usual activities while feeling this way. Not only do work, school, and regular tasks of daily living become near-impossible, but so do the smaller day-to-day things that so many take for granted, such as simply washing your hair or paying the bills.

It is stressful, it is exhausting, it is depressing... and yet the

chronically-ill person continues on in the face of it all.

For those of you who may have, at some point, been the perpetrator of an otherwise well-intentioned comment, please understand that our illness is just as real as that of an amputee or other "visible" illness. To help aid those of you who wonder how to interact with a chronically ill person, allow me to present the Ten Commandments.

**1. Thou Shalt Not Imply That We Are Not Truly Ill.**

You will not convince us otherwise with remarks such as, "You LOOK good," or "But you don't LOOK sick." Even if you meant them as compliments, we perceive those kind of statements as insults because they imply that you do not believe us.

**2. Thou Shalt Not Imply That The Illness Can Be Easily Fixed.**

People with chronic illnesses are persistent, if nothing else. We hang on, day after day. We see countless doctors, take numerous medications, do endless research, and continue hoping that the answer is just around the next corner. So please do not insult us by delivering diagnoses, remedies, or comments such as, "Why don't you just..." or "Have you tried..." or "You should..." If it truly were that simple, I assure you that we would have done it already. We are sick, not stupid.

**3. Thou Shalt Not Imply That We Brought This On Ourselves.**

We did not choose to become ill, just as we do not choose to stay ill. Simply having a positive attitude is not going to solve our problem. One would never imply that a quadriplegic chose such a trial for themselves, or could get better "if they really wanted to". Please afford chronically ill patients the same respect.

**4. Thou Shalt Not Insult or Argue With Our Limitations or Behaviors.**

If people with chronic illnesses push ourselves too hard, we can suffer serious consequences. Most of us have developed coping mechanisms to help us survive, and it is cruel to expect us to do more than we are able. One chronically-ill woman I know was actually told, "I wish I could have the luxury of sleeping all day." Believe me, we would much rather be out working, playing, spending time with loved ones, participating in normal activities. "Sleeping all day" is not a luxury for us - it is a critical necessity, one that we must take in order to protect whatever remaining health we have. Perhaps it may help to think of it in terms of being one of the medications we need to take. If you wouldn't think of denying a diabetic their insulin, then don't think of denying the sufferer of a chronic illness their critical need, whether it is a mid-day nap, avoidance of certain foods or environmental factors, or something else.

**5. Thou Shalt Not Imply That You Can Relate To What We Are Going Through.**

Unless you have a chronic illness of your own, you cannot possibly understand just how much suffering is happening. Of course you want to be compassionate and want to relate to people. But when you try to do this by telling a chronically-ill person that you are always tired too, it tends to make the person feel that you are minimizing their suffering. Try saying something more along the lines of, "This must be so hard for you," or "I can't imagine what you're going through." It really does make a difference to us.

**6. Thou Shalt Be Mindful Of Other Family Members.**

Chronic illness doesn't just affect the person who has it, but the whole family as well. The

trauma of the illness can evoke feelings of fear, depression, anger, and helplessness in all family members. The balance of family dynamics will most likely change, especially if it is a parent who is ill. The healthy spouse may end up taking on an overwhelming amount of responsibility, and even children will likely be involved in helping care for the ailing family member. Please keep these others in your thoughts as well, and make an effort to direct some special attention to them, without any mention of illness or disability. Individual family members adjust in different ways and at different paces. All members might benefit from counseling to help handle the stress involved, and each family member also needs to have time to pursue their own individual interests. External support from friends, neighbors, extended family, religious institutions, and support groups may help ease some of the burden.

**7. Thou Shalt Acknowledge Our Efforts and Celebrate Even Our Small Successes With Us.**

For the chronically ill, any day that we can accomplish a task, no matter how small, is a "good" day! Our lives are often measured in terms of doctor's visits and lab work, and our "success" measured by a rise in Natural Killer cell counts in our blood, or actually completing an entire load of laundry in just one day. Please do not look at us as if we are joking when we share these celebratory moments with you. Celebrate with us, be happy with us, and do not kill the moment by announcing that you just completed the Ironman Triathlon in record time.

**8. Thou Shalt Offer Thy Specific Help.**

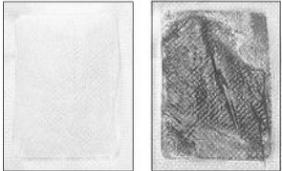
There are so many ways to help -- the most difficult part is usually getting a chronically-ill person to accept that help. They

*"Commandments"...cont'd pg 10*

**May be useful for:**

- Heavy metals
- Liver detoxification
- Weight loss
- Cholesterol
- Lyme disease
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- Diabetes
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# A Review of Martin J Walker's HRT: Licensed To Kill and Maim

by Marjorie Tietjen

Martin Walker has been writing and publishing books examining various intrigues at the heart of orthodox medicine since 1993 when he published *Dirty Medicine*, a book primarily about the war waged by science, big business and orthodox medicine against alternative treatments.

*HRT: Licensed To Kill and Maim* is Walker's third book in five years. His book *Skewed* looked at Myalgic

Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Gulf War Syndrome (GWS) and Multiple Chemical Sensitivities (MCS), and last year *Brave New World of Zero Risk*, originally issued for free on the internet, investigated the world of medicine and science lobby groups, paying particular attention to the controversies around ME and MMR.

Like Walker's other books, his latest stretches it's subject well beyond the very specific title. The book is not just of interest to those women who are considering Hormone Replacement Therapy (HRT) or to those who have been damaged by it. It is for anyone concerned about their health and who wants to learn more about how government agencies and corporations play a major role in creating and perpetuating disease. Unusually the book is also of interest to campaigners. The focus of *Licensed to Kill and Maim* is on iatrogenic illness, a disease produced by the medical industrial complex.

As a Lyme disease patient and activist, the book holds special meaning for me. As I read through the heart rending accounts of the women damaged by HRT, I was struck by the parallels between how menopausal women and Lyme disease patients have been treated. I found the book full of valuable information about the dangers and corruption of our current medical system.

Maggie Tuttle is the power behind Walker's book and her photograph is displayed on the cover along with a photo of Walker. Maggie was adversely affected by HRT and the experience compelled her to become an activist. She set up The Menopausal Helpline (MHL) to give support to the many thousands of women who, like her, suffered side effects of the drug. Maggie Tuttle funded much of the Helpline on her own, at

some expense, but she decided not to turn the MHL into a professional organization, for very good reasons. I was very pleased to see that Walker included this statement in his book. "I personally agree with her about not forming more of a "professional" representative organization. My experience of campaigning organizations since the late sixties is that their radicalism rarely survived the transitions and anyway, this is the door through which, in time, the drug companies enter."

I have found this to be very true with Lyme disease activism and politics. The majority consensus seems to be that small unified groups don't have enough power or pull and therefore cannot affect change. I have noticed the opposite to be true. Small groups, where people work together without worrying about who gets credit or if any official label is attached to them, seem to get better results in the long run. Those in these groups know each other intimately and are aware of each member's integrity. When organizations become too large, this all gets lost. Many are volunteers and use mostly their own money to accomplish their goals. This prevents drug companies or other corporations, government agencies, etc, from infiltrating and blocking any progress trying to be achieved.

Walker clearly puts into words, what many activists have been finding out through experience. "What was centuries ago, the first Hipocratic Principle to 'do no harm', has long been forgotten by the majority of medical professionals in an age of pharmaceuticals. It's modern equivalent, to 'do as little harm as possible to the majority', leaves thousands vulnerable."

Quoting directly from letters to the MHL and from interviews, Walker shares with us, in a number of extended case histories, how women have been adversely affected and changed by HRT. Not only have the women themselves been harmed but whole families often suffer. Many of the women interviewed have a com-

mon thread running through their experience. Most have never had their hormone levels measured before being prescribed HRT. I would think that measuring hormone levels would be an obvious requirement in order to determine whether or not a hormone was actually needed. Even more puzzling.....when women begin to experience side effects and acquire severe symptoms, their hormone levels still were not measured. He relates how many women had hormone implants placed in their bodies during surgery, sometimes without their knowledge or consent. Later, when they became ill and had their estrogen levels meas-

ured, their levels were found to be many times over the normal limit. When asking to have their implants removed, they were told that this was impossible. Many women still suffer severe effects of excess estrogen after ten

or more years since their last implant.

The use by practitioners of HRT, while hiding the main adverse reactions from patients, leads Walker to ask a question which echoes the title of Barbara Seaman's last book on HRT, *The Greatest Experiment Ever Performed on Women*. Walker introduces the idea of experimentation, not as some futuristic or diabolical plan but bringing the whole matter down to earth by suggesting that a major part of pharmaceutical prescription is, in fact, ongoing experimentation on patients.

Martin Walker is a very keen critical observer and has conveyed clearly the root causes of our failing medical system. It is very crucial for us to understand the history of medical experimentation on the public so we can better understand what is taking place today. In the United States it is legal to experiment on unwitting citizens. The U.S. CODE : Section 50 lists the circumstances where it is legal to experiment and test chemical or biological sub-

stances on the public.

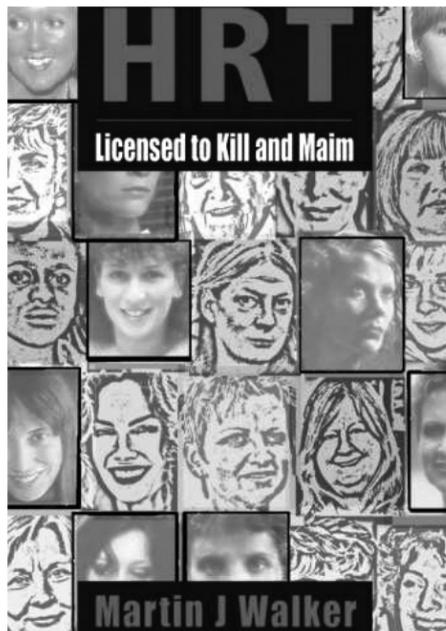
Walker does an excellent job of tying together the connections between the pharmaceutical companies, charity organizations and government agencies. He explains how profit is often the main goal, at the expense and harm to millions. For some reason many people feel that modern man has outgrown much of it's barbarism concerning human experimentation for science, profit and certain ideologies. However, Walker aptly shows us how this deception and experimentation is still occurring, creating much suffering, disability and death.

On page 172 Walker describes one channel through which experimentation is taking place. "The drug companies, in the guise of conducting research, now control almost all 'specific illness' charities. What better way to sell drugs could there be than drawing together all the patients with a particular illness or perceived illness, and then suggesting that they can help by joining drug trials?"

One thing I have found very odd, in relation to many medical charities, is that I am not aware of any cures having been developed. Isn't this supposed to be a charity's main goal - finding a cure? All I have noticed are hundreds upon hundreds of symptomatic treatments which only cover up or control the person's symptoms and does nothing for the underlying cause of the disease itself. It is much more profitable to treat many symptoms than it is to treat with a drug or natural remedy which cures. A cure would take away a charity's reason for existence and vastly lower the profits of the drug companies and other related industries.

The author goes right to the heart of the issue and explains how the drug companies reap profits from an entire segment of the population; every woman goes through menopause. They only need to be convinced that this is a medical condition and therefore they need extra assistance to get through it. A quote from page 133 sums up this misconception. "It could also be said that the great task of medical science is not to enhance and support being human but to transcend being human."

We are told that one would not be surprised or shocked to read



"HRT" ...cont'd pg 9

## The Orphan Patient

### A Plea to Fellow Health Care Providers

by *Ginger R. Savely, RN, FNP-C*

Travis had a way with words. A gentle, timid soul, he was not particularly adept with people but was expressive and insightful on the written page. He was very bright, so much so that despite his young age of 22 he often became inpatient with the ineptitude of his fellow humans and the inconsistencies of an irrational world.

Why he developed a mysterious disease that consumed him and made him lose his way is beyond comprehension. Bugs, worms or things that he couldn't describe were infesting his body and his brain, tormenting him with itching, biting and stinging sensations. Strange things were occurring that made no sense to his rational mind: fuzz balls, fibers of different colors and black pepper-like dots were emanating from his pores and making his skin feel like it wasn't his own. He couldn't sleep, he couldn't concentrate, he couldn't work or enjoy life in any way. From doctor to doctor he went in desperation, seeking to discover the cause of his misery, hoping to find a diagnosis to explain his bizarre symptoms. He hoped that even if none could diagnose his malady, someone might at least listen, look, and try to understand and help him.

Hope slipped away with each succeeding office visit. He appeared pale, thin, covered with open sores, anxious and fearful. Immediate diagnoses of "delusions of parasitosis", "self mutilation" or "methamphetamine abuse" were conferred upon him without giving him the respect of a proper history or physical. Health care providers would shake their heads in judgmental haste and refer him on to a psychiatrist.

Was he crazy? It sure seemed that way. But his craziness didn't cause the illness. The illness caused the craziness. He became obsessed with every little detail of his hygiene and of his surroundings. He tirelessly scrutinized every inch of his body, looking for signs of his invader and hoping to extract the instruments of his torture. He felt terribly sick emotionally and physically. He had to drop out of school and quit his job as a pharmacy technician. The lesions that covered his body were an eyesore. He was embarrassed to be seen in public for fear that others would think he was contagious or unclean. For over a year he stayed locked up in his room, hiding from

the world, unable to live a normal life or look forward to a promising future. His only connections to the outside world were the web blog that he faithfully maintained and the chat groups he was a part of.

Then he read an article that I wrote about the mysterious skin condition known as Morgellons disease. As he read, he gasped as he recognized every one of his symptoms. For the first time in several years he felt a glimmer of hope. Finally someone would take



him seriously and would treat him with the respect that he deserved. He came to see me and after a thorough history and exam I informed him that he fit the criteria for this unusual and little-known disease, a disease for which there was no test or cure, a disease that, although described over 300 years before, was not even recognized by the Centers for Disease Control and Prevention (CDC) or state health departments.

Validation of his illness was a huge step but there were more obstacles to overcome. Since no one has discovered the causative agent of Morgellons disease, its treatment is a shot in the dark. The patient surrenders himself as lab rat, willingly taking different concoctions of antibiotics that have been helpful to others with the same affliction, but never knowing whether he will be one of the lucky ones who respond. Some patients with Morgellons, especially those with long-standing illness, have worsening symptoms with treatment. Their condition becomes aggravated and their sensitivities sharpened. Anxiety peaks, discomfort heightens and the unusual objects flow forth with a vengeance.

This was the case with

Travis. His response to treatment was such an intensification of symptoms that on several occasions his mother took him to the local psychiatric hospital, not knowing how to handle his agitation and his inability to cope with the pain. After stopping treatment his manic episodes would disappear but the return to baseline was a return to the same lonely life of despair. From past experience I knew that our only hope was to treat aggressively with antibiotics,



but his reaction to treatment was so insupportable that it was difficult to know how to proceed. I believed that his case was too complex for me to handle, but there were no doctors within hundreds of miles who would know what to do or even take his disease seriously.

We seemed to be caught between a rock and a hard place. We'd take one step forward and two steps back. Meanwhile, other Morgellons patients of mine were having symptom flares but getting past them and going on to notice marked improvement. But without improvement there was no hope. And eventually life with pain, fear and misery and without dignity, joy or hope seemed pointless and unbearable.

One Sunday afternoon the horror of it all became too much for Travis to bear. Longing for sound sleep and relief from the pain, he took a large quantity of sedating medications and slipped away from his earthly prison. His mother found him a few hours later and through the shock and sorrow, she couldn't help but notice that it was the first time in several years she had seen a peaceful look on his face. A strange mix of feelings overcame her - the gut-

wrenching agony of a mother losing her only precious son, mixed with a protective sense of relief that his suffering was finally over.

What happened to Travis should make all of us in the medical field pause and consider the ways that we let patients down. Patients deserve to be listened to and taken seriously. To confer a hasty psychiatric diagnosis when a patient's symptoms seem too unusual to categorize is as much a transgression against humanity as it is medical malpractice. There are many more "orphan diseases," as they've come to be known, with "orphan patients" abandoned because they didn't have the good fortune to come down with a known and socially acceptable condition. Throughout the history of medicine we have seen this patient mistreatment due to ignorance on the part of the medical team - patients with tertiary syphilis locked away and put in straightjackets, epileptics believed to be possessed by the devil, gastric ulcer patients advised to learn relaxation techniques because they were inflicting their ailment upon themselves.

As practitioners, let us never forsake our patients. Let us take the time to really listen and look. May we never abandon a patient by discarding him into a lonely, bleak existence of despair. May we not disregard his concerns, ignore his feelings, nor discount his suffering. That is not the way that we would want to be treated nor would we want that kind of disrespect for the ones we love. *pha*

**For More Information About Morgellons Disease**  
[www.morgellons.org](http://www.morgellons.org)

**Suggested reading:**

1. Savely, GR, Leitaio, M. Skin Lesions and Crawling Sensations: Disease or Delusion? *ADVANCE for Nurse Practitioners*, May 2005, 16-17.
2. Savely, GR, Leitaio, M, Stricker, RB. The Mystery of Morgellons Disease: Infection or Delusion? *American Journal of Clinical Dermatology* 2006; 7(1):1-5.

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## Resurrection ... *Cont'd from page 2*

that I was prescribed tranquilizers.

For several months, when I was at my lowest point, I was unable to care for myself or my children so we temporarily moved in with my husband's parents while my husband stayed at our home to continue working. Then the doctor decided that depression must be my problem so he prescribed antidepressants. He informed me that if needed, I could take up to three at a time. That night I did end up taking three pills because they didn't seem to be working and in fact ended up making the situation worse. I woke up in the early morning in a state of fear and with the thought that I needed help. As I went to the top of the stairs to call for assistance, I fainted and fell down the stairs. My seven year old son called the ambulance which took me to the hospital. At the hospital the doctors performed several tests, including a CAT SCAN of the head. When the doctor found nothing obviously wrong with me, I was asked what I liked to do in my spare time. I told him I enjoyed boating with my husband. His only suggestion, before he sent me home, was to take more rides on the boat with my husband and that this would most likely make me feel better.

When summer came to a close, it was time to return to work at the school. I was barely able to function but wanted to press on for fear that if I gave up and quit that my life would be over. At least this way, I thought I could keep up some sort of normalcy.

My coworkers were not very understanding...to say the least. At times I was so lightheaded and weak that I would immediately have to lie down on the cement floor in the stockroom to get the blood flow back to my head. With me, it wasn't a matter of sleepiness but a simple inability to stay upright for very long. The women I worked with would say to me..."well, we get tired too sometimes you know, but we don't have to lie down!"

Time went by, as I struggled every day to function, and I was diagnosed with Chronic Fatigue Syndrome. Even though there was no cure, it felt good to have some diagnosis besides depression. I knew something was seriously wrong with me and that it wasn't just "all in my head". Actually, most of it was in my head, but in an organic way...not psychologically. Every couple of weeks a strange new neurological symptom would add itself to the others already in my repertoire.

One of the most difficult parts was that most people just did not understand. How can anyone be so sick for so long while the doctors can't find any concrete cause? I can't blame them really. One has to have had this disease to appreciate the full implications of its diabolical fluctuating nature. Because I didn't want people to feel that I was lazy or mentally ill, I set out to prove that I was really and truly organically sick. This drive led me to begin researching the vague diagnosis of Chronic Fatigue Syndrome (CFS). I would bring all my research to my doctors, hoping desperately that they would take an interest. My family doctor was very supportive but all the specialists I was sent to told me to accept my diagnosis, that I was depressed and why was I doing all this researching? The doctors would tell me that diabetics, for instance, accept their disease and get on with their life so why couldn't I do the same. My neurologist told me that I should stop all the researching because I wouldn't want her to get the wrong idea and that other doctors would also get the wrong idea about me. She was insinuating that I was crazy. I went home that day in tears. No one who is sick should have to be treated this way. Many patients with vague diagnoses, such as CFS and Fibromyalgia, often express the idea that they almost wished they had cancer so they would be taken seriously. Some have even expressed the thought that at least with cancer, many die and get it over with.

After 8 years of having "Chronic Fatigue Syndrome", my research led me to Lyme Disease. I noticed the symptoms of CFS and Lyme were extremely similar and decided I wanted to check this out. I made an appointment with a Lyme literate doctor and began my still ongoing recovery. I was tested for Lyme Disease by this doctor but the results were negative. However, I was treated anyway based on my history, symptoms and the fact that I lived in a very endemic area. At first my symptoms became worse, as I was warned. I was told that this was a good sign and meant that the antibiotics were hitting the target. I was on a high dose of oral doxycycline and it took four months before I even began to see any improvement and then finally, little by little, some of my symptoms began to fade away. It was a very slow process with many setbacks and flares...but each month these cycles of flares would

be reduced in severity. I learned that the setbacks and cycles were almost always temporary. I would often tell myself not to worry when an old scary symptom would reappear. Usually in three to four days the particular symptom would disappear and another one would take its place. Again, in my experience, each month the symptom cycles were less and less severe.

After 4 months of antibiotic treatment, I was retested and was now positive. The explanation I was given for this, which makes sense to me...is that those who are the sickest, most likely have the heaviest load of the Lyme bacteria. Many times all of one's antibodies are tied up to these bacteria in immune complexes. When the bacteria begins to be killed off, this frees up some of the antibodies which can now be measured. So...in other words...it is often those who are the sickest and chronically ill who test negative for Lyme Disease when using antibody testing.

Two years ago I had to switch to another doctor who specialized in Lyme Disease. I was beginning to slip backwards because of breaks in treatment. I had never really been on consistent long term treatment. This new doctor had me tested with the Bowen test and I tested positive for Lyme and Babesia. Now that I am finally being treated consistently for the Lyme and the first time for Babesia, I feel as though I have my life back.

During those many years in limbo, I felt as if I had lost my connection to God. Lyme Disease had pretty severely affected by brain and nervous system which made it difficult even to think...never mind to experience spiritual feelings. I couldn't understand why I would have to go through a trial or experience which would make it so difficult to feel God's presence.

As my thinking became clearer with treatment, my feelings of spirituality gradually began to reappear. I spent more and more time reading inspirational books. I wasn't trying to be healed nor was I asking or seeking anything else material or specific. I just wanted to feel and be aware of the presence of the Spirit of God. I wanted the joy and love and goodness I was receiving from God to flow through me and envelop those around me. As I focused in this way, I felt as if I have emerged from an egg into a new world of excitement, happiness, joy and love. So many wonderful people have crossed paths with me and for this I will be eternally grateful.

Intuition seems to have increased, synchronicity abounds and everyone I come into contact with is trying to serve humanity in their own special way. I have improved a great deal and seem to have acquired new abilities that I had never even dreamed of. It's like watching a play unfold...a good play. I now feel as if I have a purpose in life. The thought of growing older and losing vitality now never crosses my mind. I am finding just the opposite to be true. Not that I will now be free of all problems nor am I totally cured but this illness has brought me to a point where I appreciate life and those around me...so much more. While I personally don't believe that God sends evil or trials to us, I think our experiences reflect the degree to which we try to abide in the Spirit. We all have a desire to know God and to feel God's love so perhaps when we are focused on the wrong things something inside us creates circumstances to head us in the right direction. So, despite the fact that I still have memory and organizational problems and the world seems to be falling apart around us, I am experiencing a more consistent joy and assurance that in reality God is on the scene but that our real need is to open our awareness to this fact.

Lyme can be a devastating disease but there is always hope...especially when we look for it in the right places. I am sensing...along with a growing number of others, that despite what the media is telling us...more and more people are coming together in the spirit of love and cooperation. This spirit of love is the only thing that will truly heal our lives and the world. While, as many of you know, I feel we need to expose the corruption which is seemingly taking place all around us... it mustn't be with a sense of hate, fear or revenge.

I can actually say, even though the Lyme journey has been a very difficult struggle, that if I could, I wouldn't want to change a thing. I feel that the Lyme experience has brought me to a whole new place...one of wonder and amazement. *pha*

The thought of growing older and losing vitality now never crosses my mind. I am finding just the opposite to be true. ... I appreciate life and those around me... so much more.



# Does Anybody Truly Understand? They Will!

by Scott Forsgren



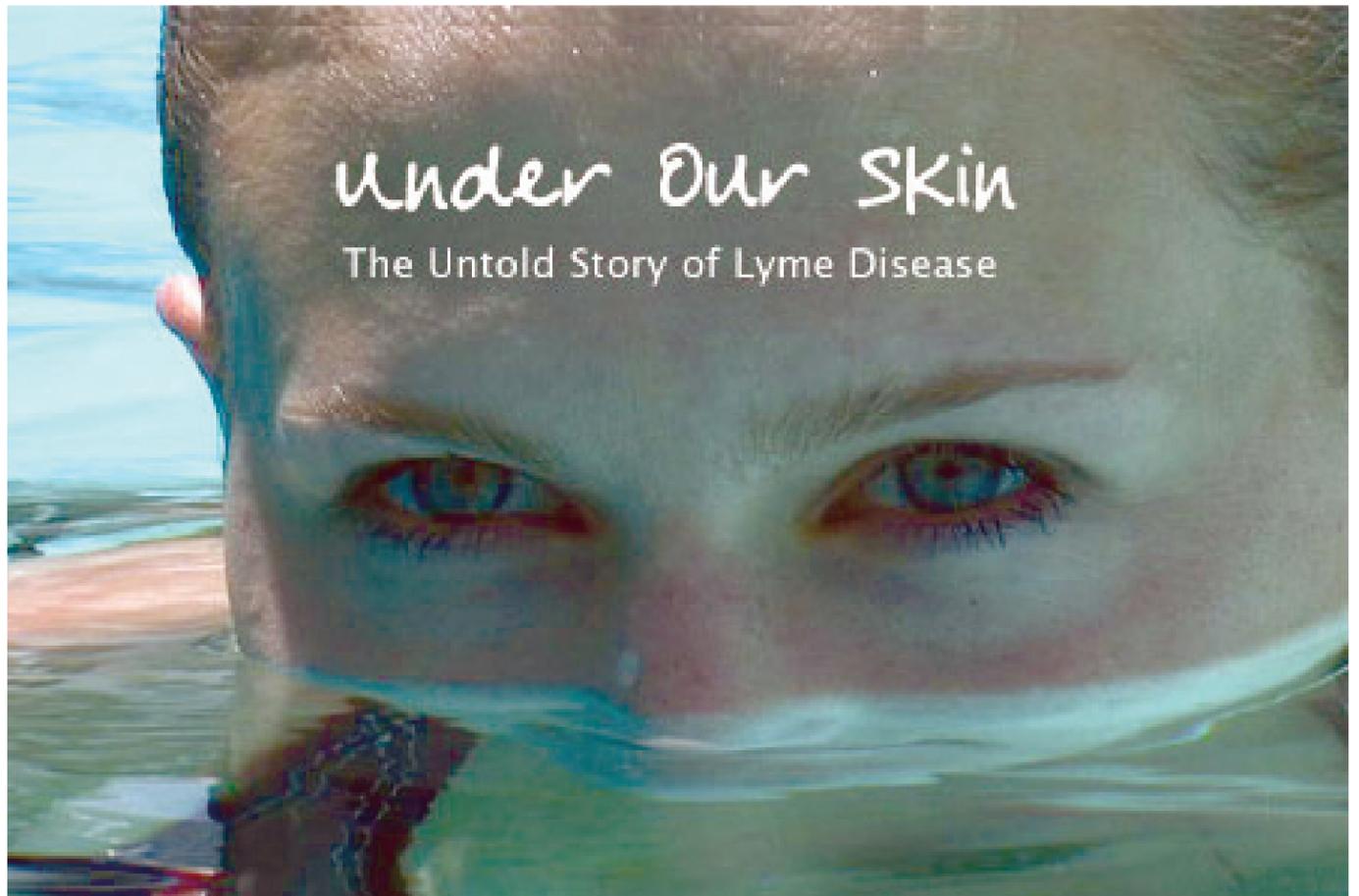
Do you ever have those moments when you tell someone that you have Lyme disease and they give you a blank

stare and indications that they clearly have no understanding of what it's all about? Then, even when they might have heard of it somewhere along the way, it seems that very few really have any concept of the hell that many of us have been through for days, weeks, months, years, and even decades. Do you ever find that even your friends and your own family just don't understand what is happening inside your body? Have you ever heard someone say, "Oh, you are still talking about THAT?" only to suggest that it was somehow yesterday's news?

Do you hear comments like "But you look great"? That one always gets me. I guess it is better than "Well, I know you are sick and you look sick too" but somehow it always feels like people say "You look great" as a way to move on to another topic or to convince themselves that you are really fine. Many of us don't look ill and yet we suffer from crushing pain, numbness, and fatigue. Sadly, most people just don't understand.

When I was first diagnosed in summer 2005, I was struck by the political nature of Lyme disease. I was disappointed at the lack of research that seemed to be underway to help find adequate treatment, and I was further struck by how little awareness there seemed to be about the disease. An in-progress film documentary from Open Eye Pictures has the ability to bring much needed awareness to our struggles and to explain the disease in a way that I have not seen done previously.

Lyme disease may be the fastest growing infectious disease in the United States, and yet it is often difficult to get an accurate diagnosis. The journey to finding that Lyme disease may be



causing one's chronic ill health can be as difficult as the journey to regain a state of health and well-being once diagnosed.

"Under Our Skin" is a documentary film that will investigate the shocking human, scientific, and political dimensions of Lyme disease. The film looks into the lives of those of us that have been inalterably changed by the disease and includes interviews with some of the foremost Lyme experts in the country.

"Under Our Skin" is produced and directed by Andy Abrahams Wilson and co-produced by Cheryl Drake and Kris Newby. Andy Abrahams Wilson is an Emmy-nominated producer, director, and cinematographer. Andy has had previous productions air on HBO and PBS. I have personally met all three of these amazing people and their passion for this film is immeasurable. Each has been touched either personally or with family members that have been diagnosed with Lyme disease. This personal understanding of the struggles we all face comes through so vividly in the film.

More than two years of research and production have already gone into the film, and the production team has shot over 200 hours of footage to date. They are now stepping towards the post-production process and will soon be starting a collaboration between a full-time editor and the film's director to craft a compelling story from the current footage. The next steps will be to hire a music composer, sound designer, and other talents needed to complete the film. This stage of the project is expected to last seven to eight months.

During the post-production effort, they will be marketing the film to public television and national cable networks. In preparation for this stage of the project, they have recently released a new trailer which both shows the seriousness of the disease as well as provides viewers with a sense of the controversy and politics surrounding Lyme disease. The current clip is available on the film's site at: [www.LymeDiseaseFilm.com](http://www.LymeDiseaseFilm.com).

The remaining steps need-

ed to bring this production to the public and help raise awareness around Lyme disease will require additional funds. Open Eye Pictures is a certified 501(c)(3) organization which means that all donations are tax-deductible. To date, over half of the \$500,000 dollar budget has been raised, but the need for completion funding remains.

As someone that has struggled with Lyme disease myself, I cannot express enough how critical I believe this project is for all of us. I also cannot be any more excited about the results that I have seen so far. This team is amazing and I hope that you will support them in their efforts to bring this project to completion. Contributions can be made online at <http://www.LymeDiseaseFilm.com> or sent directly to:

**Open Eye Pictures**  
**ATTN: Under Our Skin**  
**475 Gate 5 Rd., Suite 215**  
**Sausalito, CA 94965**

The film will open the eyes of the world to the tragedy of Lyme disease. I thank you in advance for your support of this critical project which will bring awareness to the masses. pha



# HRT...Cont'd from page 5

the following slogan 'we'll make you feel better while you continue to make yourself sick'.....and this is exactly what is happening.

Walker includes sources on where to obtain more detailed information on alternative approaches to the discomforts of menopause. He brings up the fact that diet forms the basis of our health and he summarizes the changes we need to make in our nutritional habits.

I want to share a quote from the book which I feel is key to the issue. "With respect to foods and supplementation, which provide the body with estrogens, the objective is not to raise estrogen levels to the levels that existed prior to menopause, or to exceed these levels. Nor is it the objec-

tive, as so often appears with HRT, to live the rest of your life with a high estrogen count. The idea is to smooth out the curve of the change and make it seamless."

*Licensed To Kill and Maim* not only presents the dangers and sometimes the irreversibility of HRT but most critically it shares with us the underlying political and economic issues which are allowing this crime against women to occur. In four detailed chapters he traces hormone replacement therapy from it's early synthesis in the 1940s through to it's contemporary marketing. The crimes of the medical system are clearly not just confined to HRT and Walker's book gives us the tools to understand the medical system as a whole.

Dr. Benjamin Rush, one of the signatories to The Declaration of Independence, who was also George Washington's physician predicted that "Unless we put medical freedom into the Constitution, the time will come when medicine will organize into an undercover dictatorship."

It looks as if this time is upon us. But this does not mean the situation cannot be resisted or reversed. In the closing chapter of this book, Martin Walker asks some tough questions - ones that need asking but ones that many people do not want to confront. However, if we continue to stick our heads in the sand, the current problematic state of our "health" care system will only continue to expand until we are all too sick to

do anything about it.

I highly recommend this book to anyone who is considering HRT or who has been harmed by it. I also recommend this book to anyone who is sick and tired of being ignored, brushed off and or literally made sick by the medical establishment. In essence, everyone needs to read this book. As I mentioned before, *HRT: Licensed To Kill and Maim*, gives us the knowledge and tools to take back responsibility for our own health-care. True knowledge is the source of action and power. *pha*

**For buyer inquiries contact Maggie Tuttle at [healthcentre@losbelones.com](mailto:healthcentre@losbelones.com). Outside the UK, the book is available, on the internet from [www.Slingshotpublications.com](http://www.Slingshotpublications.com)**

## QMEDRX The Lyme Company



***As patient advocates, we initiate and follow through with the appeal process (extended therapy beyond 30 days) on behalf of the patient.***

The QMedRx Lyme Advisory Medical Committee is comprised of patients, Lyme-literate physicians, pharmacists, nurses, pharmacy technicians and other experts. Our goal is to support, simplify, and increase the quality of patient care while offering the very best medical treatment possible.

**QMedRx** is the parent company of Home Care Solutions, a Lyme-literate home infusion pharmacy. We understand the Lyme patient and the needs of the healthcare professionals who provide care to those patients.

Our focus is to make available the very best medical treatment and support the Lyme community. We work hand in hand with physicians to coordinate and offer a comprehensive approach to the medical management of Lyme disease and associated illnesses and infections that are treated with specialty compounds and IV antibiotics.

The **QMedRx** clinical team of pharmacists, nurses, pharmacy technicians and support staff have years of experience managing patients in the comfort of their own home. We are licensed to dispense medication in over forty states. We are experienced with the challenges and complexities of this multi-systemic, highly variable illness, and we follow the referring physician's care plan and report back based upon their monitoring parameters.

The **QMedRx** Reimbursement Department is a dedicated team of full-time insurance specialists adept at negotiating and pursuing the challenges of claim approval from third party payors on behalf of the patient.

### Your QMedRx team offers:

- **Coordination of prescribed IV services**
- **A nurse case manager overseeing and managing the patient's IV program**
- **Pharmacist oversight and consults 24/7**
- **Proprietary outcome monitoring and quality of life program**
- **Full-time reimbursement specialist/patient advocate negotiating on patients behalf**



## Commandments ...cont'd from pg 4

do not want to feel like a "burden". If you offer a vague, "Call me if I can help," the call will probably never come. But if you are sincere, consider extending offers of specific help, such as a ride to a doctor's appointment, or picking up a few groceries or the dry cleaning. These activities can be done in a way that does not add any extra burden to your own schedule. If you have to go to the grocery store for your own family, it really isn't much extra work to grab an additional loaf of bread and jug of milk. If you have to swing by the post office, getting an extra roll of stamps or mailing an additional package isn't much

extra effort for you - but it can save a chronically-ill individual a lot of time, energy, and exacerbation of symptoms.

### 9. Thou Shalt Remember Important Events.

I'm not just talking about birthdays and Christmas. A major doctor's appointment, lab test, or new medication are all important events to the chronically-ill person. Try to sincerely ask, "How was your appointment? How did the lab test go? How's your new medication?" The chronically-ill person will appreciate that you remembered, and that you cared enough to ask about it.

### 10. Thou Shalt Get To Know The Person Behind The Illness.

The illness may be a part of us, but it's not a part of who we ARE. We want to be known as more than "that sick person". You may discover that we have a wickedly funny sense of humor, a creative imagination, musical talents, or any number of things that better describe who we are, and what we would rather be remembered for. (It makes for better gift ideas too -- rather than presenting us with yet another self-help book on the power of positive thinking, now you can give us a CD from our favorite singer or movie of our favorite actor instead.)

Most of all, please remember that the chronically-ill person is more than worthy of love, friendship, and support. Most chronically-ill people I know are the toughest nuts I have ever met. Indeed, I have come to believe that a chronic illness is not for wimps - rather, only the toughest of the tough can continually face the struggles of life while battling a debilitating disease. That kind of grit deserves nothing less than pure respect and admiration, even from our toughest critic -- ourselves. *pha*

## Special Moments... *by Barbara Gerami*

# Donny Outliving All Medical Expectations

It was October 5th, 1992 when I met this beautiful little baby in Neonatal ICU. This little baby had just turned one and weighed seven pounds. As often as I could, I would go and rock him for the next four months. He had a tracheotomy and was on a ventilator. His twin brother had recently passed away.

As I was getting ready to go visit him, the phone rang and it was the adoption agency. They wanted to know if I wanted to bring him home. I don't think I passed out, but I sure was excited. His name is now Donny Jacob. Due to privacy I cannot reveal his name before I adopted him. In February, Donny came home. The Doctors at the hospital decided to take him off of the ventilator to come home.

Donny was 11 pounds, trached, had heart and lung problems, Cerebral Palsy, was hydrocephalic and legally blind. When I tried to give him a bottle he would just go to sleep. He did not have the energy to suck. I would feed him, drop by drop with a syringe. His new doctors and I decided together that he needed to have a gastric tube. While at the hospital, before surgery, he began having respiratory distress. He ended up in Pediatric ICU on the ventilator again. He stayed at the hospital for 5 months.

After being there for about 2 months on the rehab floor, I was at home with my other medically fragile children when I received a phone call. Donny had gone into cardiac arrest and was in a seizure. They did not know how long he would stay alive. I do not remem-

ber driving to the hospital, but when I saw him, still seizing, I held him in my arms, as close to me as possible. Donny had a favorite song "Only a boy named David". We would change the David to Donny, and he loved it. As I sang the song to him, he literally calmed down. At that point they transferred him back to ICU.

He was still in ICU when I went to visit him as I had done every day. However, this day was different.

I went to his room and he was not there. The staff had not told me that they had moved him to another room.

Needless to say, my heart felt like

it had been cut in two. Donny did go back up to rehab and after his second birthday came home.

Taking care of medically fragile children is actually the easy part of life. The hard part of it is all the traffic coming through your house, as in nurses, therapists and homebound teachers. Some are a major blessing, such as Susan has always been (Donny's nurse and friend of 14 years), and others really need to get a life.

Besides having gone into

cardiac arrest several times, and also having a diagnosis of failure to thrive, Donny, however, has thrived and grown. The ventilator was discontinued when he was four and a half. The trache came out when he was five and a half. I was changing his trache one day when I pulled the trache out to put the new one in, and before I could put the new one in, he ran. Donny was laughing, saying that he did not need it anymore. I was chasing



*Barbara's biological son Isaac holds two of her medically fragile adopted children. Donny (left on ventilator) and baby Gregory.*

him and telling him the doctor had to decide that. He did let me put it back in with the promise that we would call the doctor.

Donny did pretty good health wise until

he was about six years old. He started to get very anxious and upset. We did not know that he was in the process of losing almost all of his sight. The ophthalmologist said that he had expected this by the time he was an adult, just not this soon. I have had a very hard time coming to terms with this, thinking my son is going to miss out on all the wonders that God has created. Donny has since taught me that he is enjoying all that God has created, just in a dif-

ferent way.

At seven years old Donny became very ill and ended up in the hospital, back on oxygen. He was on oxygen for one and a half years. He was so weak that he was in a wheelchair most of the time. We would carry him outside so he could be with the other children. The doctor told us that she did not know how much longer he had to live.

One particular Sunday Donny wanted to go to church, but even on full blast oxygen he was still gray. I told him no because he was too weak, in the wheelchair and on oxygen. He stood up and took his oxygen off and said, "Ok, now let's go!" As long as he put his oxygen back on we would go. Since we were there, our wonderful Pastor stopped everything and called up the church elders and prayed for Donny. By the Tuesday after that, Donny was off of oxygen. We have been at the same church with the same Pastor for 14 years. Donny and Pastor David have a very special bond.

Donny still continues to lose his sight. He still has severe medical problems. He takes medicine and feedings thru a gastric tube and gets breathing treatments several times a day. The doctors still say they do not know how much longer Donny has, but he has outlived all of their expectations. Even when he has had some pretty rough days he still bounces back and praises the Lord. Donny has aspirations of being a Preacher.

*pha*

# Urgent Action Needed From TEXANS On US Congressional Lyme Bills

Dear Friends,

You are receiving this notice to encourage you to assist in the very important issue of calling the US Congressional Lyme Companion Bills out of committee, intact, and to the floor for a vote when Congress reconvenes in September. Because of the size of our state, the number of Texas votes in the House has an especially large impact. This is an opportunity to be heard and influence the positive outcome of this legislation.

The material that follows is from the Lyme Disease Association through Lia McCabe and has been carefully crafted by Lia and Pat Smith, LDA President. My role is to get the word out to all Texans affected by Lyme, whether a patient, caregiver, medical professional or support group leader. I therefore ask you to forward this to all that you know, so that we can get the widest distribution and greatest number of responses possible. September is upon us and the timing is important and very short.

Sample letters and scripts are included to help you, but personalization is encouraged. Remember to be concise, don't make demands, rather explain the help that these bills will provide and above all always be polite even if speaking or writing in direct language. With your help we can surely get more than one Texas Representative to sign on, and with the clout Texas has these bills can be greatly helped along, benefiting the entire Lyme community.

Thanking you in advance,

Dr. J. David Kocurek  
Colleyville, TX  
drtomcat@msn.com  
817.421.0823  
www.standupforlyme.org

**From The LDA**

RE: Federal Bill HR 3427 Lyme & Tick-Borne Disease Prevention, Education & Research Act of 2005

The bill now has 77 cosponsors. Great job everyone. We need further help now.

**1st PRIORITY: We need Texans to call US Representative Joe Barton ASAP.**

Representative Barton (TX-6) is the Chairman of the Energy & Commerce Committee in the US House and he is the only one who can bring the bill up for a

vote. He holds the fate of the Lyme bill in his hands.

His Washington DC office needs to hear ONLY from people who: live in Texas, who are support group leader(s) or know of other groups with members in Texas, or who are medical professional(s) with patients in Texas, and people who have any connection to Representative Barton

DO NOT contact his office if you do not fit one of the above criteria

If you fit one of the above criteria, call both his Washington, DC and Arlington Branch office and ask to speak with the Health Legislative Assistant. If unavailable, speak with the aide who answers.

Congressman Joe Barton (Texas, District 6) can be reached at the following numbers. You may call or fax.

**Washington, DC:**

Phone (202) 225-2002  
Fax (202) 225-3052

**Local Office, Arlington branch**

Phone (817) 543-1000  
Fax (817) 548-7029

**Sample of what to say or write:**

"I am a CONSTITUENT (or I live in Texas, or I have patients/members in Texas) and I am calling to urge Congressman Barton to actively support bill HR 3427 (Smith/Kelly). It is The Lyme and Tick-Borne Disease Prevention, Education, and Research Act of 2005. I would like the Congressman to bring this bill up for a vote and move it out of committee intact. Please add me to your list in support of this bill." Give your name and address and group name you represent, if any.

If they want you to leave a voice message for the Health aide use the blurb above and remember to leave your name, zip code and phone number.

If possible give a VERY brief description of how much you or someone you know has suffered. Try to paint a picture of the extent of disability on the bad days and of the financial loss to society (disability, special school programs, sick days from work, doctor appointments, etc...) If doctor, how your patient(s) have suffered, support group, same thing.

Calls first please, but consider faxing or e-mailing a letter to his Washington DC office as well as the phone call, Sample letter

below.

**Sample letter :**

Dear Representative Barton:

I urge you to bring the The Lyme and Tick-Borne Disease Prevention, Education, and Research Act of 2005," H.R. 3427, (Smith/Kelly) up for a vote and move it out of committee intact.

Lyme disease is almost eight times more commonly reported than West Nile Virus (WNV) in the U.S., yet a significantly higher percentage of funding is being set aside to prevent and treat WNV. In 2004, CDC reported 19,804 cases of Lyme and CDC & NIH total spending was \$33.6 million. In 2004, CDC reported 2,539 cases of WNV and CDC & NIH total spending was \$77.6 million.

According to the CDC, only 10 percent of cases meeting its criteria for Lyme disease are reported. Therefore 198,040 new cases meeting the criteria occurred in 2004 in the U.S. In addition, many other cases that do not meet the CDC criteria occurred in 2004.

Lyme disease, the most common vector-borne disease in the United States, is usually contracted by the bite from a bacteria-infected tick. In humans, infection with Lyme disease bacteria can lead to early symptoms such as severe headaches, debilitating fatigue, joint pain, and skin rashes, while long-term symptoms can lead to problems related to the central nervous system including the brain, heart, joints and other musculo-skeletal problems. Symptoms of Lyme disease vary for each individual patient, and also vary in intensity over the course of the disease.

The long-term cost of Lyme disease to families, school systems, the health care system and the economy is astounding. According to a study published in 1993 in Contingencies, an actuarial trade publication, the cost to society for Lyme disease was about one billion dollars per year. Cases have doubled since then, so today's costs are probably \$2 Billion or more annually. The average treatment and diagnosis and lost wages related to Lyme disease was \$61,688 per year per patient.

Despite the prevalence, severity and economic costs of this illness, patients with Lyme disease are having increased difficulty obtaining diagnosis and treatment. You are in a unique position to

right this wrong. Your support to get H.R. 3427 (Smith/Kelly) moved out of committee intact is essential. It will improve surveillance and prevention of Lyme disease, the development of accurate diagnostic tests and fund additional research to determine long-term course of illness and the effectiveness of different treatments.

I am sure you agree that Lyme disease patients and the public deserve more from our health care system. Your support today is instrumental to making that happen. We implore you to allow this important piece of legislation which has significant congressional support to be heard by the full House. Your committee action will allow that to happen. Sincerely, John Doe. Don't forget to sign your letter

**2nd PRIORITY:** Only 1 (Ruben Hinojosa, TX-15) of Texas' 321 Congressmen (one district seat is vacant) is a co sponsor on HR 3427. Neither Texas Senator has cosponsored S 1479. Please call and write YOUR own Congressman today and urge him/her to sign on as a co sponsor and call both Texas US senators and ask them to sign on as cosponsors. Call Washington offices listed.

**Sample Blurb for Senators:**

"I am a CONSTITUENT and I am calling to urge the Senator to support S 1479 (Dodd/Santorum), The Lyme and Tick-Borne Disease Prevention, Education, and Research Act of 2005. I would like the Senator to sign on as a cosponsor today. Please add me to your list of constituents in support of this bill." Give your name and address.

**Texas US Senators:**

**John Cornyn**

Assistant: Katherine Coughlin  
DC Phone # (202) 224-2934  
DC Fax # (202) 228-2856

**Kay Bailey Hutchison**

Assistant: Matthew Acock  
DC Phone: (202) 224-5922  
DC Fax: (202) 224-0776

Don't underestimate the power of ONE phone call. Often times our Senators and Representatives will vote based on the number of calls they receive. It is likely the IDSA crowd will be calling vigilantly to stop this legislation. We have to be our own advocate. I urge you to make those phone calls. Your call could be the one that makes the difference! pha

## “Reagan” ...

multiple infectious diseases is THE correct opinion. The 'status quo' is not always correct, and sometimes David must battle some giants.

Unfortunately for Lyme patients, it is true that ILADS suffers from a smaller membership than IDSA. It would be so much better for the Lyme community were those numbers reversed because even the CDC estimates the 20,000 NEW diagnoses of Lyme disease each year is vastly underreported, and that number is more likely to be 200,000 yearly. This number, of course, does not take into account those unlucky souls whose Lyme disease did not respond to the paltry amount of antibiotics dispensed by the so-called medical professionals who believe they are 'in the know' about appropriate Lyme treatment.

## Cont'd from page 3

heroes of the Lyme community deserve to earn a living for themselves and their families? One certainly can not fault the members of ILADS when the *Borrelia* spirochete (Lyme bacteria) does not respond to one or even two rounds of antibiotics which, as suggested by the IDSA guidelines, is the maximum required treatment.

Perhaps we would be closer to a cure if we had more IDSA scientists looking at ways to truly eradicate this spirochetal infection instead of investing their time trying to prove their superiority based on their size. You know - bigger ain't always better!

Blaser goes on to assert that the IDSA guidelines are superior because they were developed by "a panel of world-renowned experts in Lyme disease, doctors

conclusion their research subjects are free and clear of the infection? I ask this because to my understanding, there is currently no test to prove the absence of *Borrelia* in a person previously infected. There is no test to say the infection is gone - so I remain bumfuzzled about the evidence to which Blaser refers. Is it a secret?

Blaser claims the new guidelines received "rigorous review" by his IDSA peers. Question: What about his ILADS peers? Did the specialists who focus primarily on Lyme disease and its associated diseases every day...did they have an opportunity to review and make recommendations for this material? Or is the IDSA more like a good ol' boys (and girls) club, full of physicians just looking to pat each other on the back and agree with the common party line, marching lock-step together to appear strong and 'correct' by virtue of their professional agreement? Perhaps the IDSA should modify their name to "Infectious Disease STEPFORD Association" to be more reflective of the activities of this great Goliath society.

I wonder if any of these 'world renowned' physicians have made peace with the contradiction of their thesis and the fact that science has confirmed that the *Borrelia* bacteria (the Lyme bacteria) can morph into 3 different forms: the spirochete form; the stealth form (a/k/a the "L" form); and the cyst form. Because of the bacteria's amazing ability to change its shape/structure based upon its sense of a threat to its existence, physicians have had to adapt treatment in order to outsmart this rather genius organism.

Because of the 3 forms, different classes of antibiotics are required to kill each of the various forms, as not one class or one particular antibiotic has been discovered to be the magic bullet. While penicillins and cephalosporins can kill the spirochetal form, it is not effective against the L form and the cyst form.

The L form is quite an interesting form because it can shed its own cell-wall and hide inside of the host's cells. In other words, this stealth form is much like one of *Star Trek's* famous Romulan alien spaceships with its special cloaking device, which would allow it to hide in plain sight. The L form of the Lyme bacteria could be hiding in your own immune cells right now - and you and your body wouldn't even know it. Tetracyclines and

erythromycins are the antibiotic classes used to target the L form.

Eradicating the cyst form is perhaps the most difficult, as the cyst form occurs when multiple spirochetes join together to form a hard little spirochetal 'adult' party where the spirochetes unite to protect each other from its potential attackers, which is also a convenient time for this efficient, evil little organism to reproduce. In order to bust up and kill the cyst form, the very strong Metronidazole antibiotic is most often used.

Again, because of the complicated nature of this bacteria, several types of antibiotics must be utilized, and several rounds are usually necessary because the bacteria is killed only during the growth phase of the bacteria's slow, yet mysterious growth cycle.

The logo for the Infectious Disease Society of America (IDSA) is displayed in a white serif font against a black rectangular background.

Therefore, those 200 members of ILADS must work long hours to provide treatment to the masses of patients that appear at their doorstep desperate for someone to guide them back to health.

One of Blaser's contentions is that ILADS doctors are making a profit from their patients, and it is ILADS members "who(m) have a vested interest in promulgating long-term treatment for Lyme disease because they make their living off such treatment". Again, I must pause to compose myself and do my best to refrain from laughing at Blaser's line of reasoning.

First, medicine is business, and for many it is BIG business - period! I can't imagine many patients arguing with this assertion. The implication that ILADS physicians should not earn a living based on their education, expertise, and service to desperately ill patients is absurd. Is Blaser suggesting that IDSA physicians work pro bono?

Do ILADS members make a living off their life-saving treatment? Yes, of course they do. Do not the heroes of the Lyme community deserve to be compensated for their skills, their determination, and their grit to stand up to their peers and provide appropriate treatment despite the peer pressure to do otherwise? Do not the

who are researchers and who regularly treat Lyme disease patients." My question is: Who are these so-called "world-renowned experts in Lyme disease"? Who are these doctor/researchers who regularly treat Lyme disease patients, and where oh where are their satisfied patients? As a Lyme disease support group leader, I am bombarded weekly with requests for referrals to Lyme specialists. If the IDSA has world-renowned experts capable of producing happy, satisfied customers - I would like to have their name and contact information so I may forward these desperate patients to physicians who can help them. However, along with contact info - please send references. I need to confirm they are not on a waiting list to see one of those 200 ILADS physicians because the IDSA guidelines did nothing to restore their health.

Blaser contends the IDSA guidelines were created using "stringent rules of evidence-based medicine".

Okey Dokey - so where is the evidence? Again, where are the legions of happy, satisfied IDSA customers? Where are the former Lyme patients who have resumed their lives, now free and clear of any *Borrelia* spirochetes? And I'm just wondering - how did these great physicians reach the

A large, white, serif letter 'V' is centered on a black rectangular background.

Much like a Stepford wife would never refuse to disobey a request from her husband, I imagine Stepford physicians would be unwilling to recognize or admit to the ridiculous implausibility that a short course of antibiotics is capable of killing all the various stages of a *Borrelia* infection. Like a Stepford wife, unable to see flaws caused by her special 'programming', perhaps some of these physicians are just too lazy, naïve, or arrogant to honestly examine their assumption that two rounds of antibiotics are sufficient to eradicate all 3 forms of a deeply rooted infection that has been present in the body for an extended period of time.

What I find most interesting about Blaser's rebuttal to Dr. Raphael Stricker's thorough article about Lyme disease is that I, a mere lay person, can see the gaping holes in Blaser's argument. And quite frankly, there are moments when I'm sure I am bordering on being a total idiot myself - most likely because I have some spirochetes playing around and reproducing in my brain tissue. Therefore, I'm just wondering why so-called 'leaders in the field' are too naïve to see this as well.

However, I'm quite sure if any of said 'world-renowned' members of

“Reagan”...cont'd pg 13

## Cont'd from page 12... "Reagan"

the IDSA or their immediate family were to acquire this vile disease, the membership of ILADS would begin to soar.

It's hard for me to believe these scientists are incapable of understanding something so basic and rudimentary, therefore, I must conclude it is they who have an agenda to keep Lyme disease on the 'down low'. So just what exactly is it? Like many issues, conspiracy theories abound. With some of the outrageous behavior and official comments made by these "scientists", it makes one wonder if any of the conspiracy theories might indeed have a ring of truth to them. What exactly are we, the people, NOT supposed to understand? What are the 'scientists' afraid that we will discover?

Blaser's claim that "no credible scientific evidence that

ludicrous protocols presented by the IDSA, and even our own governmental beast referred to as the Centers for Disease Control.

Another one of Blaser's claims, based on ONE so-called scientific study, indicated that the majority of patients previously diagnosed with chronic Lyme had indeed been found to have conditions other than Lyme disease and that their misdiagnosis caused a delay in helpful treatment. As a patient suffering daily with chronic Lyme, I find the outcome of this ONE so-called scientific study to be quite suspicious. I wonder just where and by what criteria they selected their test subjects. No matter, as that ONE so-called scientific study does nothing to sway my belief in the fact that the misdiagnoses are actually occurring the other way around.

Prior to my diagnosis with chronic Lyme, I had been tested for numerous diseases - mostly auto-immune disorders in which the outcome was either negative or inconclusive. As a patient with no diagnosis, I can tell you my frustration was sometimes as great as my fear because I had no physician capable of telling me why I was experiencing the slew of

symptoms I experienced on a daily basis. Finally, after several years, I was fortunate to encounter a physician that was familiar with the symptomology of Lyme disease. Because Lyme disease (according to the CDC's own website) is a clinical diagnosis, my physician could quite easily diagnose me with chronic late-stage Lyme disease. In an attempt to confirm the diagnosis, my doctor sent my blood samples to a lab which specializes in identifying the serologic (blood) markers for various tick-borne diseases. Igenex Labs located in Palo Alto, California, is by far the best lab to validate a diagnosis of Lyme disease.

And sure enough - my diagnosis was and remains chronic, late-stage Lyme disease. What I find quite ironic is the following scenario: Due to my varying daily and weekly symptoms, I could return to the various specialists from my past, who depending upon their preconceived biases toward their own respective medical specialty, could just as easily diagnose me with Multiple Sclerosis, Lupus, Parkinson's disease, and early Alzheimer's disease. Now - forgive me if I sound a bit sassy, but what is the likelihood of me being simultaneously diagnosed with 4 serious diseases

based on my variety of symptoms? CHRONIC Lyme disease is the only thing that makes sense. But common sense apparently does not compute to these 8,000 members of the IDSA. Perhaps they did not cover 'common sense' in their medical school classes?

Blaser's rebuttal letter speaks quite confidently of a 'vast majority of cases' that are successfully treated with two courses of antibiotics. But as a Lyme 'case' myself, I want to know to which cases is he referring? I hate to admit my lapse in retaining scientific statistics; however, if and only if Blaser is referring to patients who are diagnosed and treated rather quickly following the tick bite, perhaps his assertion is plausible.

The 'brand new' cases of Lyme disease, treated promptly

Blaser claims few patients have symptoms after the treatment course recommended by the IDSA, and in addition, the ILADS treatment guidelines may promote "the development of drug-resistant 'superbugs.'"

The position taken by Goliath is that after the 2nd round of antibiotic therapy, a patient still suffering from the exact same or worse symptoms is re-evaluated and given a new diagnosis of "Post Lyme Syndrome". Keeping in mind there are NO tests to validate one way or the other if the *Borrelia* bacteria (the Lyme disease) is gone, and remembering that even according to the CDC Lyme disease is a clinical diagnosis (based on symptoms, history, examination), we must now disregard the obvious understanding that the bacteria is still present

# S

the disease persists after appropriate antibiotic treatment indicated in the IDSA guidelines" is quite a clever, yet daring statement considering most Lyme disease patients and Lyme-literate physicians know there is NO scientific evidence to prove the assertion made by IDSA - that the disease is forever absent. In other words, there is no proof the disease is eradicated after the IDSA's paltry recommendation for a limited amount of antibiotics.

Just because Elvis was no longer center stage did not necessarily indicate that he, had indeed, left the building! In fact, even when the announcer made that famous declaration, the announcement did not necessarily make it truth. That level of assumption is for the benefit of the average simpleton.

Shame on Blaser for assuming those in the Lyme community, while battling a bona fide brain infection, were automatically incapable of understanding ill-formed conclusions. Shame on Blaser for not realizing that because of the lack of understanding within the medical community, patients have had to take it upon themselves to learn everything they can about their disease process, otherwise their lives would be in jeopardy from the

# ILADS

and appropriately have a high success rate for recovery. However, it is the patients who go months and even years without being diagnosed or treated properly who muddy up Blaser's statistical assertions.

As a simple analogy - most everyone could agree that a wet, muddy shovel is so much easier to clean if the cleaning is done before the mud has had an opportunity to dry hard. Imagine, if you will, that said shovel is covered in magic mud capable of reproducing itself causing layer upon layer of mud to cake up on the shovel. It would then be quite reasonable to assume that while both shovels are indeed muddy, the cleaning time will be vastly different for each.

This simple analogy is intended to help the lay person understand that the greater the bacterial load, the longer the amount of time the bacteria has been allowed to proliferate and establish a foothold in a the body, the longer treatment should be expected. Perhaps this analogy may help some of those IDSA folks too? To conclude my little analogy - two minutes of rinsing a shovel with layers of dried, caked-on mud and two weeks of antibiotics to treat a vastly entrenched bacterial infection are highly inadequate and stupid. Have I mentioned stupid yet?

simply because the 8,000 automations have rubber-stamped their official 'line', and no matter how ridiculous it may appear to the lay person or other health professionals - it is now called "Post Lyme Syndrome". With all due respect to Goliath... that's just plain stupid. Hey - can somebody pitch me a slingshot?

As far as the seed of fear Blaser intended to plant with his manipulative 'superbug' claim - all I can say is that it's difficult to be afraid of a potential hurricane when you're busy drowning in your own bathtub.

Finally, Blaser encourages those diagnosed with chronic Lyme to seek a second opinion, and asserts that the IDSA guidelines are the best science has to offer. I don't know whether to laugh or cry first.

For the uninformed, most individuals diagnosed with chronic Lyme disease have had from ten to forty "2nd opinions" prior to finding a doctor that could give an accurate "1st opinion" and make sense of the litany of symptoms endured by the chronic Lyme patient. As for the 'best that science has to offer,' that thought makes me almost moisten my Depends! What a scary, outrageous thought to think the IDSA's

"Reagan"...cont'd pg 15

## Preemies...cont'd from pg 1

vened by the Institute of Medicine of the National Academies.

Breathing problems at birth are common among babies born very prematurely and at very low birthweight (under 3 pounds). Because their lungs are not fully developed, premature infants are likely to have trouble breathing continuously or on their own, a condition known as respiratory failure. Oxygen and, in many cases, use of a mechanical breathing machine, or ventilator, is used to help them breathe and to protect other organs such as the brain, heart, liver, and kidneys from damage while the lungs have a chance to mature.

However, high levels of extra oxygen or prolonged use of ventilators can damage the lungs and interrupt normal development, leading to a chronic lung disease known as bronchopulmonary dysplasia (BPD). Very small babies (those born weighing less than 1250 grams, or about 3 pounds) are at high risk for BPD even if they do not require a ventilator. BPD is associated with increased risk of ongoing lung problems such as pulmonary hypertension (high blood pressure in the arteries that supply blood to the lungs), sensitivities to secondhand smoke, asthma, and respiratory infections; neurodevelopmental problems such as cerebral palsy; learning disabilities; impaired growth; and cardiovascular problems. In the United States, more than 10,000 babies develop BPD each year.

Previous studies have shown that inhaled nitric oxide (iNO) can help full-term newborns with severe respiratory failure survive without the need for treatment with a heart-lung machine, thereby lowering their risk of developing BPD and related long-term complications. But the benefits and risks of treatment in premature and

very low birthweight babies have been uncertain.

The two new trials were conducted independently at different medical centers. Both involved infants born at less than 34 weeks of pregnancy who weighed between 500 and 1250 grams (about 1 pound to 3 pounds) at birth and who needed a ventilator to help them breathe. In one study, patients were treated with iNO within the first 48 hours of life; in the other study, treatment began between 1 week and 3 weeks of age. Combined, the studies reveal important benefits without adverse effects from iNO treatment.

"The findings from these two large, multicenter trials should help us better identify which babies might benefit from inhaled nitric oxide," noted Elizabeth G. Nabel, MD, director of NHLBI. "Successful and early treatment of breathing problems in these babies would represent a significant advance in improving the health and quality of life of a growing number of premature babies."

In the first study, nearly 800 babies were given either low-dose iNO or placebo (a harmless gas) starting within the first 48 hours of life and continuing through 21 days or until they no longer needed breathing assistance. Researchers found that the effects of iNO on survival without BPD were related to birthweight. Although treatment did not lower the overall incidence of BPD at 36 weeks, iNO appeared to cut the risk of BPD in half among the

babies who weighed 1000 grams to 1250 grams (about 2.5 pounds) at birth.

In addition, significantly fewer babies treated with iNO developed brain damage, as indicated by head ultrasound. In particular, treated babies who weighed between 750 grams and 1000 grams (about 2 pounds) when they were born had half the risk of brain damage compared to babies of similar size who did not receive treatment.

"When given within the first 48 hours of life, low-dose inhaled nitric oxide reduced the risk of brain injury in very low birthweight premature newborns who required mechanical ventilation after birth," said John P. Kinsella, MD, lead author of the study, which was conducted at 16 clinical sites. Kinsella is a neonatologist with the

Pediatric Heart Lung Center at Children's Hospital in Denver and professor of pediatrics in the School of Medicine at the University of Colorado at Denver and Health Sciences Center. "We are optimistic that this therapy could prevent long-term developmental and neurological problems in many of these children."

Kinsella cautions that children need to be studied for longer periods to better understand the long-term effects of treatment and to confirm the protective effects on brain development. He and his colleagues will continue to follow these participants for another 4.5 years.

In the second study, nearly 600 very low birthweight prema-

ture babies at very high risk of developing BPD were randomly selected to begin iNO treatment or placebo beginning at between 7 days and 21 days of age. They were treated for at least 24 days. Overall, more babies treated with iNO survived without BPD at 36 weeks than those who did not receive treatment (44 percent versus 37 percent). The benefits were even more apparent among the group of infants who began treatment between 7 and 14 days after birth -- these babies had twice the rate of survival without BPD compared to their peers who did not receive treatment. All participants will continue to be followed for an additional 2 years.

"In addition to improving the rate of survival without BPD in these premature infants, we found that inhaled nitric oxide was associated with less severe lung disease among the treated infants who did develop BPD," noted Roberta A. Ballard, MD, professor of pediatrics and obstetrics and gynecology and formerly chief of the Neonatology Division at The Children's Hospital of Philadelphia and the University of Pennsylvania, and lead author of the study. "At 40 and 44 weeks, the treated infants had shorter hospitalizations and less need for mechanical ventilation or oxygen therapy than those who did not receive treatment."

Mary Anne Berberich, PhD, NHLBI project officer for the two studies commented, "Inhaled nitric oxide appears to play a role in preventing breathing problems and possibly brain damage related to prematurity and very low birthweight. The results of these two studies highlight the effects of treatment on premature newborns of different ages and sizes." *pha*

**"When given within the first 48 hours of life, low-dose inhaled nitric oxide reduced the risk of brain injury in very low birthweight premature newborns who required mechanical ventilation after birth,"**



## The Singing Forest A Journey Through Lyme Disease

**A compelling, honest story of one American family already struggling with undiagnosed Lyme disease that is forced to deal with a myriad of unexpected issues, and then is hauled through the family court system and crucified for having that illness. The story touches on the very real aspects of a complex and controversial disease. Embracing tabu subjects, it paints a clear portrait of the face of Lyme Disease, and the discrimination of its patients in many arenas.**

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# 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,

Suite 100

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

## National Lyme Disease Association

lymediseaseassociation.org/

Pat Smith 888.366.6611

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Tina J. Garcia

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## “Reagan” ...cont'd from pg 13

guidelines for Lyme disease are the absolute BEST science has to offer!

There's a little saying I grew up hearing: "The proof is in the pudding." I understand that to mean that if something is true and real it will become obvious by results seen and/or experienced.

Copernicus, Christopher Columbus, and hundreds of other scientists, researchers, and physicians have had to stand up to the Goliaths of their time in their quest to find and experience truth. Those honorable and fearless "Davids" who found their "proof" are the shining examples for the physicians - the Lyme specialists - who currently find themselves in the minority.

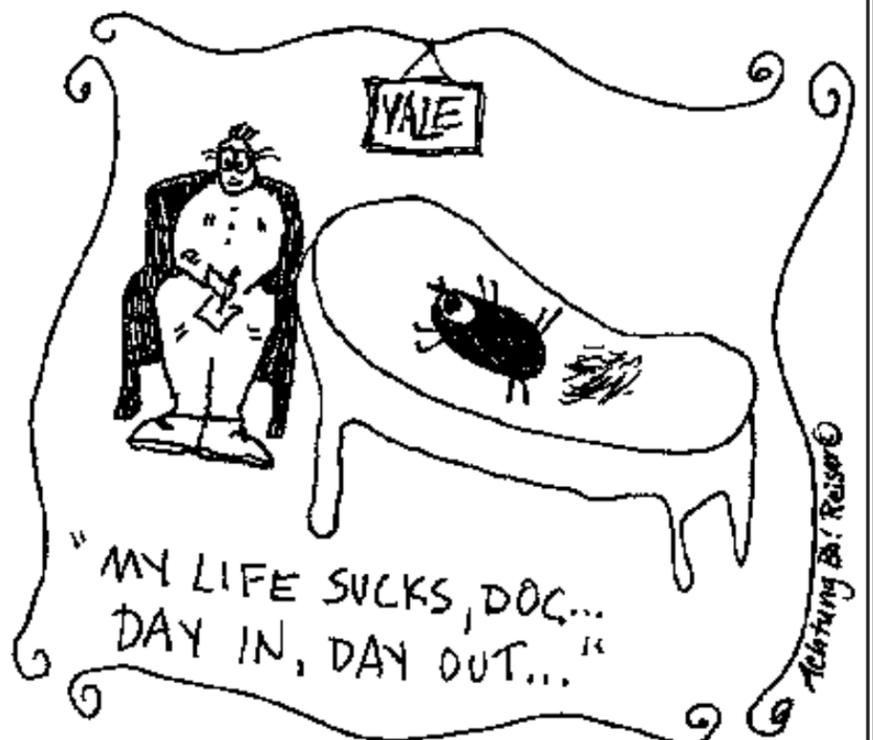
Just as David, clothed in the armor of truth, honor, courage and righteousness, walked out to meet the much bigger Goliath all decked out in the finest armor

money could buy, today's Lyme specialists depend on their faith, their brains and hearts to fight a seemingly impossible battle. Most importantly though, like David, our Lyme specialists know they have truth on their side, which in the end led to victory for David and which will most assuredly result in the long awaited victory for the thousands of silent warriors struggling daily with the ravages of their Goliath - Lyme disease.

To those warriors within the Lyme community, to the 200+ members of ILADS, I extend my most sincere gratitude. For those in the "Stepford" community - to Dr. Martin Blaser and his 8,000 member IDSA, I gently and respectfully remind: "The proof is in the pudding."

Hey Blaser - SHOW ME THE PUDDIN'! pha

## Ticktoons



by Terri Reiser

# IN THE NEWS

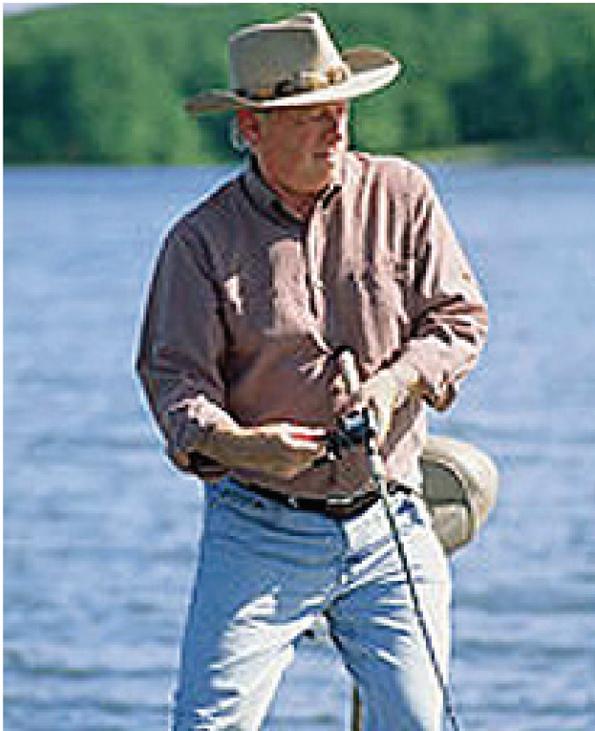
## Governor cont'd from pg 1

with the classic Lyme disease symptoms and received the best possible outcome: immediate treatment.

Ticks have been known to spread Lyme disease and a host of co-infections in as short as 4 hours to 24 hours. The longer the tick is attached the more likely the infection. 40% of Lyme patients never have the classic "bull's eye rash". A larger majority than that never even recall a tick bite.

Lyme disease, if caught early, has the best prognosis for recovery. Due to the difficulty in diagnosing Lyme and other tick borne illnesses, it is rare that the average person receives treatment right away. Lyme has been called "the great imitator" with good reason. The symptoms mimic many other diseases such as Multiple Sclerosis, ALS, and Lupus. By the time the doctor runs the patient through the battery of tests to rule out those diseases, Lyme disease can enter the central nervous system and cause neurological damage.

Governor Bredesen has received the



*Gov. Bredesen is said to be an avid hunter and outdoorsman.*

gold standard for Lyme treatment: IV antibiotic treatment from the moment he presented his symptoms to the medical professional. This should set precedence for all treatment of suspected Lyme disease or tick borne illnesses. The consequences of not treating immediately upon symptoms (as suggested by the CDC with a clinical diagnosis), and risking the disease progressing to its chronic and late stages, by far supercede the inconvenience of antibiotic treatment if the tests come back negative. *pha*

### Tennessee Health Department Facts:

**178 cases of tick borne diseases (TBD) reported in 2005**

**The state government does not track deaths related to TBD but the standard mortality rate is 3-5 percent.**



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