

# PUBLIC HEALTH ALERT

Vol. 1, Issue 2

Investigating Lyme Disease & Chronic Illnesses in the United States

August 2006

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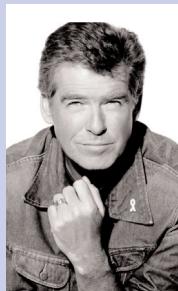
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## Leading Pediatric Lyme Doctor on Trial For His License

by Ellen Lubarsky

For most parents familiar with Lyme disease, it has always been comforting to know that if your child gets sick, Dr. Charles Ray Jones will be there to treat them.

Dr. Jones is the New Haven, Connecticut pediatrician who has treated more than 8,000 children nation wide with Lyme disease. Dr. Jones is currently in a legal battle for his medical license. He is not charged with having harmed a patient. Rather, the charges arose out of a custody battle in which the husband complained about the wife having the child treated for Lyme disease. There is controversy surrounding Lyme disease due to the difficulty in making a diagnosis and the poor sensitivity of the lab tests available. If Dr. Jones loses his license this would have a ripple effect across the nation, not only for the 8,000 children he has treated, but also for the future cases of pediatric Lyme cases that are certain to be diagnosed each year.

The Connecticut State Medical Board is currently holding legal hearings that could result in Dr. Jones having his medical license revoked. Dr. Jones is one of many Lyme specialists in the country who have been targeted by state medical boards for their treatment of Lyme patients. Lyme practitioners are under fire across America and this leaves many Lyme patients suffering in the wake of the political storm.

Dr. Jones has spent many years working 7 days a week so that he could offer medical treatment to sick children suffering with Lyme disease. He has often treated them for little or no fee. The testimony in the Jones hearings make it clear that, above and beyond this specific case, Dr. Jones is really being tried for treating Lyme disease with more than the standard 2 to 3 weeks of antibiotics which is highly disputed by several reputable Lyme researchers including the International Lyme and Associated Disease Society (ILADS) and IgeneX labs in Palo Alto, California. Treating children with Lyme has been a mission for Dr. Jones. His selfless determination



Dr. Jones shown here with one of the 8,000 children he has treated who are suffering with Chronic Lyme Disease in the USA.

has saved the lives of countless children.

Dr. Jones is a man whose life has been spent fighting noble causes. Before becoming a medical doctor he was a divinity student, where he became friends with Martin Luther King, Jr. and participated with him in the march for civil rights. His choice to move into a medical career was guided by this same drive to help people.

### YOUR HELP IS URGENTLY NEEDED RIGHT NOW

Two more hearings in Dr. Jones case are scheduled for September. Legal costs have been running about \$25,000 for each of the previous three hearings. At present, there are not sufficient funds to complete Dr. Jones' defense. We need to make sure that Dr. Jones has effective legal representation. By helping him win this battle, we will insure the ongoing proper treatment of pediatric Lyme patients as well as bringing the plight of Lyme practitioners to the public's awareness.

### PLEASE DONATE WHATEVER YOU CAN TO THE DR. CHARLES RAY JONES LEGAL DEFENSE FUND:

To pay by credit card, please go to [www.DefendLymeDoctors.com](http://www.DefendLymeDoctors.com). Click on the "Donate" button to get to PayPal.

To donate by check: Make donations payable to "The Dr. Charles Ray Jones Legal Defense Fund"

Mail to:  
George Heath, III (CPA)  
C/O Jones Legal Fund  
26 Fairlawn Drive  
Wallingford, CT 06492

Please mark "gift" in the memo field of your check.

### WHY DO THIS:

1) If Dr. Jones' license is revoked; there will be no one to replace him in treating children with chronic Lyme disease.

2) If Dr. Jones loses his case, not only will he be discredited but also all the treatment protocols he has developed over the years that have saved lives.

3) If Dr. Jones loses his case the ripple effect will deter even more doctors away from treating chronic Lyme disease.

4) It is the right thing to do. Doctors have risked their medical licenses in order to stand by patients with chronic Lyme disease. We want to give them the message that we will stand by them.

### BACKGROUND:

If you have had difficulty getting diagnosed with Lyme disease and finding a physician who would treat you until you were well, you have already been affected by the difficult world of Lyme politics.

You know first hand that the two to three weeks of anti-Dr. Jones" ...cont'd on pg 11

# EDITORIALS & OPINIONS

## Lyme Brain & Critical Thinking

### ...And Other Accidental Comedies



by Dawn Irons

My husband always tells me, "For those who think, life is a comedy. But for those who feel, life is a tragedy." And it seems, in theory, that might be true. But I think Thoreau, who was the originator of that comment never met someone with Lyme Brain.

You may not find "Lyme Brain" listed in the diseases that are studied in the hallowed halls of learning in the great medical institutions of our day, but trust me...Lyme Brain exists! Only... it has yet to be discovered. If the next Nobel Medical Prize winning doctor wants to make his claim to fame, he needs only to have one conversation with me to see the beauty and entertainment value of Lyme Brain at work! I could be the poster child and spokesperson for Lyme Brain.

My most recent example of the crushing blow of Lyme Brain was in editing my last edition of this paper. Do you know that people with Lyme Brain chase rabbit trails? At any rate, while editing my dear friend Barbara's column about her special needs children, I started typing away and when I got to the

word Hydrocephaly, I typed that it was an enlarged heart due to water on the brain. But hydrocephaly is an enlarged HEAD due to water on the brain!

As I was typing and came to the word "enlarged" my mind took a little vacation down rabbit trail! I thought back to my recent ER visit where the doctor told me I had an enlarged heart...so as I was typing I hit that little pebble of a word "enlarged" and my brain switched in gear to my ER visit..and bingo-bango hydrocephaly is now an enlarged heart, not an enlarged head! Welcome to my world! I was laughing... Barbara was not. So this is my sincere apology to Barbara for any embarrassment I caused her with my Lyme Brain moment. Barbara is a pediatric nurse who definitely knows the difference between a head and heart, she was just at the mercy of an editor on a mental rabbit trail.

This is not the only incident of Lyme Brain that has attacked me lately. A few months ago I went to a medical conference with my friends Donna and Beverly. Let me set up this scenario so you get the full humor effect. Okay...so there were these three Lymies...(you're laughing already?) We were trying to get a simple task done. We need-

ed to park the car and go to our hotel room. The nice desk clerk gave us a MAP! Let me remind you...we were 3 Lymies... remember the issue of Lyme Brain? Three Lymies and a map make for a good Seinfeld episode! In fact, as we ended up more lost than the average person would have been, we found ourselves on the opposite side of the building, in fact, an entirely separate building from the one we were supposed to be finding! We all felt like the characters in the first Seinfeld episode when they were lost in the parking garage...that was us that night!

Then there was the other time...One evening 2 Lymies were driving in Louisiana during torrential rain storms, during hurricane season. One has night blindness, the other has directional impairment ...need I say more? We did arrive home safely by the grace of God alone! Lyme Brain and critical thinking are about as dangerous a combination as drinking and driving! All Lymies need a designated WELL person . So go easy on us.

*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.*

## 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 nationwide support group leaders. These groups include the chronic illnesses of Multiple Sclerosis, Lou Gherig's Disease (ALS), Lupus, Chronic Fatigue, Fibromyalgia, Heart Disease, Cancer and various other illnesses of unknown origins.

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

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We cannot accept credit card payments.

or you may mail your donation to:

**Public Health Alert**  
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**Arlington TX 76018**

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

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

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

#### Letters to the Editor

You may send letters to the editor:

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or by postal mail to:

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

## The Faith Factor

by Christina J. Brown

Having a chronically ill child presents a series of challenges that is hard to understand unless you have been there. I had always had great sympathy for those who faced such an event in their lives, but never truly understood until my youngest child was born almost 6 years ago.

Shortly before Hannah was born I tested positive for Group B Strep. So extra precautions were taken during her birth. When she had trouble maintaining her body temperature and began rapidly losing weight, the staff was concerned. The doctor spoke to us about keeping her hospitalized. He only decided to discharge her after speaking with us extensively because he felt that being that she was our fifth baby we would have a better idea of what would be normal or abnormal and we would be better able to recognize the need to obtain immediate care for our newborn.

The doctor had us bringing her in for weight checks every third day. This soon became

## Healing Hannah

stressful. I can remember taking her (along with my 4 older children who at the time ranged from ages 2-8) into the hospital for a weight check-up. She had not gained ANYTHING... as a matter of fact she had LOST weight since the last weigh in. They had already told me that if she lost 1 more ounce she would need to be hospitalized again. I was in a panic. My husband and I knew that it would be very difficult to be with Hannah at the hospital and find childcare for the other 4 children indefinitely. So, I begged the doctor to let me go nurse the baby and I would bring her back in to be weighed again in half an hour. They reluctantly agreed and after the feeding she had gained just enough weight to be out of the danger zone for the moment.

The next several months she did begin to gain slowly, but was listed as "failure to thrive" in her medical record. I began researching what I could do to enrich my milk, because whenever I tried to supplement with formula

she became TERRIBLY constipated. I began taking cod liver oil and other Essential Fatty Acids. That seemed to do the trick. She still was gaining slowly, but was now on the lower end of the growth curve instead of beneath it.

For the rest of her first year she was a sweet, docile baby. She grew slowly, but seemed happy. Other than a delay in sitting up (which was an indicator of poor abdominal muscle tone) she was alert and meeting all the expected milestones. She was still not eliminating as regularly as my other children had and I mentioned it to Hannah's doctor every time we went in for a well-baby check-up. I was assured that it was "within the range of normal" for a breastfed infant to have only one bowel movement a day, but I just didn't feel that could be right.

It wasn't until Hannah turned one that it became glaringly obvious that it WASN'T right. I weaned her just before her first birthday and she did not have

**"Hannah" con't pg 10**

# Reagan's Ramblings Rants & Raves

by Donna Reagan

I have chronic, late-stage Lyme disease....among other things. It is not pleasant. I am not pleasant.

Most of the time I feel like I woke up with a raging case of the flu; allowed the Texas Rangers Baseball team to use me as a target for batting practice; then I was run over several times by a Mac truck transporting a load of bricks. Those are the good days.

Lyme disease - especially CHRONIC Lyme disease, has well over 350 possible symptoms (& counting), and it is possible to just wake up with a new symptom every day. Lyme disease is definitely not one of your more boring diseases - not that I can think of any disease that would be considered boring; yet that's not to say that Lyme disease, or any disease for that matter, is exciting because exciting is that last word I would use, and at this point I feel like I have started to just ramble, hence the title of this column. But if you DO happen to have an exciting disease, please write me - I want to know what I'm missing!

Because of the chronic pain and fatigue, and all of the mystery symptoms available to me - I have really come to hate the question, "How are you?"

In fact, I have spent a great deal of time ruminating on such a question and just what the *right* answer is for such an inquiry.

So far I have not found that perfect answer, but do realize that most of the time the answer should be dependent upon the nature of the relationship already established with the person posing the question.

For instance, I have slowly come to realize that describing my current condition with a slew of vulgarities (because sometimes vulgarities are the best way to really voice my true feelings) is NOT necessarily the most suitable response to someone who has posed that question, followed by the 'Would you like this in paper or plastic?' query. However, I am certain that I have inadvertently taught several 17 year old boys a few new vocabulary words, which always gives me a sense of accomplishment. I am a former English teacher, which I realize is probably a horrifying thought to some of you, but I still believe that a strong vocabulary gives one a real advantage in our culture.

On the other hand, if I do not answer my best friend - also

chronically ill - with said vulgarities, she thinks something must certainly be wrong with me, as if I were too sick to curse. Too sick to curse? I would have to be slipping into unconsciousness.

So very simply put - you must always 'know your audience'.

After awhile though, your 'audience' begins to know you and will adjust their behavior accordingly, such as pretend not to recognize you in public places, change their email address, lose your telephone number, or ALL.

Strangers and sack boys may continue to ask the trite 'How are you?' which come to find out, is really just a greeting! In case this too is news to you, please know the only acceptable answer is 'I'm fine, thank you, and how are you?' These people, it turns out, do not give a rip how you are doing; just as, honestly, you do not give a rip about their ingrown toenail or their bad case of acid reflux. It's a social nicety, regardless of whether either party truly feels nice.

Then there are the co-workers and acquaintances with whom you are friendly and thereby assume they are your friends. You expect that from time to time they will ask you: "So how you doing?" But don't be fooled! They really do not want to hear a discourse of your maladies either. They, too, want you to say you are 'just fine' so you will ask in return about them. They need support. They need to talk because THEY have that ingrown toenail, acid reflux, and constipation. Can you imagine their suffering? (*Insert sarcastic tone here.*)

If they happen to have a sincere intent, and are willing to listen to your woes, many will likely attempt to solve your little medial dilemmas. Many people think they know the answer and if you are smart, you will take their advice, such as to exercise more; eat their diet; improve your attitude; take less medicine; but take more supplements; blah blah blah. If you don't - BEWARE for these friendly novices know best. They will hound you and somehow make you feel guilty for having a disease that is not easy to cure....if at all.

In our society, it seems compassion is reserved primarily for those that are dying from a terminal illness. While it is true that many have died from Lyme disease - it is fortunate those deaths

are the exception, rather than the rule. Knowing this causes me to be quite grateful the angel of death is not hovering over me waiting for the big signal; however it does nothing to ease the daily physical suffering which is currently my lot. This knowledge and gratitude also does not provide me with the physical energy necessary to hurl my ever-expanding semi-bedridden frame up and into action, to perform life's important tasks ...such as bake healthy casserole dishes.

Let's face it: healthy people are busy thriving. Sickos like me are busy surviving. What is harder to face is the realization that healthy people do not find my illness fascinating. Last week, I could have been mistaken for a Multiple Sclerosis patient. This week, thanks to my twitching and tremors, I would more likely be considered a Parkinson's patient. And thanks to the spirochetal bacteria swimming through my brain tissue - EVERY week I could be considered an Alzheimer candidate. As disturbing as that is - it is at the very least....FASCINATING! Don't you agree?

Most people do not have the time, desire, or patience to maintain a true friendship or just a friendly relationship with someone whom is chronically ill. For the 'friend' - it is boring, and they generally can not understand why someone who is not dying is still suffering - especially when the friend has already generously supplied them with their solution to the problem.

Soon, the 'friends' stop calling, if they ever called at all. No one is at your door bringing you a tuna casserole.

For the chronically ill patient, there is a loneliness that usually sets in - a sense of isolation. For the chronically ill, the question, "So how you doing?" is the question that sets them apart from the norm. A truthful answer will alienate; a dishonest answer feels like a personal betrayal to self.

Although I have had this disease for 20 - 30 years, my symptoms did not become disabling until about 2 years ago. And for these 2 years I have struggled with just how to answer that dreaded question, and I have been rather frustrated with the fact there are no books or rules of etiquette (to my knowledge) on just 'how to be sick' successfully speaking.

## So How You Doing?

It's certainly not that I want to be sick - quite the contrary. However, it would be nice if there were some kind of reference material on just how to behave around others when you feel like you are being tortured by your very own body. What's the rule of thumb for that? What kind of behavior is acceptable? Quite frankly, I want to scream and cry rather often, almost as much as the desire to spit out vulgarities while at the grocery store; however, I am learning that most of the time those are not acceptable behaviors. So what IS!!!!

What ARE the rules for incessant suffering? Suffer in silence? Me? Don't be ridiculous!

Over these past couple of years I have experimented with various responses to "How you doing?"

For my acquaintances and my pseudo-friends who don't make phone calls or bring casseroles, I try to keep it brief, while still supplying some kind of useful information; then I abruptly and skillfully turn the focus back to their important lives, such as:

"I'm doing great! I've only been to the E.R. about 3 times this month because of the excruciating pain. So what have you been up to? When do you leave for your cruise?"

"Well, I've got cramps and a migraine that would kill a lesser woman. How are you?"

"Oh not too bad, thanks. But my ribs and my pelvic bone seem like they are trying to fuse and I think my coccyx bone is trying to drill me out a new orifice. And how about you? Did you ever get your bowels to move?"

"I think my husband is beating the @#\$% out of me in the middle of the night while I'm sleeping. You're always full of information -- do you know where I can buy a hidden camera with good night vision?"

For my more peppy pseudo-friends and religious acquaintances, I try to be more mindful of their attitudes and say something like:

"Oh, thank you for asking. I'm willing to be a lot better. How's that new Mercedes driving?"

"Well keep me on your prayer list. And you -- how are those bunions?"

"Actually I'm craving a casserole right about now. How about you?"

**"Reagan" Cont'd on pg 11**

## How Lyme Got a Bad Rap Lyme, Connecticut, That Is!

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

While working on a very comprehensive writing project for my usual advocacy efforts through Stand Up For Lyme, I found the need to research the history of Lyme disease. I think most patients are familiar that the first association between a tick bite and disease was observed in Breslau, Germany. In 1883, Alfred Buchwald described in a journal publication a degenerative skin disorder later named in 1902 as *Acrodermatitis Chronica Atrophicans* (ACA) by none other than Dr. Karl Herxheimer and a colleague. ACA is associated with a European species of a *Borrelia* spirochete.

The story usually jumps quickly to the now, too familiar, cluster of outbreaks in eastern Connecticut in the area around the towns of Old Lyme, Lyme and East Haddam. The clusters became noticeable in 1972 and, after delayed investigation, became the first reported appearance of "Lyme" disease in the United States. The name is courtesy of Allen C. Steere, M.D., a rheumatology Fellow (specialist-in-training) at Yale who had served previously as a Public Health Service Officer and so had some experience in epidemiology.

Steere was sent by Yale to investigate after the State Health Department gave in to lengthy urging by two local women, Polly Murray and Judith Mensch, who contacted them to point out the unusual number of juvenile rheumatoid arthritis (JRA) cases in the area. Both women had children with that rare diagnosis, and others in the region supposedly suffered the same fate. Murray recounts in her book, *The Widening Circle : A Lyme Disease Pioneer Tells Her Story*, that the family had moved to Lyme in 1959, enjoying an almost idyllic setting. Then strange medical symptoms started first with her, and then with other members of the family until they reached alarming proportions in 1965.

She was met with the familiar skepticism by the medical establishment and earned the label of doc-chaser and hypochondriac. Perseverance, self-education and time for similar stories from the region to come together finally convinced the medical authorities to take some action. Steere and

colleagues arrived on the scene in 1975, at least ten years after children and adults first started presenting with symptoms including erythema migrans (EM) rash, also known as a "bulls eye rash" followed by arthritis. Has anything really changed in the challenges patients are currently facing now that 30 years have passed since Borreliosis was rediscovered and renamed?

Occasionally there is mention of the true first U.S. reported case; that of a physician infected while grouse hunting in Wisconsin (he advised that chicken fried grouse is probably edible, but never order grouse prepared in the English tradition). Fortunately for this individual, an EM rash developed and he presented to a treating



*Polly Murray, the Lyme, CT mom who insisted the State look into the strange illnesses of children in her area.*

physician that was familiar with the European literature and an expert in *Borrelia* induced skin infection. Dr. Rudolf J. Scrimenti diagnosed the *Borrelia* infection and was able to arrest the disease during the acute phase with penicillin.

Scrimenti published this case and described both neurologic and arthritic symptoms exhibited by the patient (Arch Dermatol 1970 Jul;102(1):104-5. Erythema chronicum migrans). Scrimenti even corresponded with Steere and visited Yale to inform him of the long European history and strong possibility that the Lyme clusters were likely a form of Borreliosis. However, Steere, the rheumatologist-to-be had been summoned to investigate outbreaks of juvenile rheumatoid arthritis. After extensive study and consideration, guess what he concluded? He believed that he was observing a previously unrecognized form of JRA.

To distinguish his new discovery from the nearly 100 years of documented medical history, Steere added to his conclusion that the causative agent was probably a virus transmitted by an insect or tick vector. This was based on the observation that most cases occurred in the summer and that cases among family members didn't progress in a contagious manner, but rather appeared randomly. One fourth of the interviewed patients recalled a spreading rash on the torso that preceded other symptoms. "Lyme" arthritis and later Lyme disease was launched based on an incorrect diagnosis that would become entrenched in the popular and technical medical literature worldwide. Another case of ignoring established facts



*Dr. Allen C. Steere, was sent by Yale to investigate the claims of the CT State Health Dept. after Polly Murray continued her fight.*

because they were NIH - Not Invented Here.

What did happen in all those intervening years? Fortunately, Marie Kroun, M.D., a pediatrician in Denmark, compiled an extensive historic review of pre-Lyme Borreliosis in Europe as part of a presentation prepared for a 2001 conference in the U.K. Kroun's interest developed after seeing the devastating effects of the disease on her young patients.

Her volume of literature citations with summaries is astounding. From the 1883 Breslau report through 1975, the year of Steere's misdiagnosed rediscovery of Borreliosis, Kroun meticulously describes 17 references to ACA, 20 to EM, 7 to transmission and 5 discussing the granular (cyst) form of *Borrelia*, some of this last group dating to 1911. In whole the information collected covers just about all the issues known today, but observed

and studied over the past century. Granted, much of the literature is in non-English journals, but enough is in British journals that a thorough investigator would clue in on the references quickly.

A particularly interesting point is raised in modern-day references that describe two examinations of museum specimens. First, in 1884 Austria, *Ixodes* ticks collected from a fox were preserved. Two of them were more recently found to be infected with *B. burgdorferi* (Lancet 1995 Nov 18;346(8986): 1367. Antiquity of the Lyme-disease spirochaete in Europe [letter] Matuschka et al.). The second case involves an 1894 museum researcher who collected and preserved white-footed mice found in Dennis, Massachusetts. Modern DNA analysis of ear skin samples from the mice detected *B. burgdorferi* ospA. This raises the question of *B. burgdorferi* being brought to North America by European immigration and commerce or likewise taken to Europe via the reverse route.

The motive in recalling this brief history is not only to highlight the unfortunate mistakes made in the rediscovery of Borreliosis in the U.S., but also to demonstrate a far too common pitfall that traps many modern researchers. Those especially who are not properly schooled by their mentors in the process of literature review and its paramount importance to their work, and in the process of investigation are left particularly vulnerable. When challenged to assess a new situation there are a few fundamental principles that I learned some time ago and came to believe to be universal. I've found them invaluable to guide a number of graduate students and staff assistants in both research and investigative activities.

The first principle is to never jump to conclusions, no matter how obvious the perceived answer may seem. Often times experience builds false confidence in making the easy, but incorrect call. In contrast, a process employing critical analysis to deconstruct a complex of facts into essential elements while still understanding the system interaction can ultimately lead to a far different result and the most plausible, and supportable, explanation. Critical analysis skills are at

*"Bad Rap" cont'd pg 10*

# Pierce Brosnan Serves As 2006 Ambassador For Lee National Denim Day®

## The Largest Single-day Fundraiser for Breast Cancer is October 6

### MERRIAM, KAN. ---

As honorary chair of the Entertainment Industry Foundation (EIF), Pierce Brosnan, international movie star, producer, artist and activist, has added another title to his list—ambassador for Lee National Denim Day®. In this powerful new role, Brosnan will help bring more awareness to the fight against breast cancer and encourage people nationwide to participate in Denim Day.

In a new public service campaign that kicks off the second decade of Lee National Denim Day®, Brosnan urges men and women across the country to don denim on October 6, while pledging a \$5 donation to support innovative breast cancer research. The fundraising program has raised more than \$61 million to support breast cancer programs, and this next decade brings a chance to do even more.

"I'm proud to join Lee Jeans and the Entertainment Industry Foundation in this tremendously important battle to eliminate breast cancer from all our lives," said Brosnan. "Lee National Denim Day® is an easy way for friends and colleagues to unite in support of a groundbreaking scientific project to detect breast cancer in its earliest stage."

Proceeds from Lee National Denim Day® will benefit the Women's Cancer Programs of EIF. Funds will be used to help accelerate treatment research and increase patient access to some of the most significant clinical trials in the nation, as well as continue to support grassroots programs across the country.

"Lee National Denim Day® participants should be incredibly proud of what we have accomplished together the last ten years," said Liz Cahill, director of advertising and public relations for Lee Jeans. "We couldn't be more excited to launch the second decade of Denim Day with our new charitable partner EIF, with a commitment to fund some of the most important early detection and treatment research that exists, and with Mr. Brosnan's help, we know people nationwide will be inspired to act."

Brosnan, who has lost dear friends to breast cancer, has been a longtime supporter of the

cause and currently serves as Honorary Chairman of EIF. As the 2006 Lee National Denim Day® ambassador, Brosnan will appear in a national public service campaign and program materials with the hope of raising awareness about breast cancer and the exciting new developments that can have an impact on the millions affected by the disease each year.

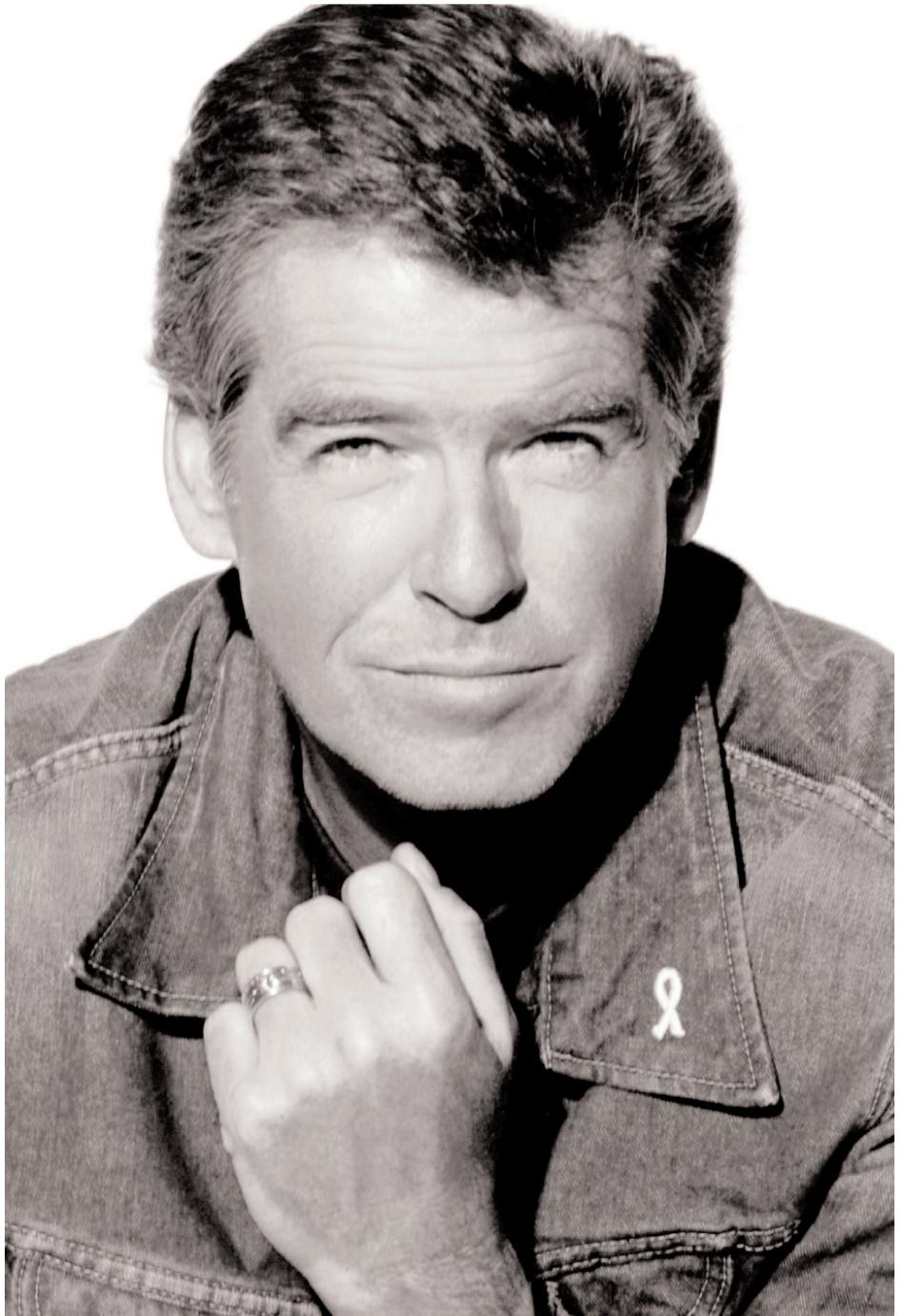
Companies, schools or organizations that register by visiting [www.denimday.com](http://www.denimday.com) or calling 1.800.521.5533 will receive a comprehensive participation kit, which includes educational materials about breast cancer in addition to supplies for easy coordination.

Last year, more than 29,000 companies across the nation participated in the single day fundraiser. More than \$8.6 million was raised for the fight against breast cancer.

Lee® Jeans is a division of VF Corporation. (NYSE: VFC). Headquartered in Merriam, Kan., Lee manufactures and markets brand denim, casual pants, shirts, fleece and knit apparel. A brand committed to the community, Lee Jeans founded Lee National Denim Day®, the largest single-day fundraiser for breast cancer. VF Corporation is a leader in branded apparel including jeanswear, outdoor products, intimate apparel, image apparel and sportswear. Its principal brands include Lee®, Wrangler®, Riders®, Rustler®, Vanity Fair®, Vassarette®, Bestform®, Lily of France®, Nautica®, John Varvatos®, JanSport®, Eastpak®, The North Face®, Vans®, Reef®, Napapijri®, Kipling®, Lee Sport® and Red Kap®.

The Entertainment Industry Foundation (EIF), as a leading charitable organization of the entertainment industry, has distributed hundreds of millions of dollars to support charitable initiatives addressing critical health, education and social issues.

EIF is committed to saving lives by raising awareness about the importance of early detection of breast and reproductive cancers, and providing funds to advance early detection and treatment research, as well as support to community programs



that assist the millions of women and their families at risk of or affected by cancer.

Through EIF's National Women's Cancer Research Alliance and EIF's Revlon Run/Walk For Women, EIF funds some of the most promising research being conducted today to develop new and more effective approaches to the treatment of women's cancers. EIF grants have helped accelerate research that has contributed to the development of a breakthrough gene treatment called Herceptin®, the first successful drug that seeks out a particular gene found in one of three cases of the most aggressive form of breast cancer. EIF grants have also supported other state-of-the-art therapies bringing new and innovative treatment approaches to breast cancer worldwide.

More recently, EIF launched its Women's Cancer Research Fund. Focused on early detection of cancer, the initiative is supporting EIF's Breast Cancer

Biomarker Discovery Project - an ambitious, groundbreaking scientific project where a group of internationally recognized scientists and clinicians from some of the best scientific institutions in the world are collaborating to develop a blood test that will detect breast cancer in its beginning stages, when survival rates are highest.

For questions about EIF's women's cancer programs and information about breast cancer, visit [eifoundation.org](http://eifoundation.org) or call 800-426-0010.

Join Lee Jeans, Pierce Brosnan and the Entertainment Industry Foundation in the fight against breast cancer. Wear denim on October 6th, and make a \$5 contribution to benefit local breast cancer prevention services, and advance groundbreaking early detection and treatment research at leading cancer centers nationwide. To sign up, call 1-800-521-5533 or visit [www.denimday.com](http://www.denimday.com).



## Lyme Disease Co-infections: Lottery Anyone?

by Scott Forsgren

Time and time again, I hear people asking the question "I've been treating my Lyme disease for years and I feel worse now than the day I started. Why?" Well, the answer might just be that treatment has been too focused on eradication of *Borrelia*, the causative agent of Lyme disease, and not focused enough on the numerous co-infections and other factors that are almost universally present.

I often ask myself why people overlook the obvious when it comes to Lyme disease. The obvious for me is Lyme disease is more than just an infection with *Borrelia*. It is co-infections, parasites, heavy metals, poor detoxification abilities, hypercoagulated blood, dental infections, and many other contributing factors. Many of these factors have been adding to one's total body burden for years or decades before actually becoming infected by a tick bite or other mode of transmission. It takes many things gone wrong to become chronically ill, and it is only through the reversal of those many things that one can hope to attain recovered health and wellness. It is my strong opinion that antibiotics, though a part of the solution for many including myself, are not in and of themselves the answer.

We may believe that we want to be well, and yet we sabotage our own healing as a result of not opening our mind to the possibility that Lyme is a complex illness that requires many different interventions. Lyme disease should be viewed much more as a multi-factorial illness and not as an infection caused solely by a spirochete.

Studies show that ticks may carry half a dozen or more of these infectious agents which may be the missing link in the treatment of those that are not improving with Lyme treatment alone. "Many people with lingering symptoms of Lyme disease may actually be infected with one or more previously unrecognized bacteria, viruses, parasites and protozoa", said Eva Sapi, assistant professor of molecular biology at the University of New Haven. It is critical to recognize and under-

stand that the more co-infections a person is carrying, the more complex their symptom picture may be and the more difficult their recovery may be as well. A significant reason for this is that the co-infections may be overlooked and thus are often not treated. Each of the co-infections may require entirely different treatment approaches, especially if using more conventional interventions. One should not assume that the treatment used

symptom presentation much more severe. Symptoms may include: high fever, muscle aches and pains, headaches, gastrointestinal symptoms, low white-blood cell count, mental confusion, skin rashes, and elevated liver enzymes. *Anaplasma* (previously known as Human Granulocytic Ehrlichiosis) is a related organism that brings with it many of the same symptoms.

Estimates on the prevalence of infectious agents found in ticks are presented below and come from data provided by Dr. Garth Nicolson. The results show how rampant these infections may truly be. Add up the numbers and one will quickly recognize that the odds are not in our favor.

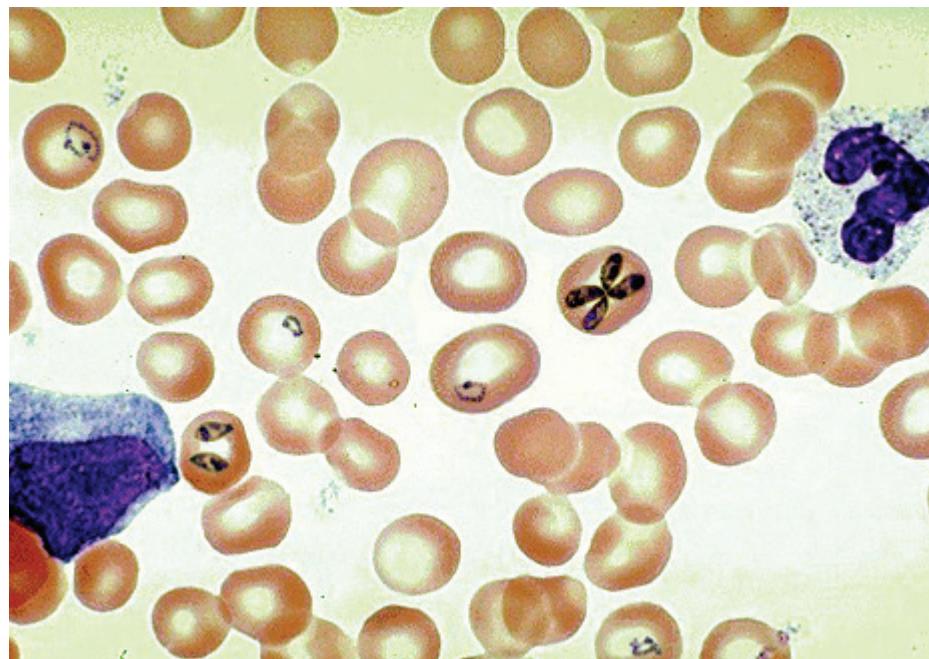
Organism	Prevalence
Babesia	8-20% *
Bartonella	40-70%
Ehrlichia	10-50%
Borrelia	18-40%
Mycoplasma	25-70%

\* Some Lyme doctors have estimated that the presence of Babesia infection may actually be 70% or higher based on their clinical experience.

When reviewing the symptoms caused by the various co-infections, it becomes clear that there is significant overlap between the symptoms which result from co-infections and those that are caused by *Borrelia* itself. Though *Borrelia* may be the ring-leader, it is critical that one not overlook the very real and almost certain reality that co-infections may be a significant part of one's current condition.

In summary:

- Co-infections are the RULE, not an exception.
  - The average child with Lyme disease has 2-5 co-infections with an average of 3.
  - Treatment of co-infections is required and often, they must be treated before or concurrent with the *Borrelia* treatment itself.
  - If you don't test for and treat co-infections, you are not putting yourself in a good position for healing.
  - Most people with chronic Lyme have 1 or more co-infections.
  - Co-infections require different treatments in many cases. Do not assume that you are covering them with only the Lyme treatment.
  - Co-infection testing is often unreliable as well and you need to repeat them over time. It took 4
- "Co-Infections" cont'd on pg 10



**Babesia infection in red blood cells in characteristic clover formation**

for *Borrelia* will also eradicate all of the co-infections. It may not.

The primary tick-borne co-infections that are often present to some degree in someone with Lyme disease are noted below.

**Babesia** - there are at least 17 subtypes of Babesia now widely known. Babesia is an intracellular parasite that lives in the red blood cells. It is an organism much like malaria and in fact, many of the treatment options used are anti-malarial preparations.

Symptoms of Babesia may include: weakness, fatigue, fever, night sweats, chills, gastrointestinal symptoms, headaches, myalgia, weight loss, arthralgia, and respiratory symptoms such as cough or shortness of breath (air hunger). Eye, brain, and dental symptoms are also often the direct result of infection with Babesia. It is my opinion that Babesia is probably the one co-infection with the most severe consequences in terms of holding one back from progressing in their recovery.

**Ehrlichia** - a bacterium that invades white blood cells. It works with *Borrelia* to make the

**Bartonella** - also known as Cat-Scratch Fever. Symptoms may include: non-healing infections of the jaw and devitalized teeth, swollen glands, fatigue, pain in the soles of the feet, flu-like symptoms, muscle and joint pain, cardiac symptoms, vomiting, nausea, and chills. There may also be a characteristic Bartonella rash which presents as stretch marks. Bartonella may be another factor in the eye-related symptoms in those with Lyme disease.

**Mycoplasma** - though not often thought of as a Lyme co-infection, mycoplasma is quite common in those infected with Lyme disease. Symptoms may include: disabling fatigue, fevers, night sweats, muscle aches and pains, short-term memory loss, headaches, gastrointestinal issues, light sensitivity, damage to the immune system, confusion, and many other signs and symptoms that defy other explanation. They are among the smallest and simplest organisms known.

Mycoplasma is also implicated as a causative agent in Gulf-War Syndrome.

# “Know Before You Go” Teaches Water Safety

## Mock Drowning Demonstrates the Urgency of a Watercraft Accident



DALLAS, TX - When the mercury rises, people flock to local lakes to beat the heat and boat with family and friends. Each summer season, dozens of kids and adults drown in those same lakes.

Children's Medical Center Dallas, YMCA of Metropolitan Dallas, American Red Cross - Dallas Area Chapter and Safe Kids Dallas Area will enact a mock drowning on Lake Lewisville as part of the drowning prevention campaign, Know Before You Go.

The campaign aims to educate lake-goers about water safety and drowning prevention and to encourage a safe summer season for all.

Included in the day's events are:

- \* Mock drowning, staged on a boat
- \* Presentation of medical information and statistics on drowning
- \* CPR demonstration
- \* Personal Flotation Device (PFDs) demonstration
- \* Presentation of laws and penalties associated with unsafe boating.

Drowning is the second leading cause of injury-related death among children ages one to 14, and 88 percent of all drown-

ings occur under some type of supervision. About 300 people drown each year in Texas, and for each child who drowns four children are hospitalized for near drowning. One of the key messages in the Know Before You Go program is that every drowning is preventable when parents take appropriate precautions.

"A common misconception is that a child who is drowning will splash and make a lot of noise," said Dr. Maeve Sheehan, medical director of transport services and an intensive care pediatrician at Children's Medical Center Dallas. "But drownings are silent, and they happen quickly. Submersion takes less than 10 sec-

onds, and a child will lose consciousness in less than two minutes. That is why it is so important to have an active water watcher paying full attention to children any time they are near or in the water."

To provide parents and other caretakers with water safety information, Know Before You Go has launched an updated website, [www.knowbeforeyougo.org](http://www.knowbeforeyougo.org), with water safety tips and contacts for water safety education. Also available online is a free PDF download of the "Water Watcher" tag, a small sign worn around the neck that can help families identify a person assigned to watching children in the water.

## QMedRx

*The Lyme Company*



**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.

*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.

### 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

**IV on the go...**



## FEATURES

# *Everthing You Wanted to Know About the CD-57 Test*

## *...but were too sick to ask!*

By Ginger Savely, RN, FNP-C  
San Francisco, CA

From coast to coast, frustrations abound among patients and clinicians regarding the diagnosis of chronic Lyme disease. Misinformed health care providers in the southern and western states consider the infection rare and non-endemic. They are inclined to rule out Lyme disease based on the negative result of a laboratory test that, unbeknownst to them, is highly insensitive.

In the absence of a reliable laboratory test or adequate experience in the recognition of the varied and complex presentations of the illness, most clinicians are ill-equipped to diagnose chronic Lyme disease. Many patients suffer needlessly for years, hopelessly lost in the maze of the health care system, looking for answers and enduring the skepticism of practitioners inexperienced with the disease's signs and symptoms.

What is needed is a better Lyme test or some other objective measure to persuade the practitioner to consider the diagnosis of chronic Lyme disease. Enter the CD57 test! You may have heard the term "CD57" tossed around on chat groups, or your Lyme-literate health care provider may have even explained the test to you in one of your moments of brain-fogged stupor. What is this number that sounds more like a type of steak sauce than a lab test, and what in the world does it have to do with Lyme disease?

Let's start by going back to basic high school biology. You may remember that white blood cells (a.k.a. leukocytes) are the components of blood that help the body fight infections and other diseases. White blood cells can be categorized as either granulocytes or mononuclear leukocytes. Mononuclear leukocytes are further sub-grouped into monocytes and lymphocytes.

Lymphocytes, found in the blood, tissues and lymphoid organs, attack antigens (foreign proteins) in different ways. The main lymphocyte sub-types are B-cells, T-cells and natural killer (NK) cells. B-cells make antibodies that are stimulated by infection or vaccination. T-cells and NK cells, on the other hand, are the cellular aggressors in the immune system and are our main focus in the discussion that fol-

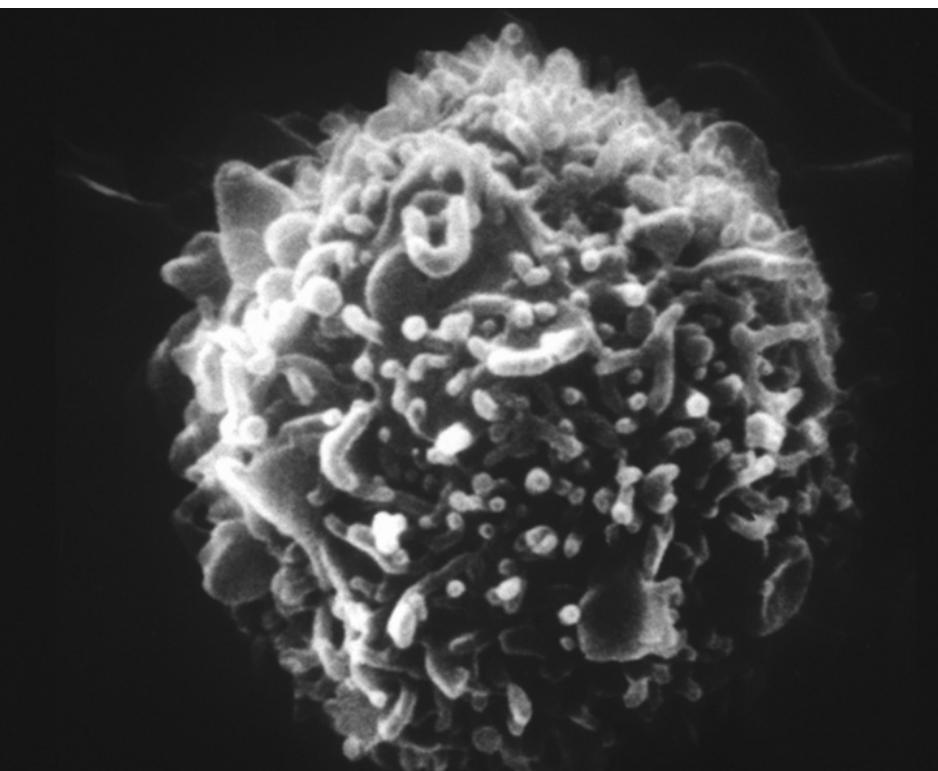
lows.

Let's pause a moment and introduce something you probably never learned about in high school biology class: CD markers. CD, which stands for "cluster designation", is a glycoprotein molecule on the cell surface that acts as an identifying marker.

Think of comparing cells as comparing people. Humans are made up of innumerable superficial identifying characteristics (such as hair color, eye color, etc.) and so are cells. Cells probably have thousands of different

counts.

A smaller population of NK cells are CD57+. A below-normal count has been associated with chronic Lyme disease by the work of Drs. Raphael Stricker and Edward Winger. No one knows for sure why CD57+ NK cells are low in Lyme disease patients, but it is important to note that many disease states that are often confused with chronic Lyme (MS, systemic lupus, rheumatoid arthritis) are not associated with low CD57+ NK counts. The good news is that for most Lyme



*Slide of the NK Cell used in determining treatment success*

identifying markers, or CDs, expressed on their surfaces, but 200 or so have been recognized and named so far.

Each different marker (or CD) on a cell is named with a number, which signifies nothing more than the order in which the CD was discovered. On any given cell there are many different cluster designation markers (CDs), giving each cell its unique appearance and function but also linking certain cells by their similarities (like grouping all people with brown hair or all people with blue eyes). Cells that have a certain kind of CD present on their surface are denoted as + for that CD type (e.g., a cell with CD57 markers on its surface is CD57+).

NK cells have their own specific surface markers. The predominant marker is CD56. The percentage of CD56+ NK cells is often measured in patients with chronic diseases as a marker of immune status: the lower the CD56 level, the weaker the immune system. You may have heard Chronic Fatigue Syndrome patients talk about their CD56

patients the CD57+ NK level increases as treatment progresses and health is regained.

CD57 markers can also be expressed on other kinds of cells, including T-cells, so it is important to distinguish between CD57+ T-cells and CD57+ NK cells. Clinicians need to be aware that many testing laboratories claiming to perform the CD57 test are actually looking at CD57+ T-cells rather than CD57+ NK cells, which are the cells of interest in chronic Lyme disease.

In order for a testing laboratory to measure the CD57+ NK level, it first measures the percentage of lymphocytes that are CD57+ NK cells. Then an absolute count is calculated by multiplying that percentage by the patient's total lymphocyte count. The standard normal range for the absolute CD57 NK count is 60 to 360 cells per microliter of blood. This wide range was established based upon test results of hundreds of healthy patients. By these laboratory standards, a test result below 60 cells per microliter would be considered below

normal and therefore associated with chronic Lyme disease.

However, a recent study of my Austin, TX patients has led me to believe that 100 cells per microliter is a more reliable threshold separating Lyme patients and healthy controls. When Drs Stricker and Winger discovered that CD57+ NK cells are low in chronic Lyme patients and tend to increase with patients' clinical improvement, an opportunity arose for Lyme-literate practitioners to utilize a handy tool to aid in the diagnosis of chronic Lyme disease, to follow treatment progress, and to determine treatment endpoint. Just as AIDS patients have always held great store in their CD4 T-cell count, Lyme patients now have a fairly reliable marker of the status of their illness.

It is important to remember that the CD57 result is just a number; far more important is the patient's clinical status. An old professor of mine used to say, "treat the patient, not the lab test!" There is still much we do not know about the CD57 marker and what other factors may lower or raise it. However, overall, the CD57+ NK count is a useful tool in diagnosing and treating chronic Lyme disease in most patients. As a measure of immune status, it provides an indirect measure of bacterial load and severity of illness. Furthermore, in a patient who has a negative or indeterminate Lyme test but is highly suspect for the disease, the clinician may utilize the CD57+ NK count as one more piece in the complex puzzle of a Lyme disease diagnosis.

**Postscript:** If you would like your health care provider to order the CD57 NK test for you, your blood sample needs to be drawn into an EDTA tube (lavender top) on Monday through Thursday and sent immediately to either LabCorp in Burlington, NC, or Clinical Pathology Laboratories (CPL) in Austin, TX. LabCorp and CPL are the only two labs that perform this test properly. **Quest does NOT.** The LabCorp test code is #505026 and is named HNK1 (CD57) Panel. The CPL test code is #4886, CD57 for Lyme disease. The test is time-sensitive and must be performed within 12 hours of collection, so blood should not be drawn on a Friday or results may be inaccurate.

# National Patient Group Tells CDC Director Chronic Lyme Patients Can't Get Treated

*Lack of treating physicians, inadequate testing, and under diagnosis are leading to more Chronic Lyme Disease with surveillance problems contributing to lack of focus & funding*

## Lyme Disease Association-JACKSON, New Jersey

Lyme patients have fought for years to have their public voice heard by the Centers for Disease Control and Prevention, CDC. They finally got their opportunity when the Lyme Disease Association, a national non-profit consisting of patients and families of patients, met with the nation's leading public health officer, CDC Director, Dr. Julie Gerberding. She and other CDC officials listened as the Lyme Disease Association and four Congressmen addressed rising Lyme cases, chronic disease and causes, inability to get treatment, and lack of funding. The government only expends \$33M each year on Lyme disease despite about 220,000 new cases of Lyme disease nationally that meet CDC surveillance criteria. That does not even include cases, usually chronic, which fall outside that non-diagnostic criteria.

Dr. Brian Fallon from Columbia University College of Physicians and Surgeons presented long-term Lyme disease treatment studies and their significance, including his recently

president Pat Smith discussed the need for direct communication between patient groups and the CDC and between treating physicians and the CDC. Congressman Christopher Smith (no relation)



**Left to Right: Don Schriber (CDC), Tanja Popovich (CDC), Pat Smith (President of LDA), and Lorraine Johnson (President of California LDA) work on getting better treatment for Chronic Lyme. Photo used with permission by the Lyme Disease Association.**

completed NIH-funded chronic Lyme disease study showing improvement in patients. LDA

offered to host a forum for those issues in New Jersey.

Ms. Smith presented the

need for mandatory lab reporting in each state, uniform surveillance, and a dual CDC reporting system allowing for clinical cases to be accepted in a separate tier of reporting. She also recommended removing the ELISA as a screening test due to its insensitivity and allowing the Western Blot to be used alone for diagnosis, after re-adding two bands removed by CDC in the mid 90's. "New technology also needs to be looked at in the testing arena," Smith added, referring to a recently published CDC article on chronic diseases and the use of cutting edge technology to diagnose.

Researcher Dr. Steven Schutzer, New Jersey Medical School, who also attended, affirmed that need.

Ms. Smith asked the CDC to write every state health department informing them that the CDC criteria are not meant for diagnostic purposes, only for surveillance. Health departments can

**"CDC & LDA" cont'd pg 12**

## Special Moments...

by Barbara Gerami

## Raising a Child With Downs Syndrome

I would like to introduce to you, Joshua, my first foster child. He has Down Syndrome. He was 11 years old when he came to live with us 16 years ago. The definition of Down Syndrome is a syndrome that causes slowed growth, abnormal facial features, and mental retardation. Down Syndrome is caused by an extra copy of all or part of chromosome 21. The physical features are a flatter face, upward slanting of the eyes, and a larger tongue. Medical problems could consist of heart defects and mental retardation to different degrees. Back in the 60's and 70's it was suggested that kids with this disability should be put in state or private institutions. Most families complied and very few stood their ground and received their blessings.

Joshua's grandmother told me that he was not walking yet at the age of four. He would watch out the window and see his brothers playing and riding bikes. She told Joshua he could go out as soon as he walked. It was soon after that, that he walked. When I got him, he was just starting to ride a bike. He wanted to keep up

with my biological son, Isaac. They rode and played together. They were not only instant friends, but brothers. We soon introduced him to different things. We took him swimming quite often. The first few times he hung on to my neck and screamed. It took several tries before we actually got off the first step. Our next step was to use a life vest. Once he learned to control it, he really enjoyed swimming. Now he swims without a life vest.

Life has always been exciting and awesome with Joshua. Some people think because Joshua has a speech impediment that he is profoundly retarded. I can attest to it, that he is very smart. One time he had been asking permission to go to a friend's house. He was in

Junior High. I explained to him that I would have to meet this child's mother and then we could arrange a day they could get together. Well, this wasn't good enough for him. He was staying with my neighbor one day until I

returned home. I called to let them know we were home and to send Joshua home. After several minutes I realized that he hadn't arrived. Upon calling them

back we realized he had flown the coop. I had just called 911 when I received a call from some people that found him walking down the road. They brought him back home. It turns out he was determined to go to his friend's house. He was actually almost there. He had directions, address and phone

number in his pocket and also was able to tell the people his home phone number. I was not excited about this transgression, but in my book that's pretty smart.

Some people are very afraid of him, probably because he looks different. Joshua just had fun with this. We were standing in line at a six flags ride, when this teenager was looking very uncomfortable. As I was still contemplating how to fix this, Joshua got up real close to him and very quietly said, "Boo!" The teenager jumped back so fast that he started a small domino effect with the people in line. We fortunately do not see that too often anymore as the kids today are more aware and are surrounded with children with special needs.

Having a child with Down Syndrome is in fact hard in many ways. However, the blessings that you reap would, in my opinion, top everything. Not only have I had the honor to raise a child with Down Syndrome, I have worked in different settings with children that have Downs. They have always been very lovable. The degrees of



*Joshua Gerami gets face painted at a community block party sponsored by The Vine Fellowship in Arlington, Texas*

**... "Downs" cont'd on pg 11**

# FEATURES

## "Hannah" cont'd from pg 2



Hannah Brown a normal, healthy 6 year old who enjoys scrapbooking with her family. Faith in God for healing is a strong part of the Brown Family's Christian faith. another bowel movement for the next SIX weeks! We tried EVERYTHING! Around this time, our doctor was transferred out-of-state (one of the joys of military life) and we had to start all over with a new doctor who soon thought I was just a panicky mom. (Our previous doctor knew me well enough to know better!)

Finally, the doctor decided to humor me and sent us to a pediatric gastroenterologist. This doctor had a long waiting list and we finally had our first appointment with him when Hannah was 15 months old. She toddled around his office while we talked and he saw that she was a bright, happy baby and otherwise "normal"... until he took off her diaper and immediately saw the problem. The mystery that had eluded the other doctors for almost a year and a half was easy for him to identify. Without being graphic, suffice it to say that her "bathroom parts" were not situated far enough apart. This resulted in the path that her waste needed to travel being more curved than it should be. Therefore, even a normal consistency of B.M. created blockages for her. So, we were given meds that would give her very loose B.M.s until one of two things could happen... 1.) As she would grow, everything might grow into the correct positions or 2.) As she became old enough to teach how to compensate with body positioning and staying properly hydrated/eating more fiber she would be able to manage the problem with lifestyle adjustments. He did not mention the third option in MY heart... 3.) that God would heal her!

For the next 2 1/2 YEARS we had to watch EVERY bite that little girl ate... no dairy, no white flour, no white rice, etc. In Sunday school we would have to provide spelt pretzels, whole grain animal crackers and high fiber graham crackers so she could have what her classmates were having! She soon learned to say "No thank-you!" to cupcakes and other treats. She would become tearful with disappointment, but she

accepted it pretty graciously for a toddler!

All this time Hannah was growing very slowly and never had the rosy, chubby cheeks that many toddlers have. Her friendly hugs and warm spirit won many hearts and she had a whole following of prayer warriors on the case! By the time Hannah turned four, she could eat almost anything! She was growing like wild fire and had the pink glow of health you would expect on a child her age! We still occasionally struggle with her becoming constipated if she has a lot of junk foods in a short period of time (this happened LAST summer over the Fourth of July weekend... too many treats in a short period of time), but I think that could happen with ANY child.

I think all three of the factors happened that we had been hoping/praying for... she grew, she learned to compensate and God began to touch her body. But during those long 4 years, we held her when she cried in pain for hours on end, we wiped away the sad, little tears that accompanied having to pass on chocolate chip cookies or pizza, we begged doctors to believe us that this was not "in the range of normal", we read and learned all we could about natural foods, and we cried and prayed over this girl every single day!

I am thankful that there are many resources, such as this newspaper, that can give information, encouragement and more importantly... the precious gift of HOPE to other families who are struggling with chronic illnesses. But the greatest resource of all is prayer. God can carry you through the trial and He does desire to deliver us into full health (mentally, physically and spiritually). Though our "healing" may come in many different ways, and maybe NOT in the way we would prefer, I would urge others out there to NOT give up. Trust your instincts. Learn all you can. And place all of it into the competent hands of The Creator of Life and Health.

## "Bad Rap" cont'd from pg 1

increasing risk as the educational process in all areas focus more and more on cramming in new information in place of teaching, learning, and processing skills. Information without understanding is of little value. When Allan Steere reached his conclusions regarding the Connecticut clusters, they came from within his experience base, in spite of competing evidence. Was this result due to limited critical analysis skills, or did it evolve into a defense of ego? Whatever the case, the long struggle of Lyme patients will forever be affected by the delay and misguidance of legitimate science caused by his work and subsequent publication.

And finally, back to the literature search as the foundation of any research investigation, it is perhaps the most dreaded task of the budding student, but also the most important. It may sound cliché to advise starting a journey into an unknown assignment area at the beginning, but by saying 'beginning' I stress the need to find and understand the founding benchmark references related to the endeavor. That's how to avoid replicating work that's already been accomplished, and to make your work contribute by extending the state-of -the- science. The requirement is to spend a great deal of time examining every relevant source of information, from the beginning to the present. However, the process is not just procedural. For instance, we all have a tendency to believe everything that we read if it's in print. Being in print gives anything written an air of authority and unquestioned acceptance. If the author is an authority figure, the issue is compounded. That's why in reviewing literature one has to maintain a vigil to identify common threads of merit and beware of tangents that are concealed self-promotion.

Steere was handed the answer by Scimenti and even given the card catalog and the library's address. Had Steere been educated in how to learn and analyze? Did he know how to perform a legitimate literature review? By all appearances, based on the reported history of events, he worked only to substantiate his experience base and his discovery claim of "Lyme arthritis" which he thought to be a previously unrecognized clinical entity. He simply started with his answer and left Lyme, Connecticut with a stigma that will be present forever.

## Got Lyme??

## Join us!!

[www.dfwlyme.com](http://www.dfwlyme.com)

group contact:

donna@dfwlyme.com

**Monthly Support Group Meetings**  
**Every 3rd Saturday of the Month**  
**1:00-3:00**

**Our Next Meetings:**  
**Sat. Aug 19 & Sept. 16**

Baylor Regional Medical Center

at Grapevine  
1650 West College  
Grapevine, TX 76051  
(817) 481-1588

continuing education room

## "Co-Infections"

...cont'd from pg 6

months for my Bartonella to appear and almost 8 months for Babesia to finally appear, but they were there.

If you think you only have Borrelia, odds are you have not looked closely enough. If you think that you are unique and that co-infections are not present, think again. It might just be that this change in thinking leads to a significant step forward in your healing journey. If just one person reads this article and gets tested for co-infections, my purpose will have been served. If after all of this, you still don't think that co-infections are a part of your chronic ill-health, please go to the nearest corner store and purchase a lottery ticket. Your odds of winning the lottery are probably better than the odds of not having a co-infection.

**Disclaimer:** The information shared here is based on Scott's personal experience as a patient with Lyme disease and as someone infected with many of the co-infections discussed in this article. This information is not intended to be a replacement for sound medical advice from a licensed medical professional.

## "Reagan" ...cont'd from pg 3

For awhile, it was like a game with me - trying to think of something creative or witty as a response, and tailor it to the specific person. But after awhile, I noticed the questions stopped coming, except from the poor sack boys...and my husband.

I acknowledge that it must be rather difficult to be the spouse of a chronically ill person because quite frankly, we are a handful. We are high maintenance, and most of the time we are not a lot of fun to be around. Sure, I know many of you are reading this thinking you'd love to be my neighbor because I'm obviously so cool...but NO. Actually I would probably only interact with you when I needed something because, again, I'm high maintenance and not a lot of fun to be around because of all my melodramatic agony and stuff.

But my husband...he deserves some kind of "Spouse of a Sicko" award. Sometimes ... when I'm not taking out all of my misery on him....I think he's a saint. And I'm not just saying that because I know he'll read this column and feel all warm and fuzzy.

## "Dr. Jones"...Con't from Pg 1

biotics commonly offered will do little to help Chronic Lyme disease.

While the problem might have originally been due to differences within the scientific community, It has now undoubtedly been worsened by insurance companies and their powerful lobbies. The shorter the treatment recommendations are, the more likely that the insurance companies will wield their power to endorse them.

With little compelling evidence to engage in debate within the scientific community, those who would limit Lyme treatment to a couple of weeks have taken to charging Lyme doctors with medical misconduct before their state medical disciplinary boards. These charges could potentially lead to physicians losing their licenses.

Over the past 6 or 7 years there has been a rash of formal charges against these doctors in a number of states. Generally, complaints are not made by the patients. Most of these charges have been ultimately dismissed, but at the cost of hundreds of thousands of dollars in legal fees.

If you have ever wondered why it was so hard to find a doctor to treat you, it's largely because the message has been sent to doctors that if they treat Chronic Lyme disease, they can risk losing

I'm really not, because most of the time my husband never reads my long-winded written rantings; most likely because he gets to hear it all the time - why should he make the effort to read? I am honestly saying it because I am grateful that I married someone that truly knows what it means to be committed through sickness and health. Some people aren't that fortunate. So I count him as one of my biggest blessings.

My husband, bless his heart, still asks me how I'm doing at least once a day. And for the most part I'm honest with him and my answers range from "Actually I'm feeling a bit better today" to "I think someone sedated me" to the very succinct: "I've put on my clean ambulance undies, the phone is in my hand and my finger is on the 9."

There was a time period when I was so irritated by the question that I told him that if he really wanted to know, I would just give him a number and that would indicate where I was on the pain and misery scale. Then, of course, he'd know just how far away to stay from me.

The reason I went through that time period where all I was willing to do was utter a pain scale number is because I felt so depressed that I wasn't pleasing all the people in my life by getting better. I think there's this under-current of peer pressure, if you will, that you are expected to 'snap out of it' and get back to health in a timely fashion. Some friends and family initially show concern when the sickness first devastates you - but then their interest in your drama soon fades after they are reassured you are not going to drop dead -- because let's face it - life marches on and your story is boring to them, no matter how fascinating you find it. Besides - they've given you their best advice, they've prayed for you, given you a self-help book to read; therefore, any remaining illness is no doubt evidence of some shortcoming on your part.

So you ask me how I'm doing? I'm apparently plum FULL of shortcomings.

How am I? I'm holding steady at a 7.5. Send casseroles. So how YOU doing?

[www.DefendLymeDoctors.com](http://www.DefendLymeDoctors.com)

their medical licenses.

We need to stand by those doctors who have risked their licenses to stand by us, particularly to Dr. Jones who has truly dedicat-



ed his life to children stricken with Chronic Lyme disease.

September is just around the corner. Dr. Jones' medical hearings will resume. This really is an urgent plea for the Lyme and Chronically Ill community to rally together financially to support this doctor who has treated so many of our children.

The information to make donations will be repeated in the cut out box to the right. Thank you for your support of Dr. Jones.

## Public Health Alert

**The PHA is in need of advertising sales reps.**

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Email Dawn Irons at [editor@publichealthalert.org](mailto:editor@publichealthalert.org) and attach resume.

**No Phone Calls Please**

## "Downs" ... cont'd from pg 9

mental retardation vary from mild to extreme. Some can speak better than others. Some are more capable of going higher in school. In my opinion, Joshua is very smart, hard to understand, but very smart. The school officials said he was unteachable. I asked them to teach him sign language, so they signed to him. When he could not sign back they said they could not teach him.

Three days a week I went up to the school and taught 4 young men from Special Ed. to read. We could not understand Joshua, but he learned to sign the words. He was reading at a first grade level. Although he is presently 27 yrs. old, I home-school him with my other children. He loves and thrives on school work. He also looks forward to participating in sports with teenagers. We do not treat him like a baby. However, we also do not treat him like a 27 yr. old, but rather like a teenager or young man. Having a child with Down Syndrome is a complete joy and blessing, and I would not mind having more of these little blessings.

**Editor's Note:** There was a typo made by the editor in Barbara's article last issue. I typed "hydrocephaly is an enlarged heart due to fluid on the brain" when Barbara actually wrote, "Hydrocephaly is an enlarged head due to fluid on the brain.". Any error was that of the editor and not made by the author.

**Help Support  
Dr. Charles Ray  
Jones  
Legal Defense Fund**

**to donate  
via credit card go to:  
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Jones Legal Defense  
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**Mail in care of:  
George Heath, III  
(CPA)  
26 Fairlawn Drive  
Wallingford, CT 06492**

**Note "gift" in the  
memo field.**

**DON'T DELAY  
DO IT TODAY!**

**THANK YOU!!!**

# NATION WIDE SUPPORT GROUPS

**National Multiple Sclerosis Association:**  
[www.nmss.org](http://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](http://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](mailto:info@msconnection.org)  
<http://www.msconnection.org>

**Colorado**  
700 Broadway, Suite 808  
Denver, CO 80203-3442  
Phone: 303.831.0700  
1.800.FIGHT.MS  
[www.nationalmssociety.org/coc/home/](http://www.nationalmssociety.org/coc/home/)

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

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

**Texas**  
8111 N. Stadium Drive,  
Suite 100  
Houston , TX 77054  
Phone: 713-526-8967  
[www.nationalmssociety.org/txh](http://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](mailto:alsassoc@alsphiladelphia.org)

**South Texas Chapter**  
<http://www.alsa-south-tx.org/>  
(210) 733-5204  
toll free at (877) 257-4673

**North Texas**  
<http://walk.alsanorthtexas.org/site/PageServer>

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[s.melson@alsanorthtexas.org](mailto:s.melson@alsanorthtexas.org)  
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877-714-0088

## The ALS Association Upstate New York Chapter

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Elbridge, NY 13060  
315-689-3380  
Toll Free for PALS:  
1-866-499-PALS  
[info@alsauupstateny.org](mailto:info@alsauupstateny.org)

**National Lyme Disease  
Association**  
[lymediseaseassociation.org/](http://lymediseaseassociation.org/)  
Pat Smith 888.366.6611

**Arizona**  
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physician referral and info:  
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928-779-2759

Southern Arizona - Donna Hoch:  
[nanandbo@cox.net](mailto:nanandbo@cox.net) 520-393-1452  
L.E.A.P.  
Tina J. Garcia  
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Lyme Education Awareness  
Program  
<http://www.leaparizona.com>  
480-219-6869 Phone

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**California**  
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Fax: (559) 570-0500  
[Membership@Calda.org](mailto:Membership@Calda.org)

**Colorado**  
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303-447-1602  
[milehighstick@yahoo.com](mailto:milehighstick@yahoo.com)

## Lyme Disease Support Groups cont'd

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[jschm47974@aol.com](mailto:jschm47974@aol.com)

**Arkansas**  
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[abeer@artelco.com](mailto:abeer@artelco.com)

**Kansas**  
913-438-LYME  
[Lymefight@aol.com](mailto:Lymefight@aol.com)

**Montana**  
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**Nevada**  
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[reeen@earthlink.net](mailto:reeen@earthlink.net)

**New Mexico**  
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**Oklahoma**  
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[Janet@LDSG.org](mailto:Janet@LDSG.org)  
[www.LDSG.org](http://www.LDSG.org)

**Texas**  
**Dallas/Ft Worth**  
[www.dfwlyme.com](http://www.dfwlyme.com)  
[donna@dfwlyme.com](mailto:donna@dfwlyme.com)  
817-455-8520

**Houston**  
Contact: Teresa Lucher  
[lucher@sbcglobal.net](mailto:lucher@sbcglobal.net)

**Washington State**  
Alexis Benkowski  
[WA-Lyme-owner@yahoogroups.com](mailto:WA-Lyme-owner@yahoogroups.com)

## "LDA & CDC" cont'd from pg 9

then notify physicians in their states. "Too many people," she said, "are being refused diagnosis, treatment, and insurance reimbursement based on surveillance criteria. This is leading to a huge increase in chronic disease, costing people their health, homes, jobs, education, and childhood." LDA presented a comprehensive notebook including statements from dozens of Lyme patients attesting to their diagnostic and treatment problems often related to CDC surveillance criteria.

Lorraine Johnson, JD, MBA, Executive Director of CALDA and Member of the LDA Professional Advisory Board, spoke about peer review and guideline issues. Her main thrust

was explaining how unsettled science and two sets of treatment guidelines have led to two standards of care, and all physicians need to be aware that there is a standard which allows for long-term treatment of chronic patients. "What we would like to see is for the CDC to treat Lyme disease the same way it treats prostate cancer—providing patients with information regarding treatment options until the science is more settled," she said.

The LDA-initiated meeting was hosted by Congressman Christopher Smith (R-NJ). Other US Representatives who personally attended were Congressman Tim Bishop (D-NY), Congresswoman Sue Kelly (R-

NY) and Congressman Wayne Gilchrest (R-MD). Each spoke about rising Lyme disease cases in his/her state and personal experiences through family and friends with the disease. Staff from the offices of Senator Christopher Dodd (D-CT) and Senator Chuck Schumer (D-NY) also attended the meeting.

Dr. Gerberding agreed that tick-borne diseases are very complicated diseases that are poorly understood. There is a lack of awareness and early primary care is critical. Her concern that there is little government funding for tick-borne diseases dovetails with the purpose of the bills currently in Congress, HR 3427 (Smith-Kelly) and S 1479 (Dodd-Santorum)

which will provide \$100 million for Lyme disease research, prevention, physician education, and surveillance issues. 73 congressmen currently co-sponsor the House version and over 100 Lyme groups support it.

In closing, the LDA mentioned the unchecked spread of the deer tick populations nationwide over the past 20 years and how we need to learn from history and try to stop the spread of the more aggressive lone star tick now invading the Northeast.

The CDC is now reviewing the recommendations made by the Lyme Disease Association.