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Lyme Disease 2nd Only to AIDS as Top Infectious Disease in USA

by Dawn Irons

What does it mean when the best trained doctors in the country concerning the diagnosis and treatment of Lyme Disease converge on a Texas metropolitan area? It means TEXAS, we have a problem.

Lyme Disease was once thought to be primarily an east coast disease, but it has now been reported in every state of the union. Typically known for being a tick-borne illness, researchers have also shown that Lyme Disease can also be transmitted through mosquitoes, biting flies, fleas and mites.

The American College of Advancement in Medicine (ACAM) recently held its annual conference in Dallas this year. Their area of special interest was Lyme Disease. Physicians from all over the USA came to the ACAM conference in Dallas to get more training and education on the diagnosis and treatment of this debilitating disease.



ACAM President Dr. Kenneth Bock and conference presenters: Dr. Raphael Stricter, Dr. Joseph Burrascano, Dr. Ritchie Shoemaker, and Dr. Daniel Kinderlehrer answer questions from doctors all across the country at the ACAM Conference held in Dallas in May.7

Renowned physicians such as Dr. Joseph Burrascano of New York, Dr. Raphael Stricter of California, Dr. Ritchie Shoemaker of Maryland spoke to many issues surrounding Lyme Disease such as

the problems of the current testing methods which have an almost 50% inaccuracy rate causing the tremendous under-reporting of the disease. Other issues included

"Lyme" Continued on page 11

Glamour Magazine Challenged to a Debate on Abortion-Cancer Link

by Karen Malec, CABC Press

The Coalition on Abortion and Breast Cancer challenges Glamour Magazine's experts to a debate on the abortion-breast cancer (ABC) link. Glamour has attempted to erase the link from the public mind twice in less than a year. [1,2]

Why doesn't Glamour want women to know that:

- 1) Experts agree on one risk of abortion - that childbearing matures breast tissue into cancer-resistant tissue, but abortion deprives women of this opportunity; therefore, the woman who aborts has a higher risk than the woman who has a baby; [3]
- 2) Experts debate whether abortion leaves women with an increase in cancer vulnerable breast tissue (the independent link);
- 3) Eight medical groups recognize an independent link between abor-

tion and cancer; [4]

4) The World Health Organization labeled combined oral contraceptives (estrogen plus progestogen) and combined hormone replacement therapy as "Group 1" carcinogens - findings that support an independent ABC link. [5]

5) Sixty significant studies link abortion with premature birth in later pregnancies; premature birth before 32 weeks gestation raises the risk of breast cancer for the mother and cerebral palsy for prematurely born children; [6]

"Follow the money," said Karen Malec, president of the coalition. "Glamour uses sex to sell its product. What's most appalling about these widespread efforts to propagandize the public is the stone-cold disregard for women's health.

"Women shouldn't be deceived by those who stand to profit from legalized abortion," continued Malec. "Consider what the tobacco industry did to protect its bottom line. Fearing massive

product liability lawsuits, its lawyers marshalled a stable of journalists, doctors and scientists who represented smoking as 'safe' and glamorous, especially for the 'liberated' woman." [7]

There has never been a debate on the ABC link because our opponents know they would lose. Breast cancer surgeon Angela Lanfranchi, MD wrote, "The normal discourse in medicine when there is controversy on a scientific issue is to present arguments for both sides in texts and debate at scientific meetings. There has not been normal discourse concerning the ABC link." [8]

The Coalition on Abortion/Breast Cancer is an international women's organization founded to protect the health and save the lives of women by educating and providing information on abortion as a risk factor for breast cancer.

For Further Review of the resources for this article see reference box on page 8.

...And You Thought Politics & Religion Was Bad!



Why do you suppose in this day and age of modern medicine and technology that a doctor would be threatened with his or her medical license for treating a disease that is somewhat controversial and highly political? Since when did controversy and politics define and mold the Hypocratic Oath: *First, do no harm.*

Lyme disease is a dire medical situation in this country that has become the political hot potato no one wants to touch. Dr. Nick Harris, president of IgeneX labs, a tick-borne pathogen laboratory in Palo Alto, California says that Lyme disease is the fastest growing infectious disease in the United States, second only to AIDS.

Lyme disease has been reported in all 50 states. It is not a “regional disease” isolated on the East Coast. It is a nation wide problem.

The Center for Disease Control and Prevention (CDC) believes that Lyme disease may be as high as 20 times more than the actual reported cases bringing the

problem to pandemic proportions. Part of the reporting problems with Lyme disease is that many doctors do not realize that cases of Lyme must be reported. A more troubling problem with the reporting of the disease is that the laboratory tests available to test for Lyme are highly inaccurate. For a blood test to be considered for screening purposes it must have a 95% sensitivity for accurately diagnosing the disease.

The tests currently available for Lyme screening only have about a 50% sensitivity level. This problem is compounded by the very narrow reporting criteria set by the CDC.

All of these problems, when mixed together, create a disastrous recipe for a major public health crisis in the US.

Knowing that we have a ticking time bomb on our hands, you would think physicians would be able to freely diagnose and treat this disease, which if not diagnosed very early has the potential to become a life threatening illness. Lyme, in its chronic form, goes systemic in the body affecting major organs and causing severe neurological damage.

So why would our doctors

be penalized for treating such an illness?

The answer is pure politics! There are two camps of people involved in the Lyme debate. The academic researchers make up the first camp. They study and theorize. The second camp is doctors that work hands-on, day in and day out, with Lyme patients. They know from first hand experience what is working and what is not. They are in the trenches, so to speak. This political controversy would be equivalent to a White House librarian telling a General in the combat field how to do his job.

The best we can hope for at this point, without legislative relief and protection, is to hope that doctors will not be persecuted for allowing a patient to make an informed consent on treatment options. There are *two standards of care*. A patient should have the right to choose which standard of care they want to follow, and insurance companies should pay for the standard of care the patient and doctor choose.

Dawn Irons, Lyme Disease patient and Editor of TPHA 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.

Letter to the Editor

Dear Editor,

I wanted to share how has Lupus (SLE) has affected my life. It has made me angry and lonely. It keeps me from participating in life to the fullest. Going shopping is an endurance test, a test in pain tolerance. It keeps me from enjoying nature as often as I would like to because sun exposure causes itching and blotchiness. I avoid contact with people quite often because I am afraid that people will think that I have been drinking because my face gets so red.

Fatigue is a big issue with Lupus (SLE). It keeps me from getting a good night's sleep, even though I am perpetually exhausted. It prevents me from exercising to the degree that I should, therefore preventing me from dealing with other health issues, as well as leading to new health issues.

Because it manifests itself through all major body systems, I don't know if certain problems that are going on are part of the Lupus (SLE), or if they are something else that needs attention.

Depression is part of the SLE package, but some doctors only seem to want to address that part of the illness and throw anti-

depressants at the disease rather than deal with the core issue. This just leads to more depression because it is evident that they think I am "nuts, or that it's all "just in your head", and it doesn't help me to effectively deal with the real health issues at hand.

I took their little anti-depressant ride at the insistence of my doctors and it was the worst year of my life. I was feeling bad enough to start with, but I came near to killing myself once I was labeled as depressed and started those anti-depressants. Were the other health issues gone because I took their "happy pills"? No, if anything they got worse.

As a result of this neglect, ignorance and indifference on the part of medical professionals, I do not trust doctors and am trying to deal with this without the medical community. Prayer is a big part of my life and, without my Heavenly Father and my husband, I would have given up a long time ago. It is important to have faith that, no matter what, Heavenly Father is in control. He WILL heal me someday. It is my hope that someday soon doctors will learn that not everything is in a woman's head and that

depression does not rule out other health issues - sometimes depression is not the cause or source of an illness, but rather BECAUSE of other health issues.

It is my hope that everyone dealing with SLE and other chronic illnesses will have a powerful support team that is willing to go to bat for them whenever they aren't able to do it for themselves.

It is my hope that there are natural ways, or better ways, to treat SLE, where current treatment often leads to liver damage and other problems along the way. It is my hope that a cure will be found for all of these things so that future generations won't have to suffer with chronic illnesses all in the name of progress.

I am glad that there is now a newspaper to address the concerns of the chronically ill community.

In Christ, Suzanne McClendon
South Texas

Editor: Thank your for sharing your story. You are not alone. Dealing with difficult medical issues is hard on doctors and patients. Depression is a very real part of chronic illness. It is certainly not “all in your head”. Try to find a good Lupus support group in your area. Best wishes!

Texas Public Health Alert

The TPHA is committed to researching and investigating Lyme Disease and other chronic illnesses in the DFW metroplex and through out the state of Texas. We have joined our forces and informational research resources with local and statewide 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.

TPHA 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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Donations:
If you would like to make a donation to TPHA you may do so through Paypal. Please send the donations to the following address:

donations@texaspublichealthalert.org

or you may mail your donation to:
Texas Public Health Alert
821 Sansome Drive
Arlington TX 76018

TPHA is a free monthly publication. We function on the sale of advertising space and donations from the public. We are currently starting our distribution in the DFW Metroplex although our long range plans include statewide distribution as we further network with chronic illness support groups across Texas.

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

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

Letters to the Editor

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

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

Study Links Cigarette Smoking with Progression of Multiple Sclerosis

First Modifiable Risk Factor for Disease Advancement Identified

Boston, MA – Researchers from the Harvard School of Public Health (HSPH) recently discovered that cigarette smoking may contribute to the progression of multiple sclerosis (MS), suggesting that quitting smoking could limit or delay central nervous system deterioration. This is the first time that a modifiable risk factor for MS progression has been identified, providing a new strategy for patients hoping to control neurological damage from the disease. Study results appear in the March 9, 2005 issue of *Brain*.

Miguel Hernán, lead author of the study and an assistant professor of epidemiology at HSPH, noted that “the findings are interesting because no modifiable risk factors for the progression of MS are known. This was the first prospective study that identified a potential intervention (quitting smoking) for reducing the risk of progression of MS.”

Analyzing over 2,000 medical

records in the General Practice Research Database (GPRD), researchers identified 179 British patients who were originally diagnosed with relapsing-remitting MS, a form of the disease in which symptoms fade and recur in unpredictable patterns. Patients who were current or past smokers were 3.6 times as likely as patients who had never smoked to develop secondary progressive MS, a later stage of the disease marked by steady deterioration of the central nervous system. This disease progression also occurred more quickly in patients who were identified as current or past smokers. The study also supported earlier research showing that smoking may increase the risk of initial MS diagnosis. Current and past smokers



were 30% more likely to be diagnosed with MS than those who had never smoked.

While more research is needed to understand the mechanisms behind these findings, Hernán and his colleagues speculate that nitrous oxide, a chemical present in cigarette smoke, may play a role in hastening the degeneration of nerve fibers. Alternatively, chemicals in cigarette smoke could damage the cells that create myelin, a protective coating for neurons, or may predispose smokers to autoimmune responses.

According to Hernán, “Our findings raise a number of other questions that future research needs to address. Does a dose-response relation between cumulative exposure to tobacco and risk exist?

How long does the tobacco effect last? Is second-hand smoking associated with an increased risk as well?”

The research was funded by a grant from the National Multiple Sclerosis Society.

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Can be contacted at:
<http://www.nmss.org/>

Reagan's Ramblings Rants & Raves

by Donna Reagan

Is There a Doctor in the House?

Gosh, I sure miss the good ol' days when it was quite commonplace for doctors to actually come TO the sick - instead of the ridiculous requirement that we have today. Granted, I'm much too young to have experienced such a wonderful phenomenon, but I watch movies. I know what I'm missing.

These days, the only time you really hear someone ask, "Is there a doctor in the house?" is during some TV show or movie when a character is choking on something bizarre like an engagement ring, Jello, or a chicken leg; and frantic restaurant patrons want someone that knows the Heimlich maneuver.

Speaking of choking on chicken legs...once when I was younger, braver, and probably more stupid, I had to save my Dalmation that started choking on a chicken leg. Naturally I did not know how to Heimlich a dog - so I had to shove my hand in his mouth & my fingers down his throat to retrieve the bone. It was scary and gross; but I was a dog hero. (And that my friends, is what we call a

little rabbit trail even though I was talking about my dog.)

But back to the subject of doctors.... I think it's ridiculous that sick people, namely me, must drag their bodies out of their bed, and drive TO the physician that has vowed to "First do no harm". I think this practice is highly ironic because I feel rather harmed when I have to shower, dress appropriately, and then drive my weary, chronically sick body & highly distracted mind which is trying to block out various pain signals so that I can appear at a professional office building where I will wait - in PUBLIC - for an unknown amount of time before getting my few allotted minutes of medical attention. I find this practice to be so absurd because many times I feel more like I should be alerting the undertaker instead. Undertakers make house calls...yes?

I personally think the American medical system started soaring downhill when it seems the focus switched from a quality of care to a quantity of care. I suspect one of the main reasons

why doctors needed to increase the number of patients served daily is most likely a complicated equation consisting of financial factors, because let's face it - money seems to be the root cause to many of the world's problems.

Logically, I DO understand the financial needs and various pressures being put upon our medical professionals; I DO understand that it is not 'cost efficient' for physicians to make house calls. Emotionally, however, I do NOT understand it. It seems like our health care system is backwards as to how it should be. Yes, I think I could solve many of the world's problems and most certainly help out with health care reform - if only I was healthy and had the energy...and more intelligence. Yes, I could solve many problems with health, energy, and intelligence.

Alas, the doctor that makes house calls is now a distant memory, and the more common question is: Is there a doctor in my network?

This is a rather stupid question because OF COURSE there

are MANY doctors "in network", otherwise it couldn't be called a network. The more appropriate question is: "Is there a doctor in my network...that knows diddly squat?"

Do those 'in network' doctors make it their top priority to serve ALL of my medical needs ...or to serve their bottom line? Do they work for ME...or the health insurance company that wants to ignore or deny payment on any condition that requires expensive treatment?

I was once told by a physician that most doctors could only spend an average of 8 minutes per patient in order to treat the quantity of patients needed to come out ahead at the end of the day. Doctors are generally good in math & they realize they have to pay their bills. From that perspective it is certainly understandable that doctors don't have the time to sit & hold the hands of those in need of their sharp diagnostic skills in order to gain an accurate diagnosis, treatment plan, or perhaps even a cure.

"Doctor" cont'd pg11

Political “Lyme Wars” Have Come to Texas

by Dr. J. David Kocurek
AUSTIN/FT.WORTH, Texas --

Lyme patients in Texas are now threatened with the ultimate insult to their care and well being: it's no longer safe for Lyme-literate medical professionals to openly treat Lyme and related tick-borne diseases in the state.

The "Lyme Wars" that are so bitterly fought in other states, at a patient's expense, are well entrenched here in Texas and the battle line was drawn by the state agency whose "mission is to protect and enhance the public's health, safety and welfare."

Recently this fact was driven home when the only Central Texas Lyme-literate medical professional, Nurse Practitioner Ginger Savely, was forced to close her Austin practice on March 31. Her decision was the direct result of a phone call to her supervising physician from the Texas Medical Board's (TMB) Executive Director, Dr. Donald Patrick, advising him that continuing to practice with her would put his medical license at risk. Savely is recognized as a Lyme disease expert among her peer clinicians across the nation.

This disturbing tactic by Patrick and its result was brought to light in the Austin-American Statesman, March 30, article "Lyme patients say they're losing

the one who will treat them" (<http://www.statesman.com/news/content/news/stories/local/03/30LYME.html>)

Texas patients have enjoyed a sense of complacency due to a perceived sense of safety resulting from the productive senate hearings held in 2000. The hearings were conducted under the 77th Legislature by the Senate Committee on Administration, chaired by Senator Chris Harris. The Committee proceedings included stern questioning of the TMB, then known as the Texas State Board of Medical Examiners. However, the forces that drive medical politics in defining parochial standards of care are once again dictating outmoded protocols with known high failure rates.

Suzanne Shaps of Austin and David Kocurek of the Ft. Worth area have co-founded the organization *Stand Up For Lyme* in an attempt to establish a focal point for coordinating a communi-



ty response and combating this now established anti-Lyme agenda in Texas. This is a small, focused group of Texas patients working to promote Lyme disease awareness and education to other patients, the public, medical professionals, and to act as a resource for Texas legislators and agencies.

Since its inception in February, *Stand Up For Lyme* has been working behind the scenes establishing relationships and communicating with patients, practitioners, legislators, state agencies and medical associations. The central goal is to make Texas a state in which Lyme-literate medical practitioners can treat patients to the highest effective standards without fear of jeopardizing their medical licenses.

Stand Up For Lyme is now working on a project in which they are gathering statistical informa-

tion from the Lyme community. If you are a Lyme patient or caregiver, *Stand Up For Lyme* needs your input. You are invited to participate by filling out a questionnaire. To find out how you can participate go to www.lymenet.org. Go to the "flash discussion" button on the left, then click on the "medical questions" forum. From there, click on the "Texas" thread. You can also follow this link directly: http://flash.lymenet.org/ubb/ultimatebb.php?ubb=get_topic;f=1;t=041440

All information provided in the questionnaire will be held in the strictest of confidence. This information is important in preparing summary information for presentation to policy makers. The data already confirms that the large majority of patients must travel out of state for proper care. *Stand Up For Lyme* knows too well what becomes of those who, for lack of mobility or financial resources, are left to struggle with the state's dwindling Lyme-literate resources. Texas has a long-standing reputation for achieving leadership status with its vast medical resources. It's well past time for Texas to become a leader in Lyme-literate care.

For more information:
www.standupforlyme.org
will be available for more complete information and up to date news.



AMERICAN ASSOCIATION FOR HEALTH FREEDOM

FORMERLY THE AMERICAN PREVENTIVE MEDICAL ASSOCIATION

Need For Access to Medical Treatment Act

by Lt. Col. (Ret.) Robert A. Beiswenger, AAHF Board Member

Do you believe there is a need for an "Access to Medical Treatment Act (AMTA)"?

My guess is that the majority of Americans do not believe so or at best are neutral. However, if you or a loved one has been faced with a serious illness, then you will be one of those who already understands the need for an Access to Medical Treatment Act (S. 2618/HR 2792).

A few years ago, a few months after our country was violently attacked on 9/11, I discovered that free access to medical

treatment, a basic human right, did not fully exist in a land founded on principles of freedom. Living outside of Philadelphia, near Independence Hall and the Liberty Bell, not far from the Statue of Liberty and so close to our nation's Capitol, this was a particularly hard pill for me to swallow.

I am a retired Lieutenant Colonel in the Air Force Reserve, and I began my military service in 1972 when I entered pilot training. After graduating from pilot training a year later, I was involved with the final years of the conflict in Vietnam, flying KC-135 (air refuelers) that brought back our fighters as the war came to a close. After that I served during the Cold

War years, followed by operations into Grenada and Panama. I was then activated for a year to fly in Desert Storm and have been a full-time reservist up to the present day and the War on Terror.

These conflicts all involved the protection of freedom in some form - either for Americans or for others in the global community.

I am not, nor have I ever been, of an "activist" mentality, preferring to believe that things are well and, if not, there are people such as members of Congress and lobbyists working to improve matters. Fighting for "medical rights" is probably the LAST thing I ever thought I would be doing -- but here I am.

Why? What events in my life led me to believe that there was a need for AMTA?

A few months after planes struck the World Trade Center towers and the Pentagon, more personal planes struck my life. One struck the tower of health: My wife was diagnosed with an advanced, Stage III, ovarian cancer. Five-year survival rates were a meager 20 to 40 percent. This disease, cancer, was the first plane that slammed into my life, working to destroy my wife's health and separate us forever.

Knowing the poor outcome offered by standard medical treatment that involved chemotherapy,

“Medical Treatment” cont’d pg 12

Scientist Discover a Solid Link Between Childhood Vaccinations and Autism

CHILDREN 27-TIMES MORE LIKELY TO DEVELOP AUTISM WITH EXPOSURE TO MERCURY CONTAINING VACCINES, FINDINGS REVIEWED AT MEETING IN DC

Washington, DC- In February 2006, the Institute of Medicine held a one-day meeting to review important new research on the link between thimerosal, a mercury-based preservative in vaccines, and neurodevelopmental disorders such as autism. One of the larger studies under review comes from the CDC's own Vaccine Safety Datalink. Under independent investigation, CDC's data concludes children are 27-times more likely to develop autism after exposure to three

thimerosal-containing vaccines (TCVs), than those who receive thimerosal-free versions.

The findings were not only disturbing to government officials like U.S. Rep. Dave Weldon, M.D. (R-FL), who spoke before the IOM panel, they suggest autism via TCVs has a higher relative risk than that between lung cancer and smoking, which according to the American Cancer Society is only 22 for men and 11 for women.

"This absolutely confirms what parents have been saying for

years," says Jo Pike, President of the National Autism Association. Like Pike, thousands of parents have reported sharp regressions in their children following a TCV and many of those children have gone on to receive a diagnosis of autism.

Dr. Mark Geier is the lead investigator in the discovery. A medical doctor with a Ph.D. in genetics, he, along with fellow researcher, David Geier, discussed their findings of the CDC data in front of an IOM panel. Among a

host of other physicians and researchers that presented was Dr. Jeff Bradstreet. He discussed the results from his peer-reviewed study which concluded that urinary mercury concentrations were six times higher in children with autism vs. normal- age/vaccine-matched controls.

For information about the National Autism Association, go to <http://www.nationalautism.org/>.

Baylor Research Institute Receives \$2.9 Million to Study Lupus

DALLAS /PRNewswire/ -- Baylor Research Institute (BRI) was recently awarded two new grants to study systemic lupus erythematosus, commonly known as lupus or SLE. The new funding from the National Institute of Allergies and Infectious Diseases (NIAID) and Alliance for Lupus Research, which totals more than \$2.9 million, will allow BRI scientists to expand their research of the disease.

Affecting more than one million people in the U.S., lupus is an autoimmune disease that occurs when a person's body is attacked by his/her own immune system, which leads to damage of healthy tissues and cells. It occurs predominantly in women (who make up around 90% of lupus patients) with a higher incidence in women of Hispanic, African, Asian and Native American descent.

Baylor Institute for Immunology Research, a component of BRI, has made significant advancements in the understanding of lupus. "A major finding was determining that increased levels of a regulatory immune system protein, interferon alpha, play a central role in lupus. An overabundance of interferon alpha is responsible for many of the changes in gene expression levels that correlate with lupus symp-

toms," said Jacques Banchereau, Ph.D., Director of Baylor Institute for Immunology Research. "A collaboration between BRI and Argos Therapeutics led to the development of antibodies against interferon alpha. Reducing the serum level of interferon alpha with an antibody could provide a successful treatment strategy for lupus patients."

Dr. Banchereau received a \$1.9 million grant from the NIAID, a component of the National Institutes of Health, to study groups of immune system cells, called T cells, to see how they differ in lupus patients and healthy individuals. Dr. Banchereau's group also will determine how these T cell populations fluctuate between times when lupus patients experience remissions and when they suffer from flares (times of intense symptoms). These findings may allow certain types of T cells to be used as early predictors for disease activity. It could also lead to new treatment options that target these T cells.

Virginia Pascual, M.D., an investigator at Baylor Institute for Immunology Research, is supported by a \$1 million research award from the Alliance for Lupus Research (ALR; <http://www.lupus-research.org/>). The ALR is a national voluntary health organization whose mission is to support

medical research into the cause, cure, treatment and prevention of SLE and its complications.

Dr. Pascual's new funding follows a previous ALR award, which allowed her group to develop a new test to monitor disease severity that is based on various markers of lupus activity.

The goal of Dr. Pascual's project, a multi-center effort that teams lupus clinicians from around the country as well as Canada and Puerto Rico, is to validate the disease 'signatures' that they have identified in the blood of lupus patients. These signatures represent altered gene expression patterns that differentiate lupus patients from healthy individuals.

Dr. Pascual's group has shown that these signatures can be used to predict disease flares and the development of serious complications. They also plan to develop a simple, inexpensive test that can be used to assess disease severity in lupus patients. This information could help doctors decide when to treat patients more aggressively to avoid such complications.

Dallas-based Baylor Institute for Immunology Research is the immunology research component of BRI, an affiliate of Baylor Health Care System. Opened in 1996, Baylor Institute

for Immunology Research brings laboratory scientists and clinicians together in an effort to increase understanding of how the immune system works. The institute is devoted to translating basic laboratory discoveries made about the immune system into effective treatments for patients. This interdisciplinary program focuses on developing new therapies to treat conditions that involve the immune system, such as autoimmune diseases, cancer, infectious diseases and organ transplants.

SYMPTOMS OF LUPUS:

Symptoms of lupus can include a facial rash on the nose and cheeks, sensitivity to sunlight, swollen joints, inflammation around the heart and lungs, kidney damage, anemia, seizures and a weakened immune system.

The severity of the symptoms often fluctuates between periods of less intense activity and times when they are much worse. These flares are unpredictable and there are no current laboratory tests to predict them.

Baylor Research Institute Related links:

<http://www.lupusresearch.org/>
<http://www.baylorhealth.com/>
<http://www.baylorhealth.edu/>

Help Wanted:Advertising Sales Reps

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Update on the Mysterious Disease Known as Morgellons

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

Itching, biting, stinging and crawling sensations with open sores and unusual objects oozing out of your skin. Sounds like a nightmare, doesn't it? Or an episode of X-Files?

This is not the fantasy plot of a television show that focuses on the bizarre and other-worldly. It is the living nightmare of thousands of people across the United States suffering from an illness known as Morgellons disease.

California, Texas and Florida are, in descending order, the states where clusters of the disease are reported most frequently. Most other states and several other countries also have victims who have registered their cases on www.morgellons.org, the web site of the not-for-profit Morgellons Research Foundation. Of interest to nurses is that their profession represents one of the highest percentage of reported sufferers.

An "orphan" disease, without a known cause, diagnostic test or cure, Morgellons disease is not recognized by the state health departments or the Centers for Disease Control and Prevention (CDC), although reports of patients with the symptoms go back over 300 years. The diagnosis, at this point, is based upon a patient fitting the symptom criteria.

There are a few dozen symptoms that all or most sufferers share in common. These include, but are not limited to, profound fatigue, anxiety, insomnia, joint and muscle pain, hair loss, cognitive disturbances (such as loss of short term memory, inability to concentrate or comprehend), disfiguring lesions, blue, white, red and black fibers poking up through the skin, black specks and "fuzz balls" on the clothes and skin, objects racing across the eyes, and hyper-pigmented scars when the lesions heal. Worst of all is the constant and unnerving aggravation of feeling as though there are bugs or worms crawling through one's body, biting, stinging and causing insupportable itching and discomfort.

As a nurse practitioner interested in unusual infectious diseases, I have now seen over one hundred Morgellons patients in my San Francisco practice. I am intrigued by the consistency of the patients' stories and the mysterious nature of the disease. Most victims seem to have already been immunosuppressed in some way before noticing the onset of their symptoms. People on immunosuppressive therapy, AIDS patients and those with chronic (often undiagnosed) tick-borne diseases seem to be particularly susceptible. A majority of the afflicted report exposure to stagnant or polluted water or to dirt entering the skin, such as by a splinter or while gardening without gloves, prior to the initiation of their symptoms.

The causative organism of Morgellons disease remains a medical mystery. Randy Wymore, PhD of the Oklahoma State University Center for Health Sciences in Tulsa, Oklahoma, is the Director of Research of the Morgellons Research Foundation. Dr.

Wymore is examining the fibers, scabs and other samples from Morgellons patients and to date his preliminary research suggests that the fibers are not merely textile contaminants and that the scabs have qualitative differences from the scabs of unaffected individuals. Research is underway with the goal of discov-



ering the etiology of the disease and identifying concrete diagnostic criteria.

Meanwhile, pending more understanding of the etiology and risk factors, a cure is elusive. Treatment focuses on symptom management and, when a patient is willing (and most are), treatment with experimental combinations of antibiotics, antifungals and antiparasitics. Many have improved with treatment but not without enduring temporary symptom intensification and the need for frequent medication changes due to an apparently uncanny ability of the organism to adapt or mutate. Every patient is unique, and so treatment involves trial and error and months of frustration for both the patient the practitioner.

Not all Morgellons patients are lucky enough to improve with the experimental treatments. One such patient was a 23 year old male patient of mine who recently chose to end his life of suffering and despair. His untimely death serves to highlight the seriousness of the disease and the urgency for a proper diagnosis and cure.

The first step to understanding this medical mystery is acceptance of the disease as a real entity. We must avoid the temptation to hastily categorize these patients as delusional, which is happening in medical offices around the country every day. When patients present with unusual symptoms, it is unjust to summarily discount them and relegate them to the psychiatrists' office without a thorough and proper history and exam. If health care providers would take the time and effort to really look at these patients' skin with illuminated magnification, they would be amazed

and confounded by the unusual things they would see.

The history of medicine is replete with instances of infectious diseases that are misdiagnosed as psychosocial problems. Gastric ulcer patients were told that their inability to handle stress was the cause of their disease, epileptics were believed to be possessed by the devil, and patients with tertiary syphilis were placed in straight jackets in insane asylums. When patients present with unusual and unbelievable symptoms, health care providers would do well to make sure that they are treated with the dignity, attention and respect that they deserve.

Suggested reading:

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

For further information about Morgellons disease please visit www.morgellons.org, the website of the Morgellons Research Foundation.

Got Lyme??

Join us!!

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. July 15 & Aug 19

Baylor Regional Medical
Center

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

in the continuing education room

Surviving Summer: A Guide for Parents



Before long, the kids will be chasing fireflies, riding bikes ‘til dusk and swimming like little fish. Summer is nearly here. And with the longer days come a few common summertime ailments.

To survive the next few months, take these tips from Dr. Casey Drake, a pediatrician on the medical staff at Children’s Medical Center Dallas.

Ticks

“Ticks are most active in the spring and early summer, and they tend to retreat to shaded areas

during the hottest parts of the summer,” says Dr. Drake. “Kids tend to ‘find’ ticks in wooded areas with small bushes and shrubs. It’s helpful to apply insect repellent before playing in an area where ticks may be present, and parents should check their child’s hair and scalp when they come inside.”

How to remove a tick:

- Use tweezers to gently grasp the tick, being careful not to crush the tick.
- The sooner the tick is removed, the better.
- Thoroughly wash the area with a disinfectant afterward.

Bee Stings

There are unique concerns if a child is allergic to insect stings,

and stings can be serious if a child gets stung in the mouth, nose or throat area. But, for most kids, in most instances, insect stings cause only minor discomfort.

How to treat a bee sting:

- Remove the stinger by gently scraping the site with a blunt-edged object such as a credit card.
- Wash the area well with soap and water.
- Apply a cold compress to help reduce swelling and pain.
- Apply a paste of baking soda and water.
- Call a physician if your child shows signs of an allergic reaction.

Swimmer’s Ear

Swimmer’s ear is an inflammation of the external ear canal. This particular ear ache

presents itself when water gets trapped in the ear canal and a fungi or bacteria grows. You may suspect swimmer’s ear if the outer ear is red, itches or if it is painful to wiggle the ear lobe. This common summertime ailment is easily cured with antibiotics. But, there are ways to prevent swimmer’s ear.

How to prevent swimmer’s ear:

- Place two to three drops of a vinegar/isopropyl alcohol/water mixture in the ear after contact with water.
- Use ear plugs.
- Do not aggressively clean the ear canal.



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.

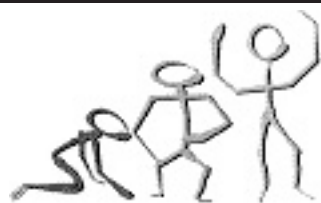
Your QMedRx team offers:

- **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**



IV on the go...

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Not Just Another Spring Day

by Scott Forsgren

Like most people in their mid-twenties, I was in the best of health. I took for granted that good health would be with me for many years to come. With my slightly obsessive-compulsive personality, I started learning about anti-aging medicine and taking handfuls of supplements by the age of twenty. I felt at the top of my game. I had just started a new career in the exciting world of Silicon Valley, California, after having relocated there from Texas. My new post-college life was very good to me. Life had blessed me in many ways.

It was 1997. I remember so vividly that warm spring day that changed my life in such a drastic way. It all started so quickly and yet from the moment it started, I knew in my inner-most self that it would not depart as quickly as it had arrived.

At first, it seemed like the worst flu I ever had. I became violently ill. It was the scariest thing I had ever felt. To this day, I have not experienced anything quite so frightening. Almost overnight, my body was ravaged by an unknown illness. I had difficulty walking, balance problems, blurred vision, low-grade fevers, rapid heart rate, burning sensations in my arms and legs, severe joint pain, nausea, digestive disturbances (we'll leave it at that), brain fog, muscle spasms, numbness, tingling, skin-hypersensitivity, motor-like tapping sensations in my hands and feet, and never-ending fatigue. I could not even sit in a chair or lie on a bed without feeling like I was falling.

Walking down the street felt something near to what I would have expected if I were ninety and yet I was in my twenties. I could not even wear shoes because the burning sensations were intensified by the unfriendly contact that they provided. I knew right away that this was not just another spring day.

Doctors and health-care professionals were baffled. They suggested that I had Epstein-Barr Virus, Mononucleosis, Fibromyalgia, Multiple Sclerosis, severe allergies, Chronic Fatigue Syndrome, and of course, that it was all "in my head". I cannot count the number of times I was

referred to a psychiatrist because conventional medicine had no answers. Somehow suggesting that it is all in one's mind lets the doctor off the hook. It is no longer the doctor that needs to find a problem; you are the problem. After more than two dozen doctors and nine months of feeling as though I had the flu everyday, I was diagnosed with an infection resulting from digestive parasites. I was also diagnosed with severe Candida resulting from the antibiotic overuse from several previous doctors, all of whom had no idea what I really had. I was also told that I had Leaky Gut Syndrome and severe food allergies. It still didn't seem to me that these were the sole cause of my downward spiraling health.

I tried so many different things to get well. Some of them were useful; others were not. I received mega-doses of vitamins via IV. I administered coffee enemas. I was "smudged" by mystic healers. I gave up wheat and fruit for years. I gave myself regular injections of vitamins to help with the malabsorption resulting from the parasitic infections. I even went to one doctor that claimed that I was ill due to a virus found in a local brand of bottled water (which of course never existed). I went through a special series of allergy and immune-regulating injections to help desensitize and heal my system. The treatments required three days of staying at home eating nothing but potatoes and water every eight weeks. Oh, how I loved that.

The list of things that I tried goes on and on... My journey back to health took the next two years and careful coordination with many doctors. We focused on the digestive infection, the leaky gut, the malabsorption, and the food allergies. Little by little, I seemed to improve.

The symptoms seemed to fade away to the point that I didn't feel "sick" any longer. Life was returning to normal. I was grateful that the nightmare was finally over. I felt well again! Once I recovered, I never thought that a difficult to diagnose illness could strike again, but it did!

After having recovered from my first bout with chronic illness which lasted for about three years, it seemed as though every-



thing was headed in the right direction. I was running 10Ks, wakeboarding, snowboarding, swimming, and doing yoga on a regular basis. Except for some ongoing allergies, I stopped identifying as "ill" and once again felt as though I had attained exceptional health.

Unfortunately, my regained health was not to be taken for granted. In September of 2004, I started having severe digestive difficulties (you name it, I had it) once again. Within six weeks, many of my original symptoms reappeared including severe burning sensations in my arms and legs and muscle twitches throughout my body. It seemed that I was revisiting the nightmare that I thought was finally over.

The doctor who had once helped me to feel well was no longer practicing and I started my quest for more answers with a new set of doctors. At this point, I had already seen over 40 doctors since my original health crisis started. I was once again diagnosed with probable parasitic infections (though every test was negative), Leaky Gut Syndrome, Candida, and multiple food allergies. It seemed all too familiar, and yet, it was no less frightening.

Unfortunately, the fact that the original bout with this unknown illness was not truly understood sent us on a similar, and once again, incorrect path. The piles of medical bills and test results reached significant proportions. I was treated for parasitic and fungal infections with a month-long combination of drugs. I began to feel better, but about a month after the treatment ended, the symptoms reappeared. I was subsequently put on another combination of drugs for 28 more days. This combination seemed to

have made some progress as many of the symptoms improved. At that point, I thought I was starting my road back to recovery. Well, I was wrong...

Just over a year ago, I started a new therapy to help with what we now believed were severe food allergies. At this point, I was unable to eat milk, cheese, yogurt, eggs, soy, wheat, oats, barley, or rye. I found that I was not only allergic to foods, but I was also allergic to the very supplements that I was taking to get well. On my very first appointment through the use of energetic testing modalities, the practitioner said that I had Lyme disease, Ehrlichia, Bartonella, and Babesia. I went back to my MD and asked for tests to be run for Lyme. The blood tests did in fact confirm the diagnosis.

Since then, I have spent hundreds of hours researching Lyme disease and adjusting my protocol to once again guide myself back to health. I have been to numerous conferences, read many books, and spent time talking with doctors and others with Lyme disease.

There are various treatments that I do to this day and find to be of value. I've done liver and gallbladder flushes. I've used Rife instruments. I do colonics. I do a BioSET™ allergy elimination program. I do far-infrared (FIR) sauna therapy. I take numerous supplements, herbs, minerals, and vitamins. I also have a coordinated antibiotic protocol.

You can learn more about my current thoughts through my web site at <http://www.BetterHealthGuy.com>. I continue down the path of treating the Lyme and related infections. I have every expectation

"Spring Day" cont'd on pg 11

What Psychiatrists Need to Know About Lyme Disease

by *International Lyme and Associated Disease Society*
A professional medical and research organization

When Should a Psychiatrist Suspect Lyme Disease?

In a published study (Hajek et al, Am J Psychiatry 2002; 159: 297-301), one-third of psychiatric inpatients showed signs of past infection with the Lyme spirochete, *Borrelia burgdorferi*. The International Lyme and Associated Diseases Society (ILADS) has found that even severe neuropsychiatric behavioral symptoms in this population can often be reversed or ameliorated when antibiotics are used along with the indicated psychiatric treatments.

Don't miss this crucial diagnosis

Patients with late-stage Lyme disease may present with a variety of neurological and psychiatric problems, ranging from mild to severe. These include cognitive losses such as: Memory impairment or "brain fog", dyslexia and word-finding problems, visual/spatial processing impairment (trouble

finding things, getting lost), slowed processing of information, psychosis, seizures, violent behavior, irritability, rage attacks, impulse dyscontrol, anxiety, depression, panic attacks, rapid mood swings that may mimic bipolarity (mania/depression), obsessive compulsive disorder, sleep disorders, attention deficit/hyperactivity disorder and autism-like syndrome.

Lyme disease is one of the fastest growing infectious diseases in the nation. The Centers for Disease Control and Prevention (CDC) reported over 23,783 new cases in 2002, and the government agency estimates that the total number may be tenfold higher. The disease is caused by the bite of a deer tick infected with the *Borrelia*

burgdorferi (Bb) spirochete and may be complicated by other parasites or coinfections. It is hard to diagnose because fewer than half of all Lyme patients recall a tick bite or develop the signature erythema migrans "bullseye" rash. As a result, many patients go

untreated and develop psychiatric and/or neurological symptoms.

Lyme disease sometimes begins as a flu-like illness accompanied by fever, headache, sore throat and joint pain. After infection, patients may develop

cardiac or early neurological problems including meningitis, encephalitis and cranial neuropathies.

Look for eyelid droop, facial weakness, numbness or pain,

shoulder droop, sensory distortions or any other focal neurological signs. There may be a history of neck pain and stiffness or muscle twitching. Some patients may have arthritic symptoms in single or multiple joints. Most patients mention this to a psychiatrist only if directly asked.

At any time after a tick bite, patients may also exhibit cognitive symptoms such as memory and concentration impairments and word-finding difficulties, ADD/ADHD-like symptoms, learning disabilities, OCD, crying spells, rages, depression/bipolar disorder, panic/anxiety disorders and psychoses - all may be caused or exacerbated by Lyme disease.

Disorders of the nervous system have been found in 15 - 40% of late-stage (tertiary) Lyme patients (Caliendo et al, Psychosomatics 1995;36:69-74).

When Lyme disease affects the brain, it is often referred to as Lyme neuroborreliosis or Lyme encephalopathy. Usually the patient is totally unaware of its presence. Neuroborreliosis can mimic virtually any type of encephalopathy or psychiatric

...cont'd pg 10, "Psychiatrists"

...fewer than half
of all Lyme
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"bullseye" rash.

~The International Lyme and Associated Disease Society

Blessings in Raising Special Needs Children

I'd like to start off by introducing myself. My name is Barbara Gerami. I'm getting close to the half-century mark and I have 9 children. I have 6 boys and 3 girls (one being my daughter-in-law.) Among my children we have various special needs within our family including autism, asthma, downs syndrome, ADHD, cerebral palsy, lung, heart and kidney problems, seizure disorders, and one child is legally blind. With all that said, they are a true blessing. My desire to work with special needs children started when I was about 11 years old. My cousin Richard had hydrocephaly. That is an enlarged heart due to water on the brain. When he was two years old he walked up the stairs with me and my aunt came unglued with excitement. I had no idea how great an accomplishment this was for him or that he had never done that before. This experience began to tug at my heart. I knew then that I wanted to help kids who couldn't do things "normally". I graduated from pediatric nursing school 27 years ago knowing that I

wanted to work with special needs children. My strong faith in God kept me focused on goal. I knew that God had prepared me for this mission, even when I was just an eleven-year-old girl.

I was involved in a car accident in 1990. I was unable to work for several months.

During this time a couple from my church asked for my help as they were bringing home 2 medically fragile foster babies and they already had one at

home. The foster father of these children had just graduated from nursing school and the foster mother was a paramedic. I agreed to help them. My son and I moved in with them for 6 months. This was a blessing in time of need for us, as our being there

helping with the nursing skills was a blessing for them.

When my time was up with this family, they asked me if I had ever considered fostering children. I told them I had considered it, but I did not think I would be allowed to foster being that I was a single

parent. My friend put me in touch with her foster agency. They knew me well and my application and home study was accepted.

That is when I received my first child. Joshua was 11 years old and had downs syndrome. He is now 27 years old and lives with me.

Two weeks after Joshua arrived, I was asked to take a baby girl with cystic fibrosis. She ended up going back home after

we taught her mother how to care for her medical needs. In 1992 I was asked to take a little boy home that had lived in the hospital for all nine years of his life. Unknown to me at the time, they had decided to "send him home to die" believing he only had a month to live. This child blessed my life for another 5 years. He was on a ventilator the rest of his life. He was autistic, retarded, and the sweetest little "forever five year old" around. He learned to walk at ten years old, and only spoke a sentence 2 times, when it was really important. The first sentence he spoke was when we brought him home and we wanted to rock in the rocking chair. I had been trying to wean him of this activity and only do so at bedtime. That day he stood at the rocking chair, took a deep breath and said, "Come on Mom!!" The second time he spoke was after being at doctors appointments all day and he was completely exhausted. He walked over to his coat, picked it up, took a

"Blessings" Cont'd on pg 11



Four of the Gerami children (left to right) Jolynn, Joshua and Rebecca. Front row: Donny

Psychiatrists...Cont'd from page 9

disorder and is often compared to neurosyphilis. Both are caused by spirochetes, are multi-systemic, and can affect a patient neurologically, producing cognitive dysfunction and organic psychiatric illness. Such symptoms may be dormant, only surfacing years later.

Dr. Brian Fallon, director of the Lyme Disease Research Program at Columbia University and principal investigator of the NIH-funded study of brain imaging and persistent Lyme disease, cites five questions that imply warning signs of possible Lyme encephalopathy:

*Are there markers of non-psychiatric disease such as erythema migrans rash, arthralgias or arthritis, myalgias, severe headaches, sound or light sensitivity, paresthesias, diffuse fasciculations, cardiac conduction defects, word finding problems, short-term memory loss, tremors, cranial neuropathies, and/or radicular or shooting pain?

*Is this psychiatric disorder atypical or unusual? For example, does a panic attack last longer than the expected 1/2 hour? Or is it a first ever panic attack at age 50?

*Is there poor or paradoxical response or excessive side effect sensitivity to medications

that are expected to be helpful for particular psychiatric symptoms?

*Is this new-onset disease without psychological precipitants such as new stressors or secondary gain?

*Is there an absence of a personal history or family history of major psychiatric disturbances?

Negative answers to these questions do not rule out the presence of Lyme disease. But a "yes" to most of the questions, especially in a patient with an out-of doors lifestyle or a pet, demands further clinical assessment. Dr. Fallon recommends Western Blot serologic studies, lumbar puncture, neuropsychological testing, brain MRI

and SPECT (single photon emission computerized tomography) scans. For more information, see www.columbialyme.org.

Other helpful tests may include PCR for *Borrelia burgdorferi* in blood, serum, cerebrospinal fluid (CSF) and urine, and/or *Borrelia* antigen testing in urine and CSF. Because blood tests at the top three general medical laboratories in the nation fail to detect 35% of Lyme antibodies, ILADS recommends use of laboratories that specialize in Lyme and other tick-borne illnesses.

Contact www.lymediseaseassociation.org for a listing of recommended labs. Blood tests should not be used to rule out Lyme disease when there is a strong clinical presentation. Dr. Robert Bransfield, a psychiatrist who specializes in infectious causes of neuropsychiatric illness, has developed a structured clinical interview to assess seronegative patients. See www.mentalhealthandillness.com

What to Do?

Screen patients for Lyme symptoms, especially those with complicated or atypical presentations. Be suspicious of Lyme if a patient mentions cognitive changes, extreme fatigue, weight changes,

headaches, fibromyalgia, a history of "mono," "spider bites," multiple sclerosis, explosive rages or sudden mood swings. To elicit data about cognitive problems ask broad questions such as, "How do you think your brain is functioning?" or "How many things can you handle at one time?"

Consider Lyme disease in children with behavioral changes, fatigue, school phobias, academic problems, learning disabilities, headaches, sore throats, GI com-

plaints and/or migrating pains. In teens, Lyme disease may be complicated by drug abuse.

The Lyme spirochete is slow growing and can be difficult to treat, so be sure the patient is treated with appropriate antibiotics for at least two to four weeks *beyond symptom resolution*. Most individuals with Lyme disease

respond to antibiotics, but the treatment course is highly patient specific. ILADS has published evidence-based

guidelines for the diagnosis and treatment of Lyme and associated tick-borne diseases (Expert Rev Anti-Infect Ther 2004 ;2(Suppl):S1-S13). For more information, visit the ILADS website at www.ilads.org.

Some of the common symptoms of late-stage (tertiary) Lyme disease and other tick-borne coinfections:

- o Profound fatigue
- o Chills, sweats and skin flushes
- o Night sweats
- o Migrating arthralgias
- o Muscle pains/twitching
- o Sleep disturbances
- o Severe headaches
- o Shifting neurologic pains
- o Tremors, shakiness
- o Numbness, tingling sensations, pain often shifting and unusual in type
- o Cranial nerve disturbance (Facial numbness, pain, tingling, paralysis, optic neuritis, trouble swallowing, distortion of smell or taste)

The more severe neurological symptoms or disorders associated with late-stage Lyme disease:

- o Progressive dementias
- o Seizure disorders
- o Strokes
- o ALS-like syndrome (similar to Lou Gehrig's Disease)
- o Guillain-Barre-like syndrome
- o Multiple sclerosis-like syndrome

- o Parkinson's disease-like syndrome
- o Other extrapyramidal disorders
- o Visual disturbances or loss

Checklist of common cognitive impairments in Lyme disease (from Marian Rissenberg, Ph.D., clinical neuropsychologist)

Losses in fields of attention/executive functions such as inability to maintain divided or sustained attention, auditory and mental tracking and scanning, and memory retrieval can affect: Memory functions (lost items, missed appointments, retold stories), language functions (halting speech, disrupted participation in conversation), visual/spatial processing (inability to find things, tendency to get lost, disorganization, difficulty reading, especially for enjoyment), abstract reasoning (poor problem-solving/decision-making), and slowed processing speed (familiar tasks take longer, can't follow conversations well).

Most or all of these impairments, if caused by neuroborreliosis, may improve with proper antibiotics combined with other appropriate symptomatic treatments.

Symptoms of Chronic Late Stage Lyme Disease:

- Profound fatigue
- Chills, sweats
- skin flushes
- Night sweats
- Migrating arthralgias
- Muscle pains/twitching
- Sleep disturbances
- Severe headaches
- shifting neurologic pains
- Tremors, shakiness
- Numbness, tingling

Edited by Drs. Virginia T. Sherr and Debra J. Solomon, Psychiatrists

For More information about ILADS go to: www.ilads.org e-mail: lymedocs@aol.com

Diagnostic Hints and Treatment Guidelines by Dr. Joseph Burrascano, M.D. available for free download at: http://www.ilads.org/burrascano_1102.htm

“Doctors” cont’d from pg 3...
From the perspective of a patient, however, I must say I do NOT understand. I am not just a social security number attached to a particular health care plan. Eight minutes to address my needs? Please!

After 20 years or more of receiving those 8 minute medical segments, I finally found an out-of-network physicians that actually spent over 90 minutes with me, evaluated my entire medical history and actually utilized his diagnostic skills, and then took enough blood-work to fill up a new human being to verify my long-awaited diagnosis.

I have tertiary Borrelia Burgdorferi, which is commonly referred to as chronic, late-stage Lyme disease, and is far more common than most realize. In fact, you could have it too, and not even know it. In addition, I also have what is referred to as co-infections: Babesiosis, and Bartonella - which I just call Babs & Bart because I'm tired and every syllable counts.

Now that I have ample diagnoses, I await a cure...

A cure! I almost say that in jest because let's be honest - when was the last time a disease was cured? Think hard. I actually know this answer, but it is locked away in a secret section of my brain for which I do not currently have access thanks to the Borrelia spirochetes swimming through my brain tissue. But frankly -- how would it benefit physicians and Big Pharma if diseases were actually....cured? A cure would seem like a bad business decision. And even if someone came up with one, I'd be willing to bet my insurance company, also a big business, would not want to fork over the bucks to pay for it.

Don't get me wrong - I'm not completely jaded....yet. I do still choose to believe there are a select number of physicians out in the world that actually treat patients first and foremost because of their love of their profession and their desire to care for the sick. Many of those doctors, I am discovering, are quite often "out of network". In order for a doctor to have the freedom to treat patients in the manner they deem best - many doctors must remove themselves from underneath the strict thumbs that keep them pinned to limited time & attention for individual patients.

For many patients, seeking care 'out of network' is not a possibility. They are therefore at the mercy of their primary care physicians or the specialist to whom

they have been 'turfed'. (FYI - "turfed" is a fancy medical term I learned from watching years of E.R. episodes. In fact I learned quite a bit of medical terminology, such as "tension pneumothorax", "ventricular septal rupture" and "thoracotomy". In truth, I do not actually know the meaning of these words; however, this does not stop me from working them into conversation when I am around dumb people - as it makes me feel even more intelligent, as in: "Too bad we don't have a thoracotomy tray handy, I could probably fix that for you." See? How smart does that sound?)

With regards to dealing with 'out of network' physicians - those fortunate individuals who can afford such medical care ...please dump the contents of your purse or wallet at the receptionist's window - as many of these 'out of network' physicians do not want to even be bothered with filing insurance, and many are quite proud of their services.

In the simplicity that is my mind, I think if I'm going to pay out the wazoo, and do all the paperwork, then perhaps we could do a little negotiating and once in a while, when I'm just too tired to crawl out of my sick bed....they could make a house call!!

I don't think that's too much to expect, do you? Of course, I cannot cope with the thought of anyone coming into my home while I am that sick and miserable and obviously unable to keep the general clutter and dust volume to a level that does not suggest a Hazmat suit is necessary attire. I realize I would drag my body from my sick bed to attempt to tidy up. So -never mind.

But even with all the doctors in the state of Texas whom have decided they no longer want to be in anyone's network....I still find myself asking: "Is there a doctor in the state...???"

Chronically ill patients need a doctor in the state of Texas that can actually help them. Thanks to the Texas State Medical Review Board now breathing down the necks of practitioners whom are dedicated to treating chronic cases of Lyme disease - a disease which often disables patients, thereby upsetting some kind of critical state health statistics - Lyme practitioners must either treat patients "under the radar" or treat less aggressively for fear that doing right by the patient will call attention to themselves and they will be called before the Texas State Medical Review Board which clearly has an anti-Lyme disease agenda.

So what's a patient diagnosed with Lyme disease to do? Leave the state?

Yes, not only are some of the sickest, most miserable patients required to drag their weary chronically ill bodies from their bed to see a physician - they are now finding themselves having to drive or fly to other states where a Lyme-literate physician is willing to treat them appropriately. How absurd is that?

Again - where does the "first do no harm" oath come into play for Lyme disease patients? When will the sanctity of human life return to its place of importance - ABOVE the bottom line and the political agendas?

Back in the good ol' days when doctors would make house calls, they would often give the patient a full exam, followed by a shot of penicillin and the recommendation that the patient receive an enema.

I've had my fair share of enemas. Perhaps those insurance company policy-makers, and those individuals sitting on the Texas State Medical Review Board should get their fair share of enemas too - because frankly, I think they are "full of it"!

“Lyme” continued from page 1

the treatment of Lyme in its late and chronic stages. If caught very early Lyme can be dealt with and treated effectively. Once it has advanced to late stages and the chronic form it is much more difficult as it effects the body systemically. With the controversy surrounding the insensitivity of the tests available for Lyme Disease, early detection is often difficult if not unlikely.

**If it weren't for AIDS,
Lyme would be the
number one infectious
disease in the United
States and Western
Europe.
~Nick Harris, Ph.D**

IgeneX labs in Palo Alto California, a specialty lab in tick borne pathogens and their co-infections, has developed much more reliable testing options. Nick Harris, Ph.D., President of IgeneX labs said, “If it weren’t for AIDS, Lyme would be the number one infectious disease in the United States and Western Europe.”

The CDC claims that the amount of Lyme Disease reported is about 20 times under reported based on the insensitivity of tests.

**HELP
WANTED**

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**The TPHA is in
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Email Dawn Irons at
editor@texaspublichealthalert.org
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No Phone Calls Please

“Spring Day” cont’d from p.8

that my situation will continue to improve. I still have distance to travel, but I hope that my experiences will be of value to you.

I've learned so many things on this journey and I hope to be able to share many of them with you here on a regular basis in future editions of the Texas Public Health Alert.

Scott can be reached by email at
Scott@BetterHealthGuy.com

or through his web site at
www.BetterHealthGuy.com

“Blessings” ...cont’d from pg 9

deep breath and said, "Home, Mom!!"

All of my children have some form of chronic medical illness. I will touch on each of the children's illnesses in future columns. I hope to give you a bit of insight into what it is like living day-to-day with special needs children and the blessing they bring to my life and the lives of others.

SUPPORT IN THE METROPLEX

ALS/ Lou Gherig’s Disease

The ALS Association North Texas Chapter offers education/support groups to persons diagnosed with ALS, their families, caregivers, and friends. It is our wish to provide an outlet for our clients and their loved ones to learn about ALS, the various resources we provide, and to network with other people who share the journey of ALS. Please contact our office for further information.

Meeting Information:

1st Thursday of every month
Time: 7:00 pm

Grace Presbyterian Church
4300 W. Park, Plano, TX
Facilitators: Laura A. Roye
l.atkinson@alsanorthtexas.org
Stephanie Melson

ALS Association, North Texas
972-714-0088
972-714-0066 (fax)
877-714-0088 (toll free)

Dust off your walking shoes!

The 6th annual Walk to D’Feet ALS is on October 7, 2006 at Bachman Lake in Dallas.

For more information, visit www.alsanorthtexas.org or email Laura l.atkinson@alsanorthtexas.org

Lyme Disease

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. July 15 & Aug 19

Baylor Regional Medical Center
at Grapevine
1650 West College
Grapevine, TX 76051
(817) 481-1588
in the continuing education room

Multiple Sclerosis

Phone: 972-504-2272
M-F 9am - 4 pm CST

dfwfightms@sbcglobal.net
dfwmssupport.org

Chronic Fatigue & Fibromyalgia

817-283-1115
Carol Sieverling
dfwcfids.org

Lupus

Ft. Worth:
Phone: 817-354-1756 (Janice)
817-246-2639 (Marilynn)
Dallas:
Phone: 972-345-4824 (Stephanie)
940-484-0040 (Paula)
support@lupus-northtexas.org

Diabetes

Dallas: 214-345-5901
Contact: Diane Foster

Plano: 214-473-7605
Contact: Shannon Mahood
shannon.mahood@lonestarhealth.com

Autism

The DFW Center for Autism Outreach program provides quality consultative and training services to families, schools, and other care providers for individuals with developmental disabilities. All providers are Board Certified Behavior Analysts (BCBA) with Master Degrees in Behavior Analysis. There are four service areas provided through the DFWC-FA Outreach program: On-going Consultation for In-home Programming; Program Review; Specialized Training; Functional Analysis.

303 W Nash St
Grapevine TX 76051
(817) 424-9797 phone (metro)
(817) 424-9792 fax (metro)

Families For Effective Autism Treatment - North Texas

<http://www.feantnt.org/>
Families for Effective Autism Treatment – North Texas (FEAT-NT) is a non-profit organization of parents and concerned professionals dedicated to providing Education, Advocacy, and Support for children with autism and their families.

Heart Disease

The Mended Hearts, Inc.
<http://www.mendedhearts.org>
Email: mhoffice@heart.org

7272 Greenville Avenue
Dallas, Texas 75231-4596

Tel. 1-800-AHA-USA1 or
(214) 706-1442

Fax: (214) 706-5231

Cancer

An American Cancer Society support group for patients and their families dealing with cancer. Meets the first and third Thursday of each month from 7:00 to 8:30 p.m. in the Cancer Resource Library in the Klabzuba Tower of Harris Methodist Fort Worth Hospital. For more information please call the American Cancer Society at (817) 737-9992.

STEPS to Surviving Breast Cancer -- For more information, please call (817) 820-4805.

STEPS to Surviving Prostate Cancer -- For more information, please call (817) 820-4868.

Interstitial Cystitis

Meets in the HMFWS Robb Rutledge Education Center on the second Tuesday of each month from 6:30 to 8:30 p.m. For more information please call (817) 222-0448.

“Medical Treatment” *cont’d from pg 4*

surgery, and radiation, we began looking elsewhere, seeking our options and alternatives to standard care. We learned about hyperthermia being used with good success in Germany; about a camphor derivative, 714-X, used in Canada; about herbal formulas and Laetrile in Mexico and numerous devices employing magnetic and electric fields used in Sweden, England and other countries in Europe.

None of these was heralded as a cure for cancer, because there often is no cure -- which is why 1,500 Americans die each and every day from this disease. But these formulas and devices had helped others in their fight against cancer, and their success stories gave us hope.

It turned out, however, that hope was a second tower about to be destroyed by a second plane called bureaucracy, one built out of red tape and outdated laws.

After diligently pursuing and uncovering numerous options

for treatments through reading books, talking with others, and scouring the Internet, my wife of 30 years would not have access to these treatment -- at least not in this country.

We quickly found that due to well-intentioned regulatory requirements of the FDA, FTC, medical boards, and other agencies, the walls originally designed and built to protect and serve us were barriers that denied us access to treatments that offered us at least hope, if not more time together.

We believed that this was a decision to be made by us -- ultimately my wife -- and not by agencies bound by antiquated laws

and red tape.

I believe that the time for the Access to Medical Treatment Act has come. The old laws we have need to reflect today's world -- a world in which cancer, AIDS, and other diseases are running

rampant. A world in which deadly biological agents may be unleashed on our cities, challenging, if not overwhelming our medical community.

A world in which the Internet has created a society that is better informed, much more than ever before, one where people will demand the best health care that the world has to offer. They will want to access all the treatment options that are available and should have the right



to do that.

However, only new, updated legislation will allow this to happen. This is why I am proud to support The American Association for Health Freedom (www.healthfreedom.net) and their efforts in creating and supporting bills such as AMTA. AAHF has a section on their website devoted to AMTA and an easy online action center where you can contact your representatives.

The time for the Access to Medical Treatment Act has come. I ask you, not only on my behalf, but on behalf of you, your families, and friends, and on behalf of all Americans to stand up and be counted as one of those who helped make it happen.

[Ed. Note: Bob's wife passed away in the beginning of 2005.]

For more information on the American Association for Health Freedom you may go to the website www.healthfreedom.net or contact the executive Director, Brenna Hill at : brenna@healthfreedom.net