FREE

Public Health Alert

Vol. 2, Issue 10 | Investigating Lyme Disease & Chronic Illnesses in the USA | October 2007

In This Issue

President Bush's Lyme Diagnosis Raises New Awareness for the Disease

by Dawn Irons

The White House recently disclosed that President Bush was diagnosed and treated for Lyme disease in August of 2006. This comes at a time when the national debate over the diagnosis and treatment of Lyme disease is at the center of controversy within the medical community. The details concerning the treatment protocol that were used to treat President Bush was not released to the public as the White House cited doctor-patient privilege. This type of omission was not used in many of the other medical reports that were released to the public. There was great detail given about the colonoscopy and polyps that were removed from the President's colon, but no information whatsoever was given to show exactly how the President was treated for Lyme disease.

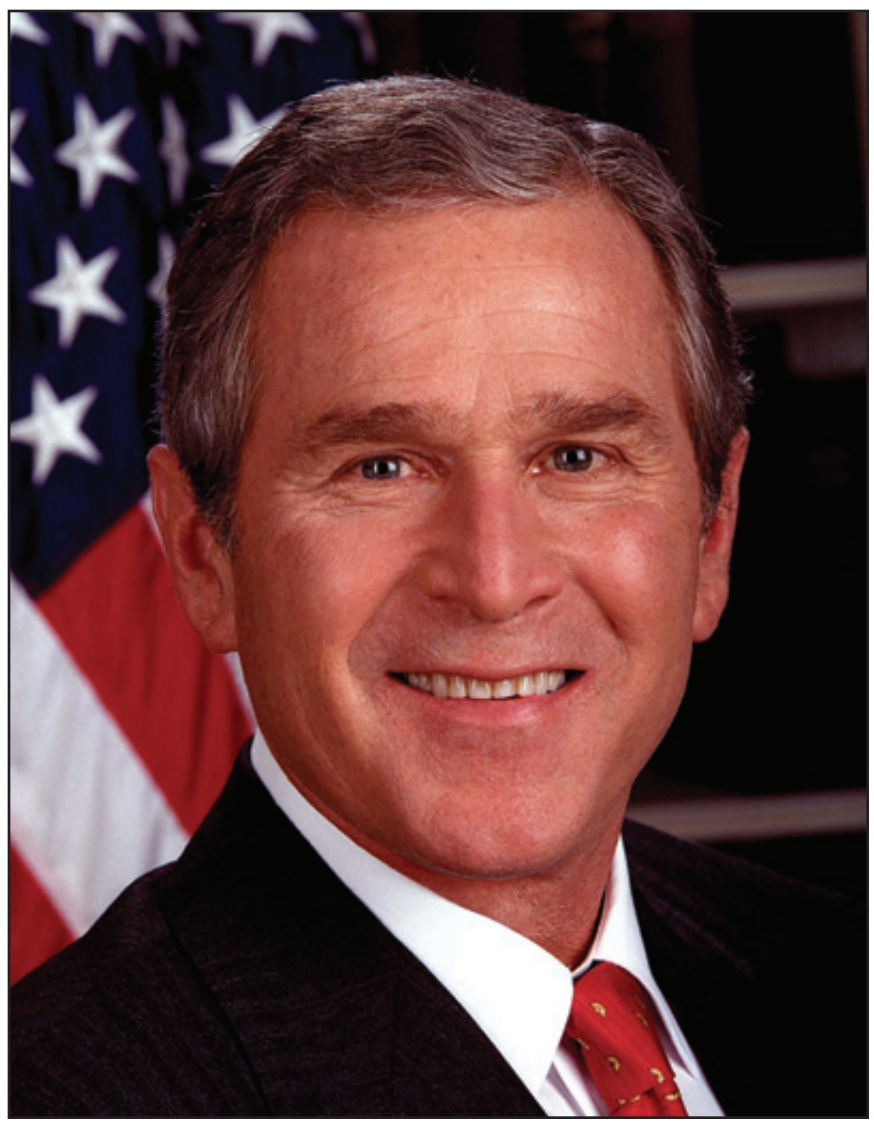
Lyme disease is primarily a tick-borne illness, but many health agencies have also isolated the borrelia bacteria in other vectors such as mosquitoes, biting flies, fleas and mites.

President Bush has spent much time at Camp David riding his bicycle on the trails. He is said to have had numerous tick bites throughout his life. The President is also well known for doing his own chores at his ranch in Crawford, Texas. He often clears his own brush on his land at the wooded ranch. He spent most of August 2006 at the Crawford ranch when he was diagnosed and treated for Lyme disease by a Dallas physician. Although it is unknown exactly when and where Bush was infected, he believes it to be while he was at Camp David riding the wooded trails and he further believes it was discovered while he was in Texas.

There is an abundance of mis-information in the media regarding Lyme disease. The Washington Post writer David Brown reported, "There are no documented cases of Lyme disease in the president's home state, where he spent much of last August on vacation."

This could not be further from the truth. The Texas Department of State Health Services lists Lyme disease (borrelia burgdorferi) as a significant reportable zoonotic disease in Texas. Lyme disease was first discovered in Texas in 1984 and the state has had two major universities open laboratories to study tick-borne diseases. Texas A&M University and The University of North Texas are both involved with research regarding tick-borne illnesses in Texas. The Texas Lyme Disease Association has well established support groups state-wide to help Texas Lyme patients get accurate information and medical help. Donna Reagan, the Dallas-Fort Worth area support group leader said they have over 200 members in the DFW metroplex alone. That does not include the support groups in Houston, Austin, Denton and Victoria.

Gary Wormser, chief of infectious diseases at New York Medical College and an "expert" on Lyme disease said if President Bush "was infected in Texas that it was undoubtedly STARI" and not Lyme disease.



STARI stands for Southern Tick Associated Rash Illness. It is believed to be transmitted by the Lone Star Tick (*Amblyomma americanum*). Wormser stated in an interview with the Washington Post that "it is not known whether treatment of STARI is necessary. There appear to be no long-term consequences of either treated or untreated infection."

According to a Microbiological Services Division, Bureau of Laboratories, and Texas Department of Health study that was titled *Isolation of Borrelia burgdorferi from arthropods collected in Texas*, it was determined that the Lone Star Tick reacted specifically when treated with monoclonal antibodies to B. burgdorferi. The study also showed it to be virtually identical with strain B31 of B. burgdorferi. This is significant in terms of needing treatment.

While the controversy in the medical community concerning treatment for Lyme disease continues to rage on, the patients who suffer are often caught in between the two polar opposite standards of care and the physicians who will and those who refuse to treat them.

President Bush was diagnosed and quickly treated which is the best possible treatment plan. This is the one common ground among both standards of care: early diagnosis and treatment is best for long term health recovery. pha

FDA Approves First Drug for Treating Fibromyalgia

by FDA News

The U.S. Food and Drug Administration today approved Lyrica (pregabalin), the first drug to treat fibromyalgia, a disorder characterized by pain, fatigue and sleep problems.
Lyrica reduces pain and improves daily functions for some patients with fibromyalgia.

"Today's new approval marks an important advance, and provides a reason for optimism for the many patients who will receive pain relief with Lyrica," said Steven Galson, M.D., M.P.H., director of FDA's Center for Drug Evaluation and Research. "However, consumers should understand that some patients did not experience benefit in clinical trials. We still have more progress to make for treatment of this disorder."

Persons with fibromyalgia typically experience long-lasting or chronic pain, as well as muscle stiffness and tenderness. Fibromyalgia affects about 3 million to 6 million people in the United States each year. The disorder mostly affects women and typically develops in early-to-middle adulthood.

There is no test for the diagnosis of fibromyalgia. Doctors make a diagnosis by conducting physical examinations, evaluating symptoms, and ruling out other conditions. Individuals with fibromyalgia have been shown to experience pain differently from other people. Studies have shown that such patients have decreased pain after taking Lyrica, but, the mechanism by which Lyrica produces such an effect is unknown.

Two double-blind, controlled clinical trials, involving about 1,800 patients, support approval for use in treating fibromyalgia with doses of 300 milligrams or 450 milligrams per day.

The most common side effects of Lyrica include mild-to-moderate dizziness and sleepiness. Blurred vision, weight gain, dry mouth, and swelling of the hands and feet also were reported in clinical trials. The side effects appeared to be dose-related. Lyrica can impair motor function and cause problems with concentration and attention. FDA advises that patients talk to their doctor or other health care professional about whether use of Lyrica may impair their ability to drive.

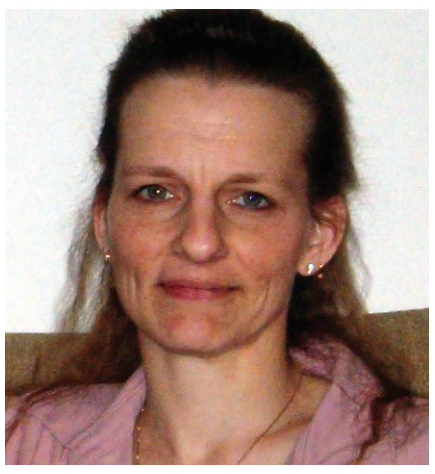
Lyrica already is approved for treating partial seizures, pain following the rash of shingles and pain associated with diabetes nerve damage (diabetic neuropathy).

Lyrica is manufactured by New York-based Pfizer Inc. Pfizer has agreed to perform a study of the drug in children with fibromyalgia and a study in breastfeeding women.

To see a consumer article called Living with Fibromyalgia, First Drug Approved, visit www.fda.gov/consumer/updates/fibromyalgia062107.html

pha

Blanket of Hope
Heroes Among the Stars



by PJ Langhoff

It is Monday night, August 13, 2007, around midnight. Everyone in the neighborhood is fast asleep. I am reclined on a lawn chair in the backyard of my home in southeastern Wisconsin. The air is cool, but easy to breathe, and to my relief, there are no mosquitoes. It is a perfect night for watching the Perseid meteor shower with its tiny bits of cosmic debris which appear to rain into the atmosphere from the constellation Perseus (in the northeast). As I lay watching the beauty of this precious event, I think about all of the things which have brought me to this moment of my life, and the appreciation for all things large and small, which I am blessed to be able to witness, because I am surviving each day with Lyme disease. I regard the stars and liken them to individual Lyme patients - each one unique, with varying "brightness" of energy; all collectively beautiful with much in common but each so singularly far apart from one another, separated by space and perhaps lacking a basic awareness of one another. Yet each struggles to shine as brightly as possible before the inevitable burn-out of a lifetime spent dealing with our collective illness.

Like others who run support groups for Lyme patients, in my day-to-day activities, I am amazed that I meet a new person nearly every day that has had Lyme disease touch them in some manner. Usually they have contracted it themselves, (like the hairstylist I randomly picked out of a phone book to do my hair), or a family member or friend who just found out they have Lyme disease and don't know what to do or where to turn and I just "happen" to come their way. What an honor it is to me, to be able to assist these individuals in their "journey of the soul", the journey that is Lyme disease. It is a chance to perhaps help them circumvent some of the years of disability which could befall them if their illness is misdiagnosed or under treated without the information able to be afforded them if our "chance" encounter had not occurred. I truly believe that we are led to one another through a higher power, and in my life that would be the hand of God, though some with other beliefs might label it otherwise.

And I regard each of these individuals as a treasured brother or sister in the fight against this incredibly misunderstood and powerful adversary. Each of these individuals is a star within their own right, as each one has a unique story to tell of humble beginnings, and the necessity of redefining their lives through willpower, perseverance, and fortitude in order to survive as a "hero" of Lyme - and each one shines to me, as brightly as the stars within the mesmerizing night sky.

I would like to tell you about one of those stars whom I had the honor of meeting through my support group. A seemingly "innocuous" email was received by me recently, from an individual inquiring whether my group holds meetings and when they might occur. Upon talking to this individual, I met a star in his own right, Mr. Brin King. Brin lives in a small town in north central Illinois, about 40 miles west of Chicago, and quite coincidentally, it also happens to be the same town in which my father commuted to work every day (when he was alive), many years ago - and a town not far from where I spent the majority of my childhood.

Brin King at his computer, the only link to the outside world for most disabled Lyme patients.

Brin's typical day since 1990 when he was infected with Lyme disease, is similar to that of many Lyme patients. He has difficulty sleeping. He arises, showers, dresses and takes medications. If he has an appetite, he will eat. He rests for 3-4 hours and sometimes goes outside for a walk. When through his joints quickly remind him that he is ill. Projects require extended time to complete - perhaps days, weeks or even a month, as the energy he has is fleeting. Following activity Brin says "payback is inevitable". He may suffer from fatigue, lack of appetite, joint pain, a headache, a lack of balance, a feeling of being disoriented, and seizures. His typical symptoms range throughout the day from blurred vision and memory loss to feeling incoherent, confused, and not knowing who people are, or where he is. And yet Brin considers himself one of the "lucky ones" because he had Lyme-knowledgeable doctors who helped him eventually get treatment as well as disability benefits.

But knowing Brin for the short time that I have, I have learned that this quiet and very humble man has actually been hit very hard by Lyme disease, much harder than most people I have known with Lyme. Despite this, his courageous spirit and desire to help others has remained intact and does not waiver. His story appears in one of my newest books coming out this fall which contains stories from Lyme patients like Brin, and from others from many parts of the world. In his story he speaks of overcoming incredible symptoms, debilitating seizures, brain surgeries, a heart attack and subsequent coma, recovery from a stroke and paralysis, kidney, bladder and prostate cancer, surgical "accidents" and tremendous losses incurred from having Lyme disease. Brin has spoken about Lyme disease to support groups, seminars, and at universities, high schools, church groups, several agencies and other organizations. At one point he even received what he considered "death threats" for speaking out about Lyme disease. Brin has difficulty traveling due to his symptoms, but he continues to help raise awareness for Lyme disease.

One of the most outstanding ways he has been achieving success at this process is through his project, The Blanket of Hope. Begun in January of 1993, the blanket arose from Brin's observations that Lyme victims need someone to listen, to care, and to be aware of the fact that Lyme disease exists, and especially chronic Lyme. He calls the blanket the "unified voice of all Lyme disease victims," representing the many who suffer in silence from a little-known, barely acknowledged disease. His hope was that the blanket might represent victims from all over the world, and offer Lyme victims hope through participation in the project. The blanket is composed of 4 feet by 4 feet personalized fabric squares (panels) sewn together, border to border, by a retired seamstress who volunteers to help Brin create the blanket. He stores the huge project, protected by plastic, in a storage facility.

When Brin first began the project, he sent word by mail to more than 600 Lyme victims. The blanket began with 1 piece of material, as Brin says, "Just as the smallest ray of hope is born-one name, one state and date of when the disease was contracted, printed onto the material". Within 3 short weeks, he received blanket panels in boxes of 15 or more; first from South Carolina, and then Michigan and Florida. The panels are sewn 70 panels to a "blanket" and are laid out 3 feet apart so that people can walk between them. Today, the blanket's size has grown and will continue to grow, encompassing panels from patients from small communities, large cities, other states and countries abroad. Brin says, "in this manner the many who suffer in silence as well as those who can speak, will be heard and will no longer be drummed out by rhetoric or empty facts and words. They will be replaced by research, by a strong and solid pursuit not only for answers, but for a cure, once and for all, for everyone who has Lyme."

The blanket is currently estimated to contain over 9,960 panels (141 blankets), and is approximately the size of several football fields. Brin has had the blanket on display twice since he began this worthy and important project. Both showings were in 1995, once in Chicago's Grant Park in the spring, and once in Washington D.C. in the fall. In order to move and show the blanket, Brin had to pay out-of-pocket (and with some help from others), the expenses to move it via an 18-wheeled flatbed truck, and to pay for special display permits. The blanket has grown considerably in size since its inception, and incorporates panels from the United States, Germany, Austria, England and Sweden. Brin was overwhelmed by the responses he received, and although not everyone sent panels, he did receive letters of support from Norway, France, Australia, Greenland and others. He was humbled and excited at such a positive response- so much so that he says, "I cried when I received the first panels, as one after another box was brought in by the postal carrier, FedX, and UPS."

As Brin began to receive blanket panels, he sent this statement out to Lyme disease support groups, to doctors, and to businesses all over: "Let the word go forth. Let the word go out across the land, to every home, to every hospital and clinic, to every level of medical personnel far and wide, to every insurance company and their underwriters, as well as to every lawyer, pharmaceutical company and politician. *The Blanket of Hope*, the unified voice of a nation on Lyme disease is growing in leaps and bounds and the drum beat is getting louder. No longer will we, those of us with Lyme disease, be ignored. No longer will we be silent on a rapidly spreading, devastating disease. No longer is it the voice of one person, of one support group, one town or city, nor one state, but now of every state! No longer is it the voice of one country, one nation, but the UNIFIED VOICE of the Blanket of Hope, coming together around the world."

Brin says that "as long as one person has Lyme, the project will continue." The support for the blanket has been bittersweet for Brin, who's own family and friends, (as is too often the case with Lyme patients), found it difficult to support and understand his situation, and chose to "turn and walk away" as Brin puts it. When asked the question, he feels that the most difficult aspects of dealing with the chronic form of Lyme disease for him have been the stroke, losing control of his body, undergoing 28 months of therapy to recover control of his body, and having to come to grips with the disease itself and the loss of family and friends in such a short period of time. Like many Lyme (and chronically ill) patients, Brin finds aspects of this question too overwhelming emotionally to put into words and many Lyme patients know exactly how he feels. But Brin feels that 1) getting someone to listen and to help; 2) being ill non-stop (long-term) with no answers forthcoming; and 3) hanging onto hope when common sense tells you not to, are also among the most difficult aspects of having Lyme. But from having Lyme disease, Brin says that he now appreciates life more, and values the positive moments he does have, like when there is laughter, and no discomfort or seizures.

The thought of such a huge number of patients joining together in a single project which continues to this day is astonishing to me. And it is equally astonishing to witness the power that one person dealing with Lyme disease has, when used to help elevate the voices of so many people to a level whereby those voices can be heard - loud and clear! Brin has this advice to people who have recently learned they suffer from Lyme disease: "Learn all you can about this disease, never stop learning. Do not give up, though it can be easy when faced with some overwhelming challenges. Never give up Hope. No battle is over until you decide it is." Brin, you are truly a star in your own right, and your Blanket of Hope offers patients a chance to participate in a very meaningful

"Hope"...cont'd on pg 4

Justice, Mercy & Strategy

by Dawn Irons

Each month I receive letter-after-letter from mothers and fathers, husbands and wives, and aunts and uncles telling me their personal family story of how Lyme disease has impacted their family.

I get the privilege of seeing the human side of Lyme. I see the faces, I read the letters, I see the children that have been affected. I awake from sound sleep and pray for people I have never met...people that somehow have a piece of my heart and soul.

I have seen families brought before the court system because their child was too ill to attend school and truancy charges were filed against them; even in light of copious amounts of medical records and doctor's notes being given to the school.

I have seen mothers who were accused of Muchausen's by Proxy for daring to question a doctor's diagnosis when they dismissed the mother's concerns about possible Lyme disease. Many of these mom's even held positive test results in their hands.

It all sounds like a cheap "B" rated movie from the 1980's, but it is more horrific than Friday the 13th, Halloween, or Freddy Kreuger ever dreamed of being. At least in the movies, it eventually ended. But the letters from these families keep coming month after month.

As I consider the complex political situation that is deeply at the root of this problem, I find myself crying out for justice and mercy.

It seems the political landscape is as strategically planned out as a complicated chess game. But one of the teams (IDSA) is skilled at slide-of-hand techniques. Can anyone explain to me how treatment guidelines were adopted as the medical standard of care when the research used to justify the protocol was written by

the very one's who adopted the guidelines.

Isn't that tantamount to a student writing the test and then grading it himself? Doesn't anyone else see the conflict of interest there?

But that is exactly the situation we are facing when we look at the controversy over treatment standards and the conflict between the Infectious Disease Society of America (IDSA) and the International Lyme and Associated Disease Society (ILADS).

IDSA is proud of the 400 journal articles they referenced when writing the 2006 Lyme Treatment guidelines. What they did not say is that they chose 400 of the research articles that they agreed with and dismissed the other 18,537 research studies that disagreed with their point of view.

And thus birthed the controversy that is before us today. They claim their guidelines are "evidence based," but BIASED "evidence-based" research should never be upheld as the standard of care.

These guidelines were so suspicious that they caught the attention of the Attorney General of Connecticut, Richard Blumenthal, who began an investigation of the IDSA on basis of anti-trust violations. In layman's terms, that means he believes the IDSA is trying to monopolize the treatment of Lyme disease to the degree of trying to crush the competition (ILADS).

It would be one thing if this were a debate of political view points. But this is a debate of medical treatment and the insurance industry has clearly sided with the IDSA because they choose to cover the cheapest treatment option available; 14-21 days of antibiotics. In the meantime, patients lives are in the balance. The obituaries write themselves each month as Lyme disease and tick-borne illnesses claim more lives.

The strategy of the players involved in this conflict is mind-boggling. People are dying while the acadamians battle the physicians-in-the-trenches who are treating these patients with their hands tied behind their backs. It is becoming a nation wide crisis.

The chess match is on! Now all we need is every other state Attorney General's office to follow the lead of Connecticut and Richard Blumenthal.

President Bush has been the latest high profile person who has wrestled with this disease. Hopefully he was treated quickly enough and for a long enough period of time that he won't have to battle the later stages or chronic form of the disease.

It is sad that we have to call on legislators to stop a medical tyranny by the IDSA. But it is time the strategy is reversed and the final move is played and we can effectively call CHECK-MATE on the life threatening guidelines that leave many people in a state of disability and chronic illness.

If you can't play fair, then the best move is not to play. *pha*

OPEN EYE PICTURES

Dear Friends & Supporters in the Lyme Community,

As many of you know, the White House just acknowledged that President Bush has been treated for Lyme disease.

The Connecticut Attorney General is investigating the IDSA for monopoly and conflict of interest in relation to their Lyme treatment guidelines. In several states, Lyme treating physicians are being threatened by medical boards of review. And, all the while, Lyme patients continue to lose their insurance coverage, their livelihoods and even their lives. The issue and epidemic of Lyme is rapidly growing. We've been covering the untold story of Lyme for the past three years. Now we're getting closer to finishing our film, and changing the picture of Lyme disease once and for all.

Recently, our 30-minute sample clip of UNDER OUR SKIN put us in the running for the Fledgling Fund award for "Best Socially Conscious Documentary." In addition, we were awarded a screening and pitch slot

at the prestigious IFP Film Market in New York in September, which will place our project in front of top broadcasters and distributors.

Interest in the film has been high, with packed fundraising screenings in five cities; a pitch meeting with HBO; and interviews with national publications such as The Washington Post, The Scientist, and Forbes (…well, we tried). And with Michael Moore's SICKO making healthcare an election issue, we feel the time is just right for our film.

We're now in the homestretch for completing our rough-cut for Sundance submission, and we'd like to call on the Lyme disease community to help us out in this final sprint. Tax-deductible donations can be made by check to the address below (write: UOS in memo area) or online through PayPal at www.LymeDiseaseFilm.com.

We have been moved to tears and called to action by your stories, and now it's time to share these stories with the world.

Thank you again for your confidence, support and stories over the past few years!

Sincerely,

Andy Abrahams Wilson
Producer/Director

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

PHA seeks to bring information and awareness about these illnesses to the public attention. We seek to make sure that anyone struggling with these diseases has proper support emotionally, physically, spiritually and medically.

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Lyme Perspectives from a Patient and Therapist

by Margo Friedman

I was 10 years old, my neck was stiff and I couldn't move from by bed. I had just been sent home from sleep away camp in Madison, CT with a 104 degree fever, conjunctivitis and severe tonsillitis. I was given prednisone to keep my throat from swelling shut. The rest of the summer was spent recuperating, but I was left with overwhelming fatigue, weakness, body aches and throat pain.

When I started middle school, suddenly my thoughts were disorganized. I couldn't concentrate and my processing was slow. I had difficulty making it through the school day without pain or fatigue, but I managed to put a smile on my face and pretended everything was fine.

I was given allergy shots and put on short rounds of antibiotics for various sinus infections and tonsillitis over the years. For the first time the allergy shots and the courses of antibiotics were not helping. I kept getting Sinusitis and Tonsillitis.

The next year, my pediatrician told me I had Mononucleosis. I was not improving so a friend recommended an allergist/nutritionist. He diagnosed me with Chronic Fatigue Syndrome and took me off antibiotics. I was put on an allergy free/yeast free diet and was given intravenous vitamins after school. I started feeling a little better and was looking forward to starting high school. I was optimistic that my health would continue to improve.

Unfortunately, by my sophomore year I was really ill again. Now my face was very swollen and my hair was falling out from the top of my head. I would cry in the morning before school because I didn't know where I'd get the strength to make it through the day. I spent a lot of time studying and resting on the weekends to try to get through another week.
In the fall of my senior year, my pediatrician diagnosed me with Mononucleosis again. My Epstein Barr and CMV tests were positive. My liver enzymes were high, I had brain fog, I felt dizzy and my other long standing symptoms got worse. I was out of school for a month.

In spite of feeling so poorly, I wanted to return to school and enjoy my senior year with my friends. My pediatrician told me that I would feel better in about six months and not to worry about going away to college far from home. I would be fine.

I managed to graduate high school in 1994 in the top ten percent of my class. I left in August for Miami University of Ohio and by October my joints hurt so badly that I couldn't walk to class. My parents flew me home and my pediatrician gave me a Lyme disease titer. It was positive. She decided to give me two weeks of oral antibiotics.

As much as I didn't want to admit it, I knew I couldn't go back to school feeling this way. In January of 2005, I decided to return to college and was admitted to Fairfield University. It was a 10 minute commute and I could rest between classes. I began to notice that my cognitive problems were getting worse. I had neuropsychological testing, He told me that he doubted I would ever graduate from college.
A few months later, my mother found a Lyme literate doctor who put me on intravenous antibiotics. Over the next two years I was on and off oral and intravenous antibiotics. I can't remember how many PICC lines I had placed in my arms.

One night after completing my junior year in college, my body began shaking uncontrollably. My muscles became stiff and I felt like there was electricity in my brain. I was aware of what was happening, but felt spacey and confused. My face drooped on the left side. My lips kept smacking together and I heard myself making babbling noises, but was unable to stop.

I was brought to the hospital. A neurologist and psychiatrist held my hands down and told me I could stop shaking. I was given an EEG, but was shaking so hard that it was difficult to interpret. I was told I didn't have seizures. They felt my problems were purely emotional and sent me home without any medication.

My own Lyme literate neurologist gave me an EEG and diagnosed me with seizures and a movement disorder. I was put on seizure medication and a 24 hour a day pump of intravenous Penicillin, which I was on for a year. I still continued to shake and have seizures, but the intensity and frequency decreased.

I didn't want anything to stop me from my dream of graduating from college in May. My mother drove me to all of my classes and took me home to rest in between. Fortunately, I was able to graduate as I had planned with my class, cum laude, in 1999.
A month after graduation, I began my Master's degree in Counseling. Towards the end of my training, my eyes would suddenly swell and then I couldn't keep them open. Eventually, I would fall asleep. This often occurred in class and was quite humiliating for me. I worried about where and when these episodes might happen. A few years later, it was finally discovered during a 24 hour EEG test that I had narcolepsy. I was put on Provigil, which changed my life instantly. I was alert and energetic.

About 5 years ago, I was referred to a multiple sclerosis specialist who had helped another Lyme disease patient with a movement disorder. It was discovered that my immune system was overactive and he prescribed me Immunoglobulin (IVIG). I have been receiving IVIG ever since with amazing success. I no longer shake and have seizures. My neurological exams continue to improve.
I graduated in January of 2003 with my Master's degree in Counseling. I became a Connecticut certified school counselor and a Licensed Professional Counselor. I knew I wanted to provide emotional support for children, adults, couples and families struggling with Lyme disease and other chronic illnesses.

Although I had been encouraged many times to write about my experiences with Lyme disease in the past, I was reluctant. I knew many emotions would resurface and memories would be relived. The erratic, unpredictable nature of the Lyme disease often complicates the grieving process. Having a chronic, misunderstood, misdiagnosed and under diagnosed illness is traumatic. When we need compassion, understanding and support, we are often met with criticism and disbelief.

When I began writing, I started to think about the lack of support of family and friends, ignorant and often cruel comments from doctors, the difficulties with our insurance company and the loss of social and academic opportunities. When a colleague asked me what I thought I gained from having Lyme disease. I didn't have an answer. I could only think about the losses. What kind of meaning could come from such a horrible experience?

As I finished writing about my experience, for the first time I could answer his question. I learned to advocate for myself, have compassion for others and to persevere. I have given meaning to my illness by devoting my life's work to help people with Lyme disease and other chronic illnesses. Being a therapist is both healing and rewarding on many levels. If am able to make a difference in someone's life then that is what I have gained. pha

Margo Friedman is a Connecticut State Certified School Counselor and a Licensed Professional Counselor. She has a special interest in helping children with Lyme disease.

"Hope"

...cont'd from pg 2

way, and an opportunity to say "I matter" to those who would dare to dismiss these patients.

In the end, all individuals, (especially Lyme patients), are magnificent, beautiful creations of the universe. Individually we are unique, complex and though separate from one another, we are truly part of a larger whole, like the panels of Brin's Blanket of Hope, or so many stars in the autumn night sky. As I watch the shooting stars fall, I smile and release a sigh of comfort, because I know that I am not alone in my struggles with Lyme disease. Each one of us has our story to tell, our difficulties to overcome, and our voice to raise to a higher volume. Together we make up the millions of panels on a blanket or stars in the sky. And like the shiny star that is Brin King, we are collectively illuminating the dark night of ignorance and misinformation that composes the vastly unknown universe of Lyme disease.

How to contribute to Brin's *Blanket of Hope*:

The blanket consists of panels sized 4 feet by 4 feet square, with a 3 inch border around all sides, which is used to sew the panels together; and made of any material of choice. Each blanket panel has first and last name of the Lyme victim, and the date Lyme was contracted on it. You may add any design you wish. You may sew, use markers, or anything to record the information on the panel. When finished, please mail directly to Brin where your panel will be joined with the many others already received. Mail to: Brin King, 222 Mill Street, Yorkville, Illinois, 60560, USA. You may enclose a note to Brin in support of his project if you wish.

Please support this worthy project and send in your panels. Be part of the United Voice of Lyme Disease. It is by joining together as a singularly united voice that we will finally have our voices heard-as we shout, "we are real people dealing with real disease and we deserve better!" pha

The 3 Ring Circus: An Overview of the Controversial IDSA Guidelines

by Donna Reagan

Step Right Up, Ladies & Gentlemen!

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

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

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

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

Before delving into these "NEW" guidelines, I briefly scanned through the 70+-page document and realized I'd rather make cocktails out of Syrup of Ipecac than to read all the drivel which was clearly going to make me sick to my stomach anyway. Ipecac cocktails seemed, to me, to be more efficient.

Unfortunately, our liquor cabinet contains neither Ipecac nor any liquor, so I forced myself to peruse the treatment guidelines set forth by this "professional" society, comprised of individuals who supposedly took the Hippocratic Oath to first do no harm'.

For those of you brave enough to have actually read that lengthy text, I know I don't have to tell you it is full of erroneous information, possibly fraudulent, which will certainly bring harm to thousands upon thousands of Lyme disease patients if unwitting physicians follow what amounts to be a set of instructions for the novice practitioner, unfamiliar with appropriate treatment of Lyme disease.

In all fairness to the IDSA, they include a disclaimer indicating utilization of the guidelines is 'voluntary'. However, when the Centers for Disease Control (CDC) quickly adopt such guidelines and recommend them on their website as THE 'guidelines' I find the word 'voluntary' to be more insidious than comical …like a clown performing an overly violent sideshow of slapstick, smiling all the while.

It should also be noted, it did not take the health insurance industry much time at all to seize what "voluntary" content it desired to use as a means to deny coverage of important treatment options for patients, such as specific and necessary antibiotics. Some may argue the guidelines are not a legally binding document, therefore patients and their physicians can choose to follow whatever treatment options they desire.

Ah, if this were only the case! While that may be true in the legal sense - we must not forget that perception makes reality, and the reality for patients and the physicians who treat them is the Infectious Disease Society of America carries a great deal of authority. Lest we forget -- these new guidelines also have the power and authority of the CDC behind them, although it is WE, the people, who have given away that power and authority with every patient who needlessly suffers with this atrocious disease.

Get Your Popcorn & Peanuts Here!

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

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

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

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

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

The directive to use "laboratories with excellent quality-control procedures" further complicates this picture because it creates a big hole for interpretation. Realizing it's not a sound financial decision for people to actually be cured, as healthy folks do not make the best healthcare consumers - can you imagine where morally debased physicians, other big business interests, and big Pharma will land on this issue?

While one would certainly expect that any lab used for such important diagnostic validation would be those with "excellent quality-control procedures," the interests of those above mentioned groups would insist upon the utilization of laboratories that do not identify the specific Western Blot bands most likely to validate a diagnosis of Lyme disease.

Furthermore, the CDC is quite aware there are other guidelines which have proven

"IDSA Guidelines"...cont'd p 6

The Faith Factor...

by Joan Vetter

Lean Not to Your Own Understanding

What a devastating diagnosis for a 9th grade freshman girl - scoliosis or curvature of the spine. The "prescription" was to wear a full torso, neck and head brace 22 hours a day, 7 days a week. Kathy Vosburg cried, felt sorry for herself, couldn't sleep, and cried out to God, "Why me - why should a child of God be crooked and unattractive." Kathy believed in healing and prayed for a miracle. However it wasn't until she was a divorced 41 year old mother of two girls and living with her parents that she began to realize that to bring up her daughters and provide for them all, that she had to be the healthiest that she could be. She began to meditate on the Word without ceasing, praying for wholeness and a healthy chance to start a new life with her daughters, whatever that meant or looked like. One morning she woke up to the realization that her constant pain was gone. Her body was still crooked, but she said to God, "O.K., I'll take whatever you'll give me and be grateful."

Then four years later, Kathy's right hip began to hurt - a new malady. She knew that if God could remove the pain from 28 years of Scoliosis, He could touch this hip in the same way.

One Sunday her pastor had a word of knowledge from the Lord and said, "Someone is having hip pain and you are to be healed". Kathy went forward, and a woman who also ministered to her said she was getting the word "Re-alignment." By the end of the week Kathy was in greater pain, with the entire left side of her back full of knots. In fact she could barely move. The Lord sent a friend who gave her a deep tissue massage. The next night Kathy woke up with a clear revelation - that God was aligning her spine, and the muscles in her back were not used to being in the new and normal position that they were forced into by the progressive healing. She got up early that Sunday morning overjoyed, and in absolute awe and amazement at the defining moment when she stood before the mirror to view a body that had not stood straight for 32 years. Her shoulders were parallel and her arms hung straight at her sides!

Kathy Vosburg Miller is now remarried and the principal designer of her own landscape company. She is grateful to a God who was able to re-design her body to reflect His Glory. She states, "His miraculous healing power is there for us all to embrace. We just need to open ourselves up, expecting God to touch us, but not telling Him how or when to do something. He's got His own plan in mind for us all. We just need to be still and know that HE is God."

pha

Joan Vetter is a church member at The Vine Fellowship in Arlington, Texas. She is also on the Area Team of Women's Aglow International www.TheVineFellowship.org

"IDSA Guidelines"...cont'd from pg 5

to be more effective, and are in fact, clinically tested guidelines provided by the International Lyme & Associated Diseases Society (ILADS). Yet the CDC's own website fails to mention them. I find it intriguing that the CDC does not choose to recognize how the recommendation of these "NEW" and rigid IDSA guidelines, in lieu of the more effective ILADS guidelines, reflects poorly upon the attainment of their own mission statement: "To promote health and quality of life by preventing and controlling disease, injury, and disability." (http://www.cdc.gov/about/mission.htm)

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

"To base all public health decisions on the highest quality scientific data, openly and objectively derived. To place the benefits to society above the benefits to the institution."

Perhaps the biggest irony here is the IDSA guideline writers do not treat chronic forms of this spirochetal infection because they don't believe in it. "In many patients, post treatment symptoms appear to be more related to the aches and pains of daily living rather than to either Lyme disease or a tickborne coinfection. Put simply, there is a relatively high frequency of the same kinds of symptoms in "healthy" people." (IDSA Guidelines - Post Lyme Disease Syndrome, pg. 33)

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

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

Yet a reasonable question to me is 'How can IDSA dictate the method and manner other physicians are to employ to treat or rather, NOT to treat, various forms of this chronic disease when they don't believe in it?'

To me, that's like an atheist dictating to Jews, Muslims, and Christians how they are to worship, or rather, NOT worship God. Isn't it?

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

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

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

Animals on Parade

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

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

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

These scientists, along with their many secret successors have tinkered with a wide assortment of nasty microorganisms that can be delivered upon a population through various vectors (Vectors are "carriers" such as ticks and mosquitoes. See http://www.cdc.gov/ncidod/dvbid/). Such laboratory achievement comes with risk, and it also requires experimentation. Some of us are victims of poorly enforced laboratory safety standards, and some of us are the unlucky subjects of said "experimentation" simply because of our weakened immune systems, and its inability to keep a host of unwelcome microorganisms at bay.

Again, I may sound like a conspiracy nut - which would be the precise impression many of the players in this scenario would prefer. But sometimes the ugly truth must be exposed. To borrow a phrase from a friend- Lyme is a weapon of mass infection. Focus on the facts; follow the story. There's a seedy undercurrent in some of our health bureaucracies (the CDC) because some of the primary agendas are to maintain secrets which would surely cause severe backlash if the American people were finally to know.

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

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

Recently I was reminded of the old adage about the blind men and the elephant; how each of the blind men described different parts of the elephant and each were quite certain their own description was the 'right' one. If that axiom can be applied to this particular situation, may I humbly suggest which part of said elephant (standing prominently in the middle of the room) the alleged medical "professionals" from the IDSA & CDC are describing? Although comparatively BIG - I assure you nothing of much use comes out of that end, unless of course you need it for your compost bin. *pha*

Donna Reagan is the leader of the DFW Lyme support group in Texas. This story is re-printed from an earlier edition of the PHA. With the recent TV awareness and coverage of Lyme issues, we felt it would be good to review the issues surrounding the IDSA guidelines.

Major Causes of Sleep Disorders in Chronic Pain/Fatigue States

by Dr. Jonathan Forester, M.D.

Sleep is the caretaker of the brain, a necessity for positive well being. In sleep studies where healthy patients were kept awake, at seventeen hours symptoms of impaired cognition and fatigue began to emerge, and worsened as time progressed.

But sleep is more than just being "not awake". It is clear that certain phases of sleep are paramount for health. In one study, college students were allowed to sleep, but were awakened before entering delta or stage 3 /4 sleep (commonly called deep sleep). Otherwise, they slept through the night. Most complained of pain, fatigue, and cognitive dysfunction the following day.

Another study revealed that the pro-inflammatory cytokine, TNF-alpha increases as the nocturnal awakening progresses. When physiologic somnolence occurs, this cytokine shuts down. However, if insomnia persists, then TNF-alpha continues to rise the following day, and was not surprisingly associated with generalized myalgias and pain.

It is well known that growth hormone, which is a necessity for quality of life, is secreted during delta sleep. Since most Chronic Fatigue Syndrome/ Fibromyalgia (CFS/FMS) patients have inadequate growth hormone levels, impairment of delta sleep is a postulated mechanism. Most FMS patients are overweight, a fact that may be associated with lack of sleep.

In the *Wisconsin Cohort Study*, those patients who slept 5 hours or less were found to secrete 15% more ghrelin (adipose hormone that stimulates appetite) and 16% less leptin (adipose hormone that decreases appetite). Many other studies have subsequently proven, not only the critical importance of sleep, but its cyclic activity, and its relationship to quality of life issues.

In fibromyalgia and other chronic neuropathic pain states, such as spinal injuries, chronic Lyme disease, and transformed migraines the appropriate treatment (ie, Gabapentin, Tiagapine) for stage ¾ impairment generally promotes a concomitant decrease in pain and fatigue, as well as an improved cognition. Otherwise, sleep is disordered and may be compared to insomnia. In essence normal cycling of sleep is significantly impaired in one of three major ways.

1. Alpha-intrusion. The alpha wave on the EEG is an "awake" wave occurring during daytime hours and should disappear during sleep. If it occurs during sleep, it disrupts and distorts delta sleep. This probably represents dysautonomia and is in part due to an abnormal sympathetically induced neural discharge(s) likely due to the pain. Chronic pain states are predictive of alpha-intrusion and cause the pain sufferer more pain the following day. Therefore, it is an enemy to both restorative sleep and quality of life.

Nightly alpha waves may be compared to a mild thunderstorm in the brain with frequent lightning strikes, disrupting normal electrical brain activity during a night of peaceful sleep.

Treatment of this abnormality includes:

a. Low dose tricyclic antidepressants (tca's) includes amitryptiline (Elavil), doxepine (Sinequan), imipramine (Tofranil), the latter having the mildest side effects.

b. Muscle relaxants cyclobenzaprine (Flexeril) and tizanidine (Zanaflex).

c. Tiagapine (Gabitril) initially shown to be an effective medicine for anxiety, has very salubrious effects on both the alpha EEG disorder and on RLS/PLMS. On paper it appears an almost perfect medication for the chronic pain sleep disorder, but side effects may limit its usefulness.

d. Gamma hydroxybutyrate (GHB) a drug previously removed by the US FDA, but can be prescribed now for the use of sleep disorders. It has an incredibly positive effect on the sleep cycle, including removal of the alpha wave and the improving of delta sleep.

e. Hormone therapy including growth hormone, DHEA, and testosterone, if abnormalities exist, appropriate replacement may improve the quality of sleep. Natural estrogen and progesterone are likely helpful, but are unproven.

f. GABA agonists such as zaleplon (Sonata) and zolpidem (Ambien) do not alter normal sleep architecture, however, neither do they remove sleep dysregulations, and are therefore only used adjunctively in FMS. The have a short half-life of one and three hours, respectively which is great for the average insomniac. For chronic pain patients, these agents may not provide adequate sleep time. I have found that zolpidem is the most effective of the two in FMS/CFS.

g. Eszopiclone (Lunesta), a new novel non-benzodiazepine, with a six hour half-life may be an excellent adjunct for these sleep-resistant illnesses. Recently, in some of my FMS patients, this drug has greatly decreased, if not eliminated, pain on the subsequent day. As far as I know there are no studies to explain this salubrious effect. I personally believe it may be down-regulating NMDA activity in addition to a possible decrease in alpha activity.

h. Exercise which of course must be limited in FMS/CFS patients is effective in improving delta sleep and removing alpha interference.

2. Restless Legs Syndrome/ Periodic Limb Movements of Sleep (RLS/PLMS) are abnormal limb movements which are interruptive of the normal sleep cycle. The former is described as an unusual stretching or motor activity of the legs, causing a sensation whereby no position is restful. The problem occurs or worsens at night, or during the day when the patient is at rest. The latter is abnormal jerks or flings of the limbs occurring spontaneously. Both represent downregulated dopaminergic pathways and will consistently interfere with normal sleep. The same medications will improve either or both conditions. It is worthwhile to restate that fibromyalgia represents a low dopamine state. The treatment includes:

a. Mineral therapy, primarily FeS04 if serum ferritin <50. Remember that iron is a cofactor of l-Aromatic amino acid decarboxalase enzyme in the conversion of l-DOPA to dopamine, and chelated Magnesium salts, which have calming effect on the CNS. These are a necessity in the pre-drug treatment plan.

b. Clonazepam (Klonipin), a time-honored treatment for RLS, is a benzodiazepine. It promotes sleep, but only masks the true problem of increased motor movement due to a lack dopamine. This drug plus gabapentin, in the past has been my favorite combination for these restless limb activities. Recently, however, I am prescribing ropinirole (discussed below) plus gabapentin as my first choice for three reasons.

1. Addictive potential of clonazapam is eliminated

2. Dopaminergic stimulation, lacking in FMS, is improved.

3. Neuropathic pain is significantly diminished in most patients.

c. Gabapentin (Neurontin), an anti seizure medication, used more so in neuropathic pain, migraine prevention, now proven to be effective in RLS/PLMS. This GABA agonist (most likely the mechanism of action) also decreases central pain sensitization, and is one of the very few medications that improve delta sleep. Prescribed in increasing doses at bed time, it is my drug of choice for FMS and chronic pain.

d. Antiparkinson medications, includes L-DOPA/carbidopa, Pramipexole (Permax), pergolide (Mirapex)…to name a few. My experiences with these medications have been disappointing due to side effects. However, one of these dopaminergic agonists, ropinirole (Requip) is the first drug to have a U.S. approved indication for RLS. With a low drop out rate due to side effects, the effectiveness is virtually unmatched. The major side effect, nausea, is usually transient, and the second most common, sedation, in my view is welcome, since this medication is administered an the evening. It is my drug of choice.

3. Obstructive sleep apnea (OSA). OSA is a disruptive sleep disorder characterized by loud cyclical snoring associated with cessation of breathing.

Risk factors include obesity, hypothyroidism, and narrowed upper airway, to name a few. Hypersomnolence, fatigue, pain exascerbation, corpulmonale, hypertension, arrhythmias, and sudden death are complications. Definitive diagnosis is made by a polysomnogram in a sleep lab, in which apneic episodes may be observed to last up to one to two minutes.

Treatment includes:

a. Weight loss is the most important recommendation for patients, since a significant number have a BMI greater than 27.

b. Continuous positive airway pressure (CPAP).

c. Uvuloplasty if indicated.

d. Allergen immunotherapy or allergy medications.

e. Nasal septoplasty if gross abnormalities exist.

f. Mandibular surgery.

g. Dental splints.

ONE FINAL NOTE: for those patients who are cognitively impaired, drowsy, and atigued after a poor night's sleep, the non-addicting medication, modafinil (Provigal) may be the answer. It was curiously given a schedule IV classification by the US FDA. It's mechanism of action is thought to be in the histamine and orexin pathways of the hypothalamus, and not in the adrenergic system of the CNS, like sympathomimetics, which induce tolerance and habituation. It is very well tolerated, and very effective for hypersomnolence in most patients. pha

Dr. Jonathan Forester has a medical practice in Pineville, Louisiana where he deals with Chronic Lyme. He has recently begun taking pediatric cases with children over 3 years old. He is the owner of The Christian Oasis and he recently returned from a medical missions trip to Zimbabwe, Africa.

NVIC Analysis Shows Greater Risk of GBS Reports

When HPV Vaccine Is Given with Meningococcal and Other Vaccines

Washington - The National Vaccine Information Center (NVIC) today issued a new report on HPV vaccine (Gardasil®) safety analyzing adverse event reports to the federal Vaccine Adverse Event Reporting System (VAERS). The analysis gives evidence for a reported association in VAERS between Gardasil and Guillain-Barre Syndrome (GBS), with a statistically significant increased risk of GBS and other serious adverse event reports when Gardasil is co-administered with other vaccines, especially meningococcal vaccine (Menactra®).

NVIC is calling on the Centers for Disease Control (CDC) to issue an Advisory and amend its March 12 policy by alerting the public that Gardasil has been associated with 15 cases of GBS and an increased risk of GBS and other serious adverse event reports made to VAERS when the vaccine is administered simultaneously with Menactra and other vaccines. "The precautionary principle dictates that good science should precede CDC vaccine policy recommendations," said Barbara Loe Fisher, NVIC co-founder and president. "Parents have a right to expect proof of safety and not assumption of safety before new vaccines, like Gardasil, are given simultaneously with other vaccines to their children.

GBS is a disorder in which the body's immune system attacks part of the peripheral nervous system, and can cause total paralysis. "Our analysis of Gardasil reports to VAERS indicates there was a two to 12 times greater likelihood that serious adverse events, such as GBS, were reported when Gardasil was given in combination with Menactra rather than given alone," said Vicky Debold, PhD, RN, NVIC director of patient safety. "Accepted scientific standards indicate that these findings are statistically significant and cannot be dismissed as coincidence. In particular, the available VAERS data show there was a more than 1,000 percent increased risk of GBS reports following Gardasil administration when Menactra was given at the same time."

Reported GBS and Other Serious Adverse Events

NVIC found that, as of May 31, there have been 2,227 Gardasil adverse events filed with VAERS, including 13 suspected or confirmed cases of GBS (two more GBS reports were made in June for a total of 15) and 239 cases of syncope (fainting with temporary loss of consciousness), many of which resulted in head injuries and fractures. Seven deaths have been reported after receipt of Gardasil. Nearly 10 percent of all Gardasil adverse event reports to VAERS involved avoidable medical errors.

A total of 1,930 reported Gardasil adverse events involved administration of Gardasil alone, and 135 adverse events involved co-administration of Gardasil with Menactra. NVIC's comparative analysis of those two categories of VAERS reports indicates that when Gardasil was given simultaneously with Menactra rather than alone, there was a statistically significant increased risk of reported adverse events:

* respiratory problem reports increased by 114 percent;
* cardiac problems reports increased by 118 percent;
* neuromuscular and coordination problem reports increased by 234 percent;
* convulsions and central nervous system problem reports increased by 301 percent;
* reports of injuries from falls after unconsciousness increased by 674 percent; and
* GBS reports increased by 1,130 percent.

On February 21, NVIC expressed concern about the safety of administering Gardasil simultaneously with other vaccines because the manufacturer (Merck), the FDA and the CDC had not provided evidence to the public that co-administration was safe. (1) On March 12, the CDC published recommendations for Gardasil use in MMWR that acknowledged there is a lack of evidence that Gardasil can be safely administered with other vaccines, while encouraging physicians to co-administer Menactra and other vaccines with Gardasil based on assumption of safety. (2)

Adverse Event Reports to NVIC: Shannon Nelson

Nineteen Gardasil adverse event reports from 12 states have been made to NVIC's Vaccine Reaction Registry involving unconsciousness and injury, convulsions, numbness, weakness and other neuromuscular and coordination problems and GBS.

Shannon Nelson, 18, a Chicago area athlete, musician and artist entering college reported to NVIC that she received HPV vaccine (Gardasil), meningococcal vaccine (Menactra) and chicken pox vaccine (Varivax ®) simultaneously on June 21. Symptoms of tingling, numbness and muscle weakness began within a week and progressively got worse. By July 3 she could barely walk or raise her arms. She was hospitalized, paralyzed with GBS on July 5, and spent 22 days in the hospital.

"Before the shots, I ran six miles a day," said Nelson. "The doctors told me that I might have been put on a respirator if I hadn't been in such good shape," she said. "I am out of the hospital now and getting a lot of physical therapy. I just want to go to college and do the things I did before, like play the guitar and draw or even just be able to smile. My Mom and I wish we had known about HPV vaccine risks, especially what could happen if I got other vaccines at the same time."

To view a copy of NVIC's report on HPV vaccine (Gardasil) safety, go to www.nvic.org/Diseases/HPV/HPVHOME.htm. pha

To report a vaccine reaction:
www.nvic.org/report/reaction.htm.

http://www.nvic.org/Diseases/HPV/pr022107HPV. htm.

Learn more about vaccines, diseases and how to protect your informed consent rights at www.nvic.org

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Founded in 1982, the National Vaccine Information Center (NVIC) is a non-profit (501C3) organization working for child health, public education and consumer empowerment. NVIC is dedicated to preventing vaccine injuries and deaths .

What Parents Need to Know About Alcohol and Drug Addiction

Part 2: an Interview with Dr. John Flemming, M.D.

by Sue Vogan

The behaviors of addicts may begin early in the addiction process? Correct?

Correct. We typically think of lying and manipulation of addicts and their ability to "train" those around them to be enablers as a post-addiction process. However, after observing kids at various levels of the addiction process, I must say that these behaviors usually PRECEED full blown addiction. That is why if parents are trained to extinguish these maladaptive behaviors in kids as they emerge; they have a much better chance of preventing addiction.

This includes deceptive behavior, dishonesty in relationships, lack of character, unwillingness to take responsibility, tendency to run away from problems, moodiness, low self-esteem, family problems, poor job/school performance, legal problems.

As you go through this list, you could apply these characteristics to kids in general. That is why many authorities conclude that addiction is not a change of behavior toward a self-centered existence but rather lack of growth in all spheres of personality---emotional, maturity, honesty, character, etc. Kids begin life as "the center of the universe". Only after growth and maturity do they become responsible, caring adults who can parent others. Addicts never transition to maturity. They become vapor-locked into a self-centered, self-deceptive, immature existence. This becomes so extreme in some cases that young children in a family of addicts will often take on the role of parent for the addict in very unusual and unexpected ways.

Is drug addiction preventable - if so, how?

YES! The facts are quite biological. If parents do nothing more than keep their kids from using any addicting substance until at lease age 18, they will have done a lot (and much more than most parents) toward lowering the risk of addiction to near zero. The other things are important, too, but this is of paramount importance.

One of the things that lead people to addiction is depression. What causes depression and what are the top 3 signs of depression?

Depression is a strongly inherited disease that strikes 10-20% of the population at some time in their lives. It occurs when one or more of three main neurotransmitters of the brain drop to inadequate levels. Treatment requires antidepressant medication, which does nothing more than gradually increase the levels back to normal. The classic symptoms of depression include feeling depressed, feeling hopeless and insomnia.

In recent years research has shown us that depressive disorders include a lot more symptoms than this. We now know that many people with depressive disease do not even feel depressed at all. Recent research has shown us that this deficiency of brain neurotransmitters may manifest itself also as fatigue, anxiety, short temper, obsessive thoughts and behaviors, chronic pain, bowel and muscle pain, just to name a few. So, any depressed person may have any combination of these symptoms. We have called this problem depression for many years because that was the first symptom that brought us to understand this disorder. We now know that the symptom of feeling depressed is just the "tip of the iceberg."

Do people suffering from depression always know they are depressed?

No, often they do not. Sometimes they feel bad and want to know what medical disease is making them feel that way. They are often skeptical at first when they are diagnosed to have depressive disorder. They become believers when the medication makes them feel normal again. Even more surprising is the fact that depressed people feel that they are perfectly normal. They will come with a spouse of parent to see the doctor because they have become difficult to live with and have no perceived symptoms of anything! Even after beginning medication, they may have no insight into their problem except that people around them find them much more pleasant to live with. Parenthetically, I must add that antidepressant medications have absolutely no potential for abuse or addiction. I carefully explain why in my book.

What type of help is there for depression and is it safe?

Antidepressants are the "gold standard" for treatment. They are safe and effective. There has been some discussion lately that they may increase suicide or homicide rates among those being treated. This is quite rare. Many people with depressive disorder may benefit from counseling as well because stress and life problems may be contributing factors.

Many have said that antidepressants make them feel like a zombie; men claim it interferes with their sex life. Please comment.

The "zombie" complaint was much more common when we used the older forms of antidepressants. The modern medications we use today will rarely cause any such effects in proper doses. The goal is always to feel normal. If that does not occur, the medicine should be changed.

There is no question that antidepressants can cause delayed orgasm in both men and women. In men this is usually viewed as a benefit as premature ejaculation is a common male problem. In higher doses, libido may also be affected. There is one antidepressant, Wellbutrin, which appears to have no negative effect on sexual function. In fact, I and other doctors have heard anecdotal stories from female patients that it enhances their orgasmic intensity. Therefore, sometime we will substitute it for other antidepressants or give a combination of both.

The facts are quite biological. If parents do nothing more than keep their kids from using any addicting substance until at lease age 18, they will have done a lot (and much more than most parents) toward lowering the risk of addiction to near zero.

ADD is also another cause for depression. What causes ADD?

Humans, though we have the highest intelligence among all mammals, have the longest delay in our ability to begin learning. This is why kids aren't sent to school just after birth. The reason is that the human brain matures slowly. Some parts of the brain develop slower than others. There is a genetic tendency in about 3% of the population for some kids to mature very slowly in the part of the brain that manages attention span. So, while their young "minds of mush" are well prepared to learn, the circuitry that manages attention span will not allow them to focus long enough to effectively learn.

Can adults suffer from ADD and how will they know?

Yes, a certain percentage of kids will continue to have this problem on into adulthood. Most will not require medication as they will no longer be in a learning environment.

Some have speculated that ADD may be caused by vaccines. Is there any truth to this?

Nope! It has been extensively studied and there is no truth to this. ADD is clearly passed on genetically from parent to child. Like depression, ADD has become a political football such that certain groups with an angle or "axe to grind" have used to be critical of what are really very important and effective treatments. For instance, the Church of Scientology has been critical of treatment of both of these conditions. But as their organization and beliefs are neither a church nor based on science, it is clear that their arguments are dishonest and self-serving in my opinion.

How is ADD diagnosed and treated?

Though the practice of medicine has become high-tech in many ways, there are still many medical conditions that can be diagnosed only the old fashioned way---with a good history and physical exam. ADD is one of these.

Having said this, it is not hard to diagnose ADD. Typically these kids are unable to stay on task based on age-adjusted norms. They may or may not demonstrate excessive movements or energy, which is commonly referred to as hyperactivity.

What critics fail to understand about the treatment of this condition is that medication in the proper dose does not "drug" or sedate the child in any way. We use stimulants like Ritalin, which activate the under-active part of the brain that controls and manages attention span. It is very easy to determine the effectiveness of treatment. We simply gather before and after treatment reports from the teachers and parents and follow the child's academic progress. If properly diagnosed and treated, these kids will blossom.

Sometimes kids are presented by parents or teachers with a complaint of ADD, yet they turn out to have something else. Most commonly this turns out to be simply a lack of home discipline. Another common issue is depression. Childhood depression can manifest as lack of attention span also.

Sometimes kids are brought to me with a complaint of ADD with hyperactivity because they won't sit still in class, yet they make straight A's. Usually these kids are simply bored as they are highly intelligent and are simply not challenged enough.

Is ADD among the list of chronic diseases?

No. By chronic disease, I am referring to adult diseases with a definite potential for disability and mortality. They fall into two categories---heart disease and cancer. These two categories make up the vast majority of causes of premature death among adults. By premature I mean death before 100 as humans clearly have the potential to live that long if not succumbing to a chronic disease.

Can we prevent chronic disease?

The vast majority of chronic diseases in these two categories are either preventable or manageable all the way until death from old age---100.

The top three chronic diseases (heart disease, diabetes, cancer) are a serious concern for the American public. Are there any steps that we can take to reduce our risks of these diseases?

Presently I would consider diabetes to be part of the "heart disease" group. I will split the two major groups into subgroups and indicate what we can and should do to prevent disability and death from them.

1. Heart Disease: We are referring to coronary artery disease and peripheral vascular disease here. These lead to strokes, heart attacks, congestive heart failure and kidney failure.

a. Prevention

1) Avoid diabetes by controlling weight and exercising regularly.

2) Aggressively search for and treat pre-diabetes in all adults.

3) Check blood pressure periodically and take medication to control it if it occurs.

4) Check for and manage high LDL cholesterol levels. If LDL is brought down low enough,
arterial disease may even be reversed.

5) Eat a proper diet, but this is actually less important than controlling weight and exercising.

6) Consider getting a periodic treadmill test or even the new heart CAT scan that can diagnose heart disease in its earliest and most treatable stages.

b. Treatment

1) Daily baby aspirin for all adults.

2) Consider taking Omega 3.

3) Exercise and weight control.

4) Aggressively search for and treat pre-diabetes in all adults.

5) Aggressively push LDL cholesterol levels as low as possible.

6) Aggressively treat diabetes.

2. Cancer: The most common cancers are the ones that we can best prevent or treat early.

a. Prevention

1) DON'T USE TOBACCO OF ANY KIND!

2) Avoid excessive sun exposure.

3) Control weight and exercise.

b. Early detection

1) Mammograms for women as outlined by their physician.

2) Annual breast exams for women.

3) Periodic colon exams for men and women after age 50 or younger if there is a family history of colon cancer.

4) PSA blood test for black men over 40 and other men over 50 at least every 3 years. Prostate cancer is a common cancer among older men and it is easily treated if discovered early. pha

Treating HIV-Infected Infants Early Helps Them Live Longer

by NIH News

Hundreds of thousands of babies around the world are born each year with HIV -- more than half a million in 2006 alone. Caring for these children is complicated by the fact that their immune systems are not fully developed in the first year of life, which makes them especially susceptible to rapid HIV disease progression and death. The current standard of HIV care in many parts of the world is to treat infants with antiretroviral therapy -- but only after they show signs of illness or a weakened immune system.

Now the initial results of an ongoing clinical trial sponsored by the National Institute of Allergy and Infectious Diseases (NIAID), part of the National Institutes of Health (NIH), suggests that more HIV-infected infants survive if they are given therapy early on, regardless of their apparent state of health.

This trial, called the "Children with HIV Early Antiretroviral Therapy" (CHER) study, is a phase III, randomized clinical trial led by Avy Violari, M.D., FCPaed (SA), of the University of the Witwatersrand in Johannesburg, South Africa, and Mark Cotton, MBChB, MMed, of the University of Stellenbosch in Cape Town, South Africa. Dr. Violari will present these findings on Wednesday, July 25 at the 2007 International AIDS Society Conference in Sydney, Australia.

"Children with HIV infection frequently show rapid disease progression within the first year of life due to their developing immune systems and susceptibility to other serious infections," says NIH Director Elias A. Zerhouni, M.D. "This is the first randomized clinical trial that shows that infants treated before three months of age will do better than infants who have their treatment delayed."

"The results of this trial could have significant public health implications worldwide," says NIAID Director Anthony S. Fauci, M.D. "Because these findings will cause experts to consider changes in standards of care in many parts of the world, NIAID has released details of the interim results to the World Health Organization, local ethics committees, regulatory authorities and other key stakeholders for their consideration and evaluation for possible implementation."

"Children with HIV infection frequently show rapid disease progression within the first year of life due to their developing immune systems and susceptibility to other serious infections," says NIAID Director Anthony S. Fauci, M.D. "This is the first randomized clinical trial that shows that infants born with HIV do better if you treat them sooner rather than later."

These initial results also highlight the importance of diagnosing HIV infections early -- within the first six to twelve weeks of life," says Edward Handelsman, M.D., chief of the Pediatric Medicine Branch in NIAID's Division of AIDS, which is overseeing the CHER study. Dr. Handelsman stresses, however, that the study results cannot necessarily be generalized to asymptomatic adults or older children because young infants are very different in immune function, time since HIV infection and susceptibility to other serious illnesses.

The evidence came to light last month after a routine review by the trial's data and safety monitoring board (DSMB), an independent committee composed of clinical research experts, statisticians, ethicists and community representatives from Africa, Europe and the United States that regularly reviews interim data from the CHER study to ensure the safety of study participants.

CHER had begun two years earlier to evaluate whether early antiretroviral therapy given over a limited period of time would delay disease progression. The idea was that this approach might allow the immune system to develop and possibly allow the child to stop treatment for a period of time and therefore avoid continuous therapy from an early age.

Starting in July 2005, HIV-infected infants between 6 and 12 weeks old without immune suppression or severe symptoms of clinical disease were enrolled at the Perinatal HIV Research Unit in Soweto and Tygerberg Children's Hospital in Cape Town. By early 2007, 377 babies were enrolled in one of three groups -- those receiving immediate antiretroviral therapy for 40 weeks, those receiving immediate antiretroviral therapy for 96 weeks, and a control group whose treatment was initiated after doctors observed signs of clinical or immunological progression toward the development of AIDS (the current standard of HIV care in many parts of the world).

The trial is designed to continue through 2011, but after reviewing early trial data on June 20, 2007, the DSMB found a significant increase in survival among infants who received immediate antiretroviral therapy. At the time of the DSMB review, 96 percent of these children were alive, compared to only 84 percent of the children in the control group. Based on this finding, the DSMB concluded that providing early antiretroviral therapy to infants is more effective in preventing early death than delaying treatment until clinical or immunological disease triggers are observed.

The DSMB recommended that no additional infants be placed in the deferred-treatment arm of the study and infants previously enrolled in this arm be evaluated for potential initiation of antiretroviral therapy. NIAID accepted these recommendations and informed the study investigators at each site. The doctors at those sites have been contacting the parents and legal guardians of the infants involved in the study to inform them of the interim findings and call them in for evaluation. The DSMB also recommended that all infants enrolled in the study be followed for the planned duration of approximately 3.5 years and those in the 40- and 96-week treatment groups continue with the study.

For more information about the CHER study, see www3.niaid.nih.gov/news/QA/cher_qa.htm.

NIAID is sponsoring the CHER trial through the Comprehensive International Program of Research on AIDS (CIPRA) program, which supports research and development efforts in resource-limited areas to create practical, affordable and acceptable ways to prevent and treat HIV/AIDS in adults and children The trial is part of the CIPRA-SA collaborative research program, led by James McIntyre, MBChB, FRCOG, of the Perinatal HIV Research Unit. *pha*

National Support Groups

National Multiple Sclerosis Association:

www.nmss.org

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

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

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700 Broadway, Suite 808
Denver, CO 80203-3442
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1.800.FIGHT.MS

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Email: info@flc.nmss.org
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8111 N. Stadium Drive,
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Phone: 713-526-8967

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http://www.alsinfo.org/
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toll free: (866) 348-3257
fax: (301) 978-9854

Great Philadelphia ALS Chapter
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South Texas Chapter
http://www.alsa-south-tx.org/
(210) 733-5204
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Greater Austin Area Lyme Council. Teresa Jones
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Contact PJ Langhoff
(920) 349-3855
www.Sewill.org
www.LymeLeague.com (Intl)
Lyme Coalition of N. Wisconsin
Pat Jackson (715) 356-3364
www.pattyknack.com
pattyknack@charter.net

CALLING ALL TEXAS LYME PATIENTS AND CAREGIVERS!

STAND UP FOR LYME (SUFL) invites you to join our email list to receive news of advocacy activities and events promoting awareness of and solutions to issues faced by Texas patients.

To join the list, go to www.standupforlyme.org and click the "Contact Us" link in the left hand side menu bar. Then have a look around the site to learn more about Lyme in Texas and the nation.

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

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

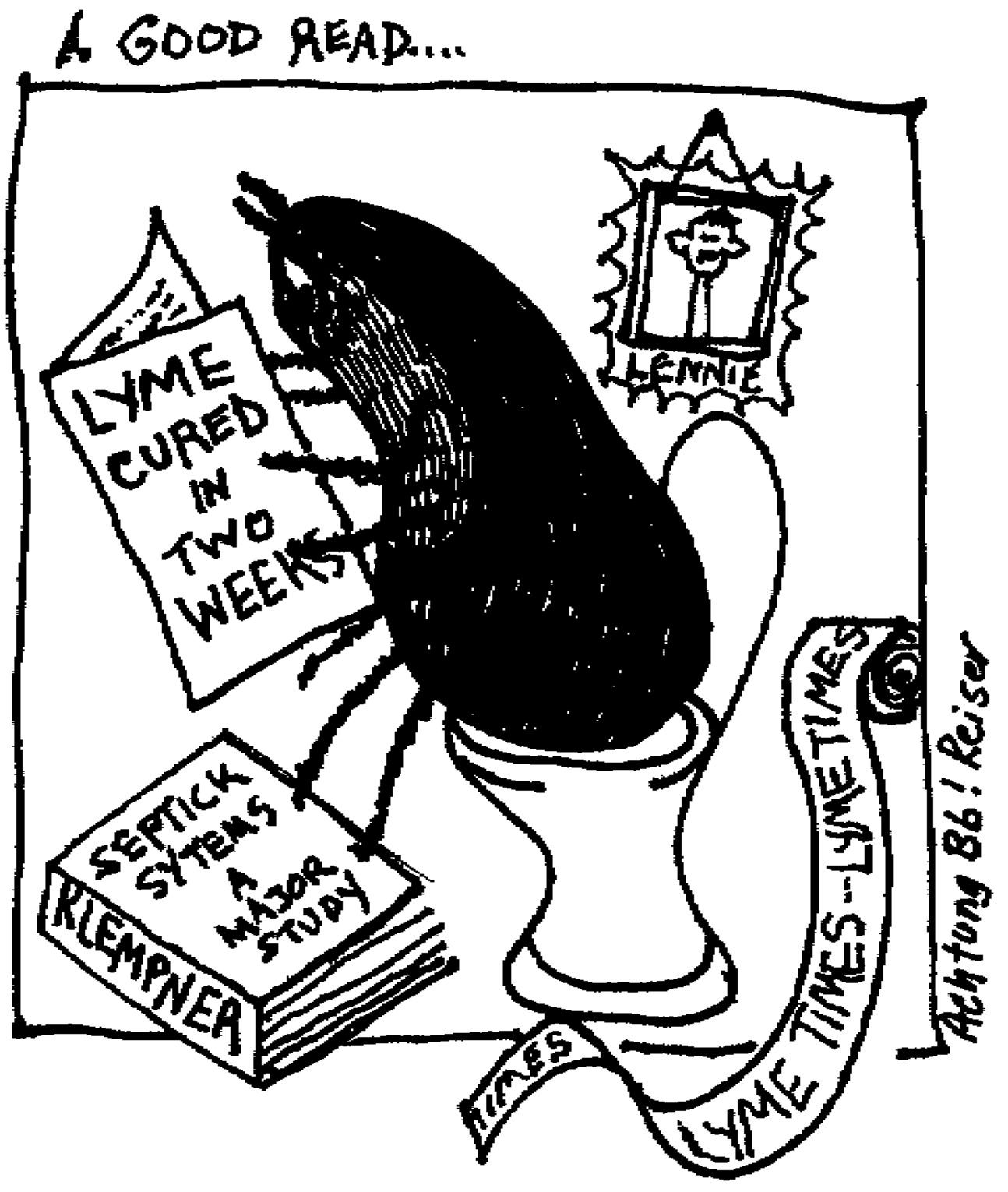
Working together we can make Texas a leadership state for quality care of those suffering from Lyme and associated vector-borne diseases.

Join us!

The STAND UP FOR LYME Team

www.standupforlyme.org

Ticktoons



by Terri Reiser

Miss Cumberland County Educates Seniors on Lyme Disease Awareness

by Maggie Sabota

One of my goals as Miss Cumberland County has been to present my Lyme Disease Awareness platform to a wide variety of age groups. In the spring I focused on educating children, while this summer I focused on educating seniors. During the month of July, I visited several local senior centers and gave presentations on Lyme disease.

One key point that I chose to focus on was the fact that Lyme disease likes to disguise itself as many other illnesses, such as Parkinson's disease, Alzheimer's disease, Multiple Sclerosis, Lupus and Rheumatoid Arthritis. Many of the seniors shared with me their own experiences with Lyme disease.

Several people expressed that they were misdiagnosed several times before they discovered it was Lyme. Symptoms like sore joints, headaches, memory loss, or trouble concentrating are often just dismissed as normal aging, when in fact they could be symptoms of Lyme disease.

Another concern often brought up was proper tick removal. Many of the seniors had heard conflicting information about removing ticks, from drowning them with water to suffocating them with petroleum jelly. I encouraged them to just use tweezers and pull the tick straight out. We also discussed the importance of using a magnifying glass to check for ticks. These pencil point sized bugs are very difficult to see, especially with poor eyesight.

Talking with the seniors was truly a rewarding experience. It is always encouraging to have an appreciative and responsive audience. I also gained a different perspective on how Lyme affects people of different ages. Along with my presentations, I sang patriotic songs and autographed pictures. I loved how the seniors treated me like I was famous! It made me feel really special and I was happy to share this important message with them. *pha*

Sharing Our Stories: SOS

by Laura Zeller *laura@wildcondor.com*

The Anna Duffy Story

Anna Duffy's Lyme disease story begins like many others. However, her particular struggle with rapid onset neurological symptoms, and her attempts to attain a correct diagnosis highlight the importance of getting prompt treatment.

While camping in a local Missouri state park, Anna discovered an attached and engorged deer tick on the back of her left knee. Following the advice of her friends, Anna burned the tick off with a match. Anna had no idea it was the wrong way to remove a tick. When she discovered a second tick attached on her big toe, Anna incorrectly removed it by slathering it with rubbing alcohol. Within a week of returning home, Anna discovered circular red rashes on both her knee and her big toe. At the time, Anna did not connect the tick bites with the rashes that appeared. Instead, she attributed them to bug bites, applied hydrocortisone cream, and thought nothing more of it. Anna has since come to realize that her lack of education about proper tick-removal likely contributed to the severity of her coming illness.

Anna's symptom display began with insomnia. Anna explains that she had been feeling unusually drained, and increasingly anxious, both of which she attributed to the stress of a recent relationship breakup. Even after two or three nights without sleep, Anna was often only able to take naps of a few minutes before waking again. When she did sleep for a slightly longer interval, she experienced violent, horrific nightmares filled with strong sensations of evil and dark images of death. Anna says she would wake up feeling shaken and sweaty. She described feeling as if continuous current of electricity had been jolted through her brain.

In the first few weeks after her tick bites, she felt like she had the flu. Weak and shaky, she felt feverish in the evenings, yet her temperature appeared normal. She felt tired all the time, not surprising considering her lack of sleep. Anna had a headache, but she described it as "weird." It consisted of a constant "buzzing sensation" that would flare up horribly when she exerted herself physically in any way. After exercise, Anna experienced post-exertion malaise that lasted for days, along with dizziness and nausea.

When another red rash appeared on Anna's leg, she looked at the rash with a growing sense of unease. It was definitely time for a trip to her family doctor. After examining Anna, her doctor explained. "This is not the kind of rash we worry about. This is a black fly or spider bite. What you are experiencing is a perfectly normal response to emotional stress. Insomnia does not occur with Lyme disease unless you have been infected for two or more years." Instead of treating Anna for early Lyme disease, her doctor prescribed the sleep-aid Ambien® to help her return to a normal sleep pattern. Thankful that she did not contract Lyme disease, Anna left the doctor's office and cried tears of relief. She wanted to believe the doctor was right.

A few days later, after accompanying her nephew Matthew on a school outing,

Anna knew in her heart that something was wrong. During the trip, Anna became horribly nauseated by the St. Louis summer heat. The light from the sun hurt her eyes, and the noise of the children talking and laughing felt deafeningly loud. Weak and dizzy, Anna drove herself back to her doctor. At Anna's insistence, and for her peace of mind, her doctor ordered a Western Blot test, and prescribed a single dose of Doxycycline. Relieved, Anna struggled to continue with life as usual. Unfortunately for Anna, the dose of antibiotic prescribed to her was grossly inadequate.

Anna took the antibiotic as prescribed by her doctor at the (incorrect) dose of two 100 mg pills of Doxycycline. After that, Anna slept through the night thanks to the Ambien®. However, after sleeping through the night, Anna woke up un-refreshed and exhausted. Anna began having sharp muscle pain and twitching throughout the day which interfered with her ability to work. During the night, strong twitches in her neck would literally jerk her awake when she was on the brink of sleep. Sometimes Anna would drift off, only to be woken up by "electric shock" sensations that made the inside of her head feel like it was buzzing and vibrating.

After a dreadful week of suffering, Anna's doctor called and told her that she was "in the clear for Lyme disease," because her Western Blot test had come back negative. By this time, Anna had done some research on the Internet. She asked her doctor to consider that the test result might be a false negative. She begged her doctor to prescribe another course of antibiotics at a higher dose. Anna's doctor refused to prescribe further treatment, and explained this to her in the gentlest way possible. Still, Anna felt that her doctor was not listening to her, and instead treated her like a patient on the verge of a nervous breakdown.

Over the next few weeks, Anna started feeling a fatigue so profound that she could barely stand in the shower. Getting dressed felt like running a marathon. Anna did not have the appetite to eat, or the strength to prepare food. She lost fifteen pounds and grew weak and malnourished. Getting ready for work was a job in itself. In the mornings, exhausted from improper sleep, Anna could barely raise her arms above her head to dry her hair. She began wearing the same outfit to work all week, too tired to be bothered with laundry.

After dragging herself to work, she became too tired to sit upright at her desk during the day. The responsibilities of Anna's job as an Administrative Assistant were so overwhelming, she often spent a good portion of her work day lying on the bathroom floor. Small details that had been second nature to her began to cause confusion. She was filing things in the wrong places and her coworkers had to help her hunt down all her misplaced documents. Labels Anna put on envelopes were found upside down, and out of order. Anna could no longer handle her job responsibilities, especially ones which required extended periods of concentration.

Towards the end of her work day, Anna would often make frantic phone calls to her mother, (whom she moved back in with because she was so sick) and asked her to drive her home. Driving was a nightmare for Anna because the noise and heat from traffic made her feel even sicker. Anna

"Anna"...cont'd pg 14

The FDA - Is The Agency Beyond Fixing?

by Sue Vogan, Lyme Blog

The Federal Drug Administration (FDA) - An administrative agency of the U.S. Department of Health and Human Services that regulates the safety and quality of foodstuffs, pharmaceuticals, cosmetics, and medical devices. But is there more to this agency than meets the description? Some say there is.

The FDA formed the same year (1906) that Upton Sinclair's book The Jungle described grotesque conditions in the meatpacking industry. The author, it has been said, was actually attempting to focus the spotlight on poor conditions for immigrants. However, President Roosevelt signed into law the Food and Drug Act - thus, the beginnings of what we now know as the FDA.

The real history of the FDA starts in 1927 with the first recorded name of the agency - Food, Drug and Insecticide Administration. In 1940 the FDA became part of the Federal Security Agency, and in 1953 the FDA joined the Department of Health, Education and Welfare. In 1968 the FDA became part of the Department's Public Health Service. And in 1980 the Department of Education was created, and the department to which the FDA belonged to was renamed, "Department of Health and Human Services."

The FDA began to make progress. In 1938 the Federal Food and Drug Act was adopted. This bill was the result of nearly 100 people dying in 1937 after ingesting a product called Elixir Sulfanilamide, which was prepared using a chemical called diethylene glycol (elixirs are noted to contain alcohol). The Act was intended to compel manufacturers to show the FDA that their product was safe prior to marketing, among other now legal avenues (i.e. seeking injunctions from courts). In 1951 the Act was amended to divide prescription and over-the-counter (OTC) drugs. Until this amendment, all drugs were dispensed OTC.

In 1958 a Food Additive Amendment was added. This required "pre-market" approval by the FDA. If a food additive is approved, the FDA publishes a regulation in the Federal Register for conditions of usage.

In 1960 another law, much like the Food Additive Amendment, was passed for color additives to food, drugs, and cosmetics. There were to be no additives that were shown to be carcinogenic (cancer causing) to animals or humans.

In 1996 pesticide residues were removed from the ACT, but there was to be "reasonable certainty of no harm to consumers" with regard to raw and processed foods.

In 1962 another amendment was introduced that required drug manufacturers to show effectiveness and safety of their products, report adverse effects; required the drug companies to disclose in their ads the risks along with the benefits, and to receive informed consent from clinical trial participants. Along with these new regulations came the new drug application which was to be approved before a company could market a new drug.

In 1976 yet another amendment was adopted. This time it was for medical devices. Medical devices were to meet certain performance standards and adverse events were to be reported to the FDA.

In 1982 the anti-tampering regulation was introduced. This came about because 7 people died after ingesting cyanide-tainted Tylenol capsules. The regulation requires an array of products be offered to the consumer in tamper-resistant packaging. The product is required to display a label that alerts the consumer to the measures that are being taken with this product. Tampering with consumer products is a felony and punishable by up to 10 years in jail.

In 1983 the FDA added the Orphan Drug Act. This Act was intended to help promote research on rare diseases and substance abuse products. "Rare disease" is defined as a disease "affecting fewer than 200,000 people or diseases that affect more than 200,000 people but where circumstances are such that a company is unlikely to recoup its costs."

The law applies to drugs and medical devices. For the use of this act the company receives tax credits "to help defray half of the cost of clinical research and 7 years of marketing exclusivity to a drug manufacturer (in addition to the time granted under patents held by the company) for the treatment of the rare disorder once a product is approved." The law allows for incentives to develop products when the company may not recoup its investments.

In 1987 the FDA unveiled the Prescription Drug Amendment. It was thought there were not enough safeguards to prevent sales of "substandard, ineffective, or counterfeit drugs" and a concern that "samples provided to doctors were being sold to consumers rather than freely distributed as intended by drug manufacturers."

In 1992 the amendment was amended so the FDA could "accept user fees from drug and biologic companies in return for committing to review new drug and biologic products within a certain time frame."

There are even more amendments: 1992 Mammography Quality Standards Act (the FDA charges for some inspections - known as a user fee); Nutrition Labeling and Education Act of 1990 (FDA-approved health claims on food labels; certain foods served in restaurants are exempt); the 1994 Dietary Supplement Health and Education Act (the burden of proof for safety is on the FDA; manufacturers do not have to demonstrate the safety, supplements used to be regulated in the same manner as food and drug additives before this amendment); and the last, but certainly not least, the 1997 Food and Drug Modernization Act. This is the fastest of the fast, quicker than a speeding bullet, and more profitable than saving pennies in the piggy-bank. It's a "fast-track approval" for certain new drugs and accelerated approval for innovative devices. The Act allows the FDA to use "expert panels in the drug approval process, regulated health claims in food, reauthorized the Prescription Drug User Fee Act, and provides additional marketing exclusivity time to companies that conduct pediatric studies."

In 1990 the FDA attempted to regulate tobacco. They were unsuccessful in classifying it as a drug.

The Federal Drug Administration just celebrated their 100 years in business in 2006. The agency started out to protect the consumer. After 101 years, do they still have the consumer's best interest in mind? Some say not.

> Speed, just like in a car race, has the potential to be deadly. So why is it important for the FDA to speed up drug tests?

Just this year, there is another amendment proposed - PDUFA IV. This amendment's goals fall into three categories: 1) "Proposals to ensure sound financial footing for the human drug review program;" 2) proposals to enhance the process for premarket review of human drug applications;" 3) proposals to modernize and transform the postmarket safety system."

Staring in 2008 the FDA wants $392,783,000 before adjustments, for PDUFA IV.

Are they not charging enough "user fees?"

"Although user fees have provided substantial resources to FDA since the beginning of the program, user fees have not kept up with the increasing costs of the program associated with inflation in pay and benefit costs to the agency, rent and rent-related costs, and workload." (Federal Register, Vol. 72, No. 9/Tuesday, January 16, 2007/Notices).

Is it so much to ask that all foods and drugs proposed for consumers be made to go through rigorous clinical testing before they have an opportunity to harm or kill human beings? And, is it possible to allow doctors and scientists the right to speak up publicly about their concerns over a drug's adverse effects?

In October 2005 it was reported that the FDA Advisory Panel on psychiatric drugs wanted "almost immediate approval of new drugs" (Washington Post).

On June 2, 2007 questions were publicly raised about possible adverse effects of Avandia, a type-2 diabetic drug marketed by GlaxoSmithKline. A doctor had even accused the pharmaceutical company of intimidation when he spoke out about his concerns over the drug possibly causing cardiovascular problems (NY Times).

And we all recall the Vioxx story (the non-steroidal anti-inflammatory drug approved in 1999 and removed in September 2004 because it increased heart disease) or anti-depressants possibly being the reason for suicidal thoughts, behavioral changes and worsening depression with regard to the top 10 antidepressants (anti-depressants now with a warning label are: Prozac, Zoloft, Paxil, Luvox, Celexa, Lexapro, Wellbutrin, Eddexor, Sersone, and Remeron - FDA)

The FDA wants to offer an express lane for pharmaceutical companies. Speed, just like in a car race, has the potential to be deadly. So why is it important for the FDA to speed up drug tests?

It's estimated that 2 billion prescriptions are filled each year. To get a drug to market takes approximately 8 years (note: AZT was approved in 107 days). This includes a laboratory study that can take 1-3 years before experimented on with human subjects, and another 5 years of testing on human beings. The FDA would oversee testing plans and insure that the plans were properly conducted and analyzed.

The FDA, however, cannot make determinations on facts not presented or altered results. One example of this is aspartame. It is common knowledge that adverse laboratory results were omitted in Searle's presentation to the FDA, the sweetener was rejected by FDA, and was only approved by a "presidential order." (Gary S. Goldman, Ph.D. - In Short Order radio show)

According to popular belief, there are many waiting for new drugs to be approved. Drugs for cancer, asthma, and HIV are among the list. Some say that drugs just released are similar to the drugs already available. Isn't there a database at the FDA that could be used to see if drug X (which is already on the market) is similar to drug Y (which has just been offered up to FDA for approval)? If it is, and drug Y proves to be no better than drug X, how is this helping patients? And how is it helping the pharmaceutical company, since they are already complaining about the cost and length of time it takes for approval?

Why is it always about money? Pharmaceutical companies want to make money, everyone does. But there are people in prison for lying to get money. What happens to doctors and scientists who sit on the panel with ties to the manufacturer of the drug they are evaluating and then are on the panel that monitors the drug for its safety? Or what about those that take bribes or who falsely report their stocks in companies regulated by the FDA?

Lester Crawford, former FDA Administrator, was recently sentenced to 50 hours of community service, 3 years supervised probation, and $90,000 in fines. His crime: false reporting and conflict of interest. It seems Mr. Crawford lied about the stocks he owned in companies his agency regulated. The court was actually lenient with Mr. Crawford since the two charges carry a maximum combined penalty of 3 years in prison and $200,000.00 in fines.

In China, the penalty for taking bribes is death! Imagine what the punishment would be for lying and conflict of interest.

What is the penalty for holding back adverse reactions in a drug trial; especially when the drug is approved for consumers and then removed years later because it has harmed or killed?

Concerta, for example, used for ADHD by McNeil Consumer & Specialty Pharmaceuticals, may cause hallucinations, suicidal thoughts, psychotic disorders, and aggression. The labeling "merely suggests the problems aren't serious" (Dr. Joseph Mercola's website).

Baydhol, a cholesterol-lowering drug, was removed from the market after killing 100 people. (LifeExtension website)

Baycol claimed 31 people before it was removed from the market. Omniflox (antibiotic), Rezulin (diabetes drug), Fen-Phen and Redux (weight loss medication) were removed for adverse effects, as well.

Is this a conflict of interest? Is there a user express lane installed in a government agency? Is funding so low that they have to charge to use the express lane; like the state charges for use of a highway?

Does this FDA-approval express lane compromise our ability to receive drugs that won't harm or kill us?

"To expedite new drug approvals, since 1992 the brand name drug companies paid the FDA more than a billion dollars. In the first five years (i.e. from 1992-1997) the FDA's new drug approval efficiency increased dramatically and new medications caught in FDA red tape were approved without further burden to America's taxpayer.

In exchange for reducing the burden on taxpayers, there were no new drug approval efficiencies after year five. U.S. citizens pay nearly twice as much for their medications as anyone else in the industrialized world. U.S. citizens have become the world's guinea pigs by testing newly released medications first.

An unethical partnership was created between the regulated and regulators. U.S. citizens can no longer trust the FDA to protect them. Known deadly medications are given FDA approval and remain on the market far longer. Very few new breakthrough medications have been produced, and the well-being of Americans by the tens of millions have been put in jeopardy: more than 200,000 Americans died." (Nine Penny Savings, Gary W. Lawson,

"FDA"...cont'd on pg 16

Daryl Hall Comments on President Bush's Lyme Diagnosis

Los Angeles, CA --

The news that President George W. Bush has been suffering from Lyme Disease for more than a year really caught the attention of Daryl Hall, one-half of the world's biggest-selling music duo of all time Daryl Hall & John Oates, and someone who was also diagnosed with the illness over two years ago.

Hall is hoping the President's admission will focus more attention on the causes and antidotes of the little-known malady:

"While I'm sorry when anyone gets Lyme Disease, maybe it takes a person in power to draw attention to what all of us who have the disease, are going through. The withholding of information for a year points out the confusing politics of the disease. Now, George Bush can feel our pain."

"Lyme and other tick-related diseases are very serious maladies that for some reason have been underplayed by the media and medical profession"

"I'm still under treatment, but I've made major improvements," he says. Because these illnesses are so often misdiagnosed, Hall encourages people with symptoms to seek information online, at sites such as www.LymePA.org.

"They're on the Main Line. They print a great brochure and talk about treatment and what people need to do."

- Daryl Hall

"Anna"... cont'd from pg 12

was afraid she might pass out while she was driving.

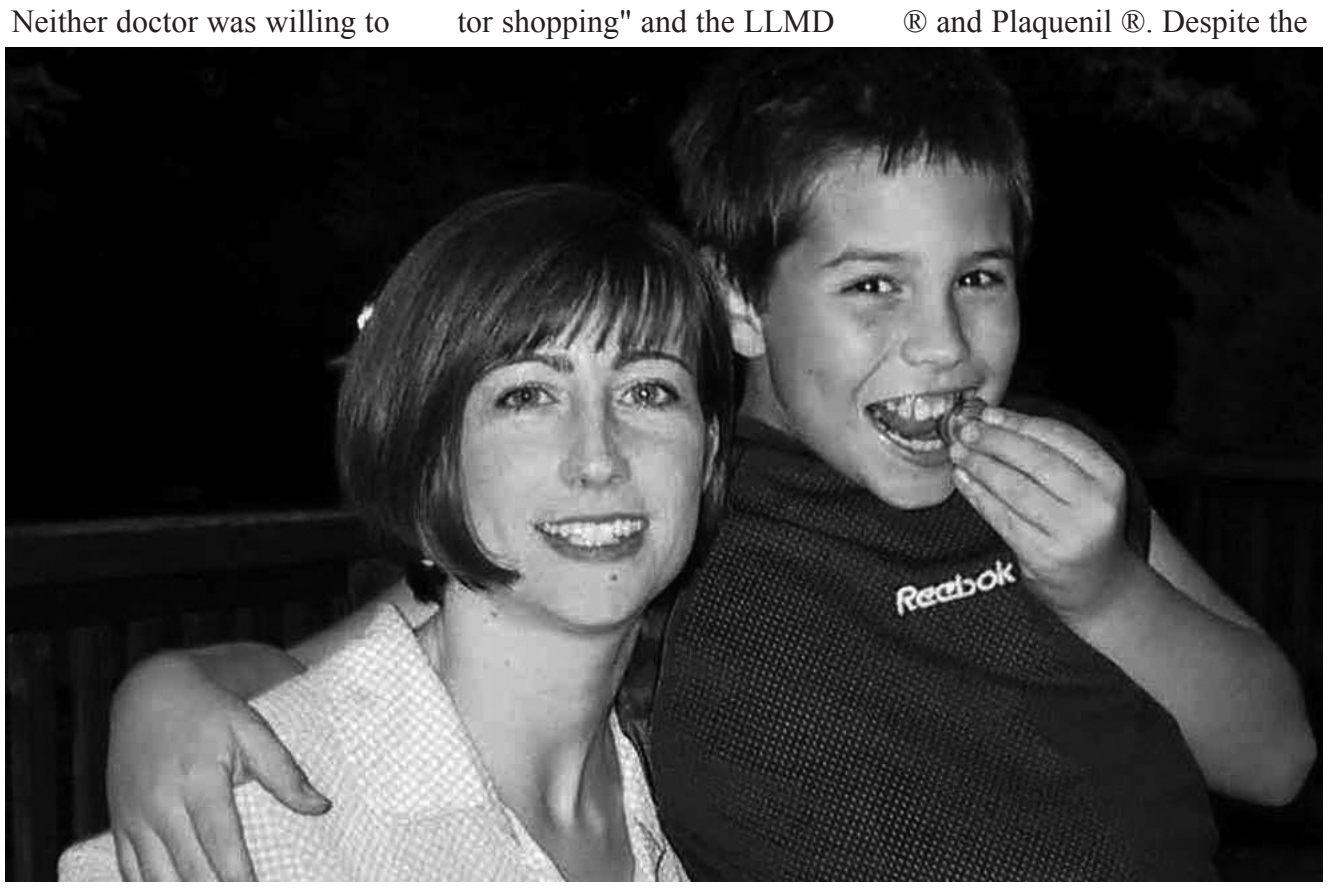
Anna also experienced frightening pains in her chest. Anna felt like an old lady. Instead of walking upright, Anna staggered, and shuffled slowly. She would clutch the area at her heart, and was uncomfortable even sitting upright to eat dinner. Anna felt heart palpitations, first as if her heart was racing incredibly fast, then abruptly slowing down and skipping beats. Much to her surprise, each time her doctor listened to her heart, it sounded perfectly fine.

Anna soon began experiencing the worst anxiety and depression in her life. Frightening panic attacks came out of the blue and would often last two to three hours. Random negative thoughts would begin to race through her mind, spiraling out of control and making her believe at her lowest point that her life was no longer worth living.

Anna began having "brain fog" on a daily basis. She explains this as an almost indescribably awful feeling that she thought of as "brain freeze". It was as if her brain had slowed down at its core like an overloaded computer. It was impossible to think and function properly in that confused state. Anna felt frustrated and lost. She wrote her name and address on a large piece of paper and kept it in her purse, thinking if she passed out somewhere, at least people would know her identity. Anna wrote goodbye letters to friends and family because she thought she might die.

Realizing that her first doctor couldn't, and wouldn't help her, Anna decided to see a second physician, whom she learned had recently treated a friend of her mother's for Ehrlichiosis. After listening to Anna's growing list of symptoms, her doctor stated "There is no Lyme Disease in Missouri. What you have sounds like Fibromyalgia. I could diagnose you with that but it would be too horrible." She continued, "I would say that you have cascading stress-related trauma as a result of a tick-bite."

Anna insisted upon further Lyme disease treatment, and begged for more antibiotics. Anna's new doctor left her in his office while he went to look up Lyme disease treatment. Thankfully, when he returned, he agreed to prescribe Anna one month of Doxycycline at 200 mg/day. Anna's doctor was unassumingly following outdated and incorrect treatment guidelines published by the Infectious Disease Society of America (IDSA). Her family doctor had also previously prescribed "the standard treatment" which was two pills of 100 mg Doxycycline. According to the IDSA, this treatment would easily treat Anna's symptoms. Neither doctor was willing to officially diagnose Anna with Lyme disease because her Western blot test came back negative. Despite her new doctor's opinion, her begging for antibiotics had paid off, and she left the office with a prescription in hand.



Anna and her nephew Matthew

Despite following the IDSA Lyme disease treatment guidelines, Anna's symptoms continued to worsen. After completing the month of Doxycycline, Anna's new doctor refused to give her further antibiotic treatment, and instead prescribed anti-depressants, and suggested that Anna see a psychiatrist. Her doctor told her that together they would "get to the bottom of this," and that Anna should consider him a "partner in wellness."

Anna had no time to wait for the doctor to get to the bottom of things. She needed more than subtle assurances to feel that her doctor cared for her. Anna knew she was in big trouble! She knew the cause of her illness was physiological, not psychological. She felt bad enough physically to think she might be dying. Neglected by her doctors, Anna felt backed into a corner, and was forced to seek treatment on her own.

Through research on the Internet, Anna was able to locate a Lyme Literate Medical Doctor (LLMD). Even in her frightened state, she insisted on seeing him even though she had actually been accused of "doctor shopping" and the LLMD had a four-month wait for a consultation.

Desperate to feel better, and armed with the correct and updated Lyme disease treatment guidelines from the International Lyme and Associated Diseases Society (ILADS), Anna felt forced to "treat" herself while waiting out the few months to see her future LLMD. She took 400 mg of Doxycycline per day, and although treating yourself is never advised, Anna feels that she probably saved herself from a lifetime of disability because she acted quickly.

When Anna finally saw her LLMD, she was officially diagnosed with Lyme disease. She was diagnosed clinically, based on her history of tick bites and resulting symptoms. Anna began a long-term course of antibiotic treatment. She was finally placed on adequate doses of a combination of antibiotics. Once she began treatment, she had some powerful Herxheimer reactions, a clinical clue that the antibiotics were working well. Anna's herxing brought on severe pain and alarming outbursts of anger. Anna felt overwhelmed with dark and depressing thoughts, and wondered if she would ever feel normal again.

Luckily, Anna's symptoms did gradually decrease. She cycled her way through a battery of drugs including Flagyl®, Zithromax ®, Biaxin ® and Plaquenil ®. Despite the initial delay in treatment, Anna fortunately experienced a steady improvement in all of her symptoms. She has been symptom free for three months and she is off of antibiotics completely.

In her own words, Anna explains, "I consider myself almost 100% recovered after only ten months of treatment. My insomnia and the profound fatigue that disabled me for nearly one year have almost completely resolved."

Although near fully recovered, the medical struggle that tormented Anna has left a lasting impression on her. "The trauma of the illness and the ordeal that I went through trying to get help from the medical profession remains with me. I will probably never trust any doctor in the same way as I did before. I consider myself extremely lucky that I was able to find the information I needed so that I could be treated relatively quickly. I believe that if I had listened to those first two doctors, I would still be sick, in pain and debilitated to this day."

Although Anna fought hard to acquire her correct diagnosis and treatment, she was lucky when it comes to Lyme. Many thousands of Lyme patients end up permanently disabled after suffering for years before receiving proper care. The majority of chronic Lyme disease patients typically see anywhere from 5-40 doctors before receiving a correct diagnosis and adequate treatment. Anna's case highlights what can go wrong if inadequate Lyme disease treatment is given. It also demonstrates the serious flaws in the IDSA guidelines.

Anna followed all the rules. She went to her doctor with a tick bite, and received the "standard treatment" for Lyme. Anna did everything "right" yet still ended up very ill. Anna believes the IDSA should be held accountable for their irresponsible and unprofessional guidelines that have resulted in the miseducation of many thousands of family doctors across the United States, and the world.

If a tick bites you, seek immediate treatment, and make sure your doctor follows the correct guidelines; those published by ILADS. There is no substitute to receiving care from one of the world's top Lyme Literate Medical Doctors (LLMD's). Do not settle for inadequate treatment if you are still sick and suffering. It is your right to seek out the best possible care, and always strive to achieve optimum health.

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http://www.ilads.org/
St. Louis now has its own support group of people who can be easily contacted for help and information about finding a Lyme-literate physician in the region. The website is http://www.stllymefoundation.org.

pha

I recommend Researched Nutritionals® for my patients

...Joseph Burrascano, M.D.

Joseph Burrascano, M.D.

Due to the efficacy and the science behind the products, and the experiences in my clinic, I have found Researched Nutritionals® very useful. A few of my personal favorites:

NT Factor Energy™
I prescribe this to my patients because it provides a noticeable improvement in their energy levels. By promoting healthy mitochondrial membrane repair (and not through the use of any stimulants), most of my patients report that they feel better.

I discovered this product at a medical conference, and was intrigued by the research. One of the published studies reported that patients experienced a 40% decrease in fatigue[1] in eight weeks. The product is formulated to deliver a stabilized unique phospholipid matrix (this is what composes the mitochondrial membranes), wrapped in pre and probiotics as well as Mitochondrial Pro Regulator™ to optimize mitochondrial function, Krebs Cycle Glucose Absorb™ to propel the burning of glucose, creating energy and removal of excess ammonia which can cause fatigue, and RN Fatty Acid Metabolizer™ to maximize ATP production by regulating fatty acid buildup which, if left unchecked reduces mitochondrial function and increases cellular toxins. Normally, cells produce and repair their own mitochondrial membranes. However, these membranes may become compromised during long-term illness or interestingly, intense physical exercise by healthy individuals. This product helps the body help itself. By improving cell membrane potential, nutrients are better able to enter the cells for greater ATP fuel production, toxin removal is improved and oxidative stress is reduced.

CoQ10 Power™ 400mg
I actually tested the blood level of a patient on this product versus another well-known CoQ10. The patient using CoQ10 Power™ had three times the CoQ10 in the blood than the other product. The product is produced in the preferred soft-gel form, allowing the oil base to optimize absorption. As I have come to expect from Researched Nutritionals®, the raw material is of the highest quality and is imported from Japan.

Transfer Factor Multi-Immune™
People have asked me what differentiates transfer factor from colostrum. I generally reply that it is supercharged colostrum. In every gallon of colostrum, you derive only an ounce or two of pure transfer factor. This is where you find the heart of immune support.

Maintaining natural killer cell function is essential for achieving optimal health. Each capsule of Transfer Factor Multi-Immune™ combines the following complexes to provide optimal natural killer cell support:

- ***NK Maximizer Bioplex™*** *- Super blend of transfer factor, larch arabinogalactan, IP-6, shiitake and maitake mushrooms to promote healthy NK cell levels & immune modulation[2] [3]*
- ***Macrophage & T-Cell Pro-Blend™*** *- Proprietary blend of beta glucan, astragulus, and TMG for healthy macrophage an neutrophil support, aiding removal of cellular debris and recovery of damaged tissue. Unique blend also supports proper T-cell function, cellular replication and liver function. [4] [5]*
- ***Healthy Cell GTP™*** *- Potent extracts of green tea and pomegranate to promote normal cell division and containing high levels of crucial antioxidants.*
- *Plus an integrated blend of folic acid, vitamin B-12, zinc, and selenium to strengthen immune function, promote normal cell growth and boost antioxidant levels. [6]*

I believe a healthy energy level and a fortified immune system are essential to good health.

Best Regards,
Dr. B.

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*These statements have not been evaluated by the FDA. This product is not intended to diagnose, treat, cure or prevent any disease.

"FDA" ...cont'd from pg 13

Ph.D., DPA)

If one wants a drug approved or label guidelines softened, but doesn't want to spend a lot of time going through proper channels, is there another way?

"In the 2004 elections alone, nearly $1 million was contributed to President Bush, $500,000 to his opponent John Kerry, and over $100,000 was contributed to approximately 18 members of Congress. The drug and chemical industries employ over 1,200 full-time lobbyists, including 40 former members of Congress. The drug and chemical corporate lobbyists are extremely successful at what they do, which puts the FDA at the mercy of the very same chemical industry that they aim to regulate (Dr. Joseph Mercola's website).

From 1998-2005, the drug and chemical companies spent approximately $760 million on lobbying politicians. Their goal was to win favor for what food and drugs can be marketed and the labeling guidelines.

Does anyone notice things out of control?

Dr. David Graham, epidemiologist and Associate Director at the FDA for over twenty-years, spoke out against FDA policies and their inability to protect the public from harmful drugs. "I was pressured to change my conclusions and recommendations," Dr. Graham said. (Vioxx) It is stated that there were up to 139,000 heart attacks from the drug, 30-40% were fatal. "Frightened by threats of incarceration, Graham sought help from GAP (Government Accountability Project) offices after being referred by congressional staff and members of the media. GAP Legal Director Tom Devine warned FDA investigators, outlining how they were incurring personal liability by violating laws such as the Whistleblowers Protection Act and Anti-gag Statute, resulting in a swift halt of the investigation." (GAP)

Others weren't as fortunate.

"Joe DiStefano, a licensed nutritionist, and Daniel Mayer, an osteopath, had two Florida clinics in which they administered a product called Albarin, an extract of aloe vera, to cancer patients. Albarin had been developed by Ivan Danhof, M.D., Ph.D., a retired professor of medicine known as the "father of aloe vera" because he had spent much of his career researching the plant's properties. After two decades of research, he developed the intravenous extract, which proved highly effective against cancer. The clinical program was part of an investigational new drug (IND) application Danhof had submitted to the FDA.

Hinchey claims that 2001 user fees paid by drug companies funded 32% of FDA's budget from drugs and by 2005 it was up to nearly 50%. He further states that the FDA must negotiate with the drug industry how user fees are allocated. It's also been stated that 10 of the 32 scientists on the FDA's Cox-2 advisory panel had ties to the manufacturer of the drugs.

Danhof, in Texas, was about to file data from these cases to support his IND application when the FDA raided the clinics and closed them down, in direct opposition to the wishes of the patients there. One said to the FDA agent in charge, "We're all adults here, making free-will choices. Why don't you get out of here and leave us alone?" To which the FDA agent replied, "This will be your last treatment!" A number of the patients demonstrated repeatedly at the Tampa federal courthouse, and eight were dead by 2002.

The FDA conducted the raid because it had received complaints about the treatments-but not from patients. The complaints were from local oncologists, who regarded the clinics as competition. Apparently satisfied with putting the clinics out of business, the FDA did not prosecute DiStefano, Mayer, and Danhof." (GoodHealthInfo.net) There is also the case of John "Jay" Kimball, owner of Discovery, who developed a product in the late 1980's which showed success not only with cancer but with Parkinson's and Alzheimer's. Kimball contacted the FDA in 1990 to point out that a small pharmaceutical company's version had contaminants "detrimental to the actions of the product."

Kimball charges, "The FDA threatened me with serious repercussions if Discovery made public any statement regarding any use of deprenyl not authorized by the FDA."

Kimball repeatedly applied for approval of his product, but his paperwork never made it through the channels for reasons ranging from lost to ignored. Kimball claims that the small pharmaceutical company (owned by two larger companies) had an interest in eliminating the competition. Kimball's home was raided three times and he was incarcerated. (GoodHealthInfo.net)

Can the FDA be fixed?

If it's as bad as Congressman Maurice Hinchey (NY) says, the FDA needs a total makeover. Hinchey claims that 2001 user fees paid by drug companies funded 32% of FDA's budget from drugs and by 2005 it was up to nearly 50%. He further states that the FDA must negotiate with the drug industry how user fees are allocated. It's also been stated that 10 of the 32 scientists on the FDA's Cox-2 advisory panel had ties to the manufacturer of the drugs.

But, the Congressman has a few good suggestions: redirect the user fees to the U.S. Treasury; increase FDA funding; cut off negotiations with drug companies; and allow lawsuits for unsafe drugs.

In a 2005 Forbes article, there were more good ideas with regards to fixing the ills of the FDA not covered by the Congressman: give power to the FDA so that they might compel drug companies to test their products more thoroughly; track existing drugs; and fund drug studies through other means than the drug companies.

The consumer has a right to safe and effective drugs. The pharmaceutical companies have a need to make money. The FDA has a responsibility to make sure both happen - in this order. *pha*

YOU'RE INVITED!

To Take the Bite Out of Lyme!

PLEASE JOIN THE LYME COMMUNITY AT THE CALIFORNIA LYME DISEASE AWARENESS WALK

WHEN: Saturday, Oct. 6th, 4:00-6:00 p.m.
WHERE: Embarcadero Marina Park North (near Seaport Village)

The San Diego Lyme Support Group is organizing a California Lyme Disease Awareness Walk at a location-which is just steps away from the San Diego Convention Center where the ***IDSA*** will be holding their convention.

This walk is very important and we ask that you come out and bring as many people as you can. What we want is numbers. If people want to give a donation that's great, but what we want you to stress is that we need actual bodies at the walk for it to be a success. We ask that you reach out to your family, neighbors, co-workers, kids' soccer teams, local restaurants, everyone and anyone that you have or used to have contact with. We realize that for many, due to the toll of illness, our circle has narrowed and we have lost contact with people.

Please come support the many Californians who have been stricken by Lyme disease. Participants will carry a memento bearing the name of a Californian with Lyme disease. We will be walking, running or rolling around the Marina on an easy wheelchair accessible path.

For more info:
maritza@plant-people.com

Turn the Corner Foundation Board Member, Brooke Landau, Discusses Lyme Disease Awareness on Good Morning America

by Turn the Corner Foundation

NEW YORK-- Turn the Corner Foundation (TTC) Board of Directors member, Brooke Landau, appeared on Good Morning America on Tuesday, August 28, 2007 to discuss the importance of Lyme disease awareness and the need to find a cure. Brooke is the Traffic Anchor for ABC affiliated 10 News/KGTV in San Diego.

As a Board member of TTC, Brooke is dedicated to the Foundation's mission to support research, education, awareness and innovative treatments for Lyme disease and other tick-borne diseases. Each year, TTC hosts its annual fundraising gala, Unmask A Cure, at Guastavino's in New York City to raise funds to support its mission. This year's gala will be on Thursday, November 1, 2007 from 6:00 PM to 10:00 PM and will feature a musical performance by Daryl Hall.

Brooke was first diagnosed with Lyme disease in 1995 and has spent twelve years fighting for her life. Physicians once told her that she may not live due to compromised brain functioning as a result of Lyme disease.

Fortunately, Brooke was treated by physicians in an experimental study five years ago that saved her life and is now living at a level close to where she was before she contracted Lyme disease. Lyme-literate physicians eventually brought Brooke back to full capacity, just in this past year alone.

Lyme disease is incredibly difficult to diagnose and treat. Many physicians are not trained to deal with this epidemic and thousands of people are misdiagnosed annually.

Lyme disease is the number one tick-borne illness in the US and has been diagnosed on every continent. The CDC reports there are 24,000 new cases of Lyme disease in the US annually, but the CDC says that figure could be underreported by tenfold due to physicians who are not trained to identify symptoms of Lyme disease.

TTC has been influential in Lyme disease research and education since its inception, providing grants to organizations nationally. Columbia University, International Lyme and Associated Diseases Society, Lyme Disease Association, Genesis Laboratories and Lyme Induced Autism Foundation are examples of some of the organizations who have benefited from TTC's funding this year. In addition, TTC has created education and Lyme-literacy training programs that are nationally recognized such as The Physicians Training Program and the Lyme Educational Awareness Development Series.

pha

Parental Rights Violated in HPV Vaccine Case

INDIANA - Parents in Indiana are in a state of shock after a local doctor gave their 14-year-old daughter a controversial vaccine without their permission.

The vaccine, Gardasil, protects against Human papillomavirus (HPV), a sexually transmitted virus that can cause cervical cancer. The parents of the 14-year-old girl said they would have refused the shot for their daughter, but were never given that option. So far, their doctor has declined to explain what happened.

Gardasil has garnered significant attention in recent months. According to the University of Pennsylvania, 41 states have introduced legislation in the past year to either require vaccinations or fund educational programs about Gardasil.

At ParentalRights.org, we believe that parents have the right to ask questions and make medical decisions for their child before medical procedures are done.

Parental involvement is especially important in cases of emerging medical treatments, such as Gardasil. While the bulk of the scientific community favors the new drug, some important questions about the risks have been raised.

Research conducted by the National Vaccination Information Center found that patients who took Gardasil in conjunction with other vaccines had increased rates of respiratory and circulatory problems. In early June, the U.S. Centers for Disease Control and Prevention reported 13 cases of GBS (a disorder which causes the body's immune system to attack the nervous system, resulting in muscle weakness or paralysis) among persons who had received Gardasil.

Thankfully, American law still largely defers to parents' medical decisions, but this deference is constantly being challenged, particularly by the rising specter of international law.

The UN Convention on the Rights of the Child (UNCRC) seeks to undermine parents by changing American law so that the responsibility to determine "the best interests of the child" falls upon the government, instead of a child's parents. As one principal drafter of the UNCRC puts it, the Convention's premise "challenges the concept that family life is always in the best interests of children and that parents are always capable of deciding what is in the best interests of children."

Both the parents and child in Indiana said that they would have refused the Gardasil vaccine if they had been given the chance. But ultimately, that doesn't matter under the UNCRC, because acting in the "best interests" of children "provides decision and policy makers with the authority to substitute their own decisions for either the child's or the parents." In other words, the government becomes the new parent.

When it comes to the best interests of the child, no one knows children better than their parents. As parents, it's up to us to be aware of the risks and dangers they may face, whether medical or otherwise, so that we can guide them, provide for them, and protect them from harm.

Please forward this on to your friends and encourage them to join the fight to protect children by signing the online Petition for Constitutional Recognition of Parental Rights at www.parentalrights.org/

pha

For Those Who Fought a Valiant Fight

Bruno C. Malvezzi

Bruno C. Malvezzi passed away at Morristown Memorial Hospital on July 29, 2007, at the age of 87; he had suffered and was paralyzed for the last year with Lyme disease.

Born and raised in Weehawken, NJ he had summered in Denville since the 1930s and moved there full time in 1952.

Bruno served in the US Navy during WWII and received a Bronze Star and Presidential Citation for exceptionally meritorious achievement in the performance of outstanding combat service against enemy forces.

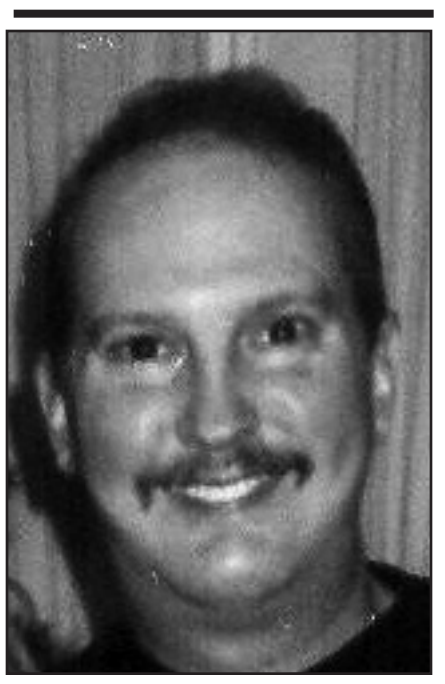
He had been a jeweler, or platinum smith since 1940, and worked his last 25 years at Van Cleef and Arpels Jewelers in Manhattan before retiring in 1982.

He was a member of the Elks Club in the Denville /Rockaway area, and was an avid gardener and farmer.

His wife Mary (Pont) of 50 years preceded him in death in 1995.

His sons Frank of Emmaus, PA, Joseph of Guilford, CT, and Charles Malvezzi of Wallingford, CT and his grandchildren Matthew, Ben, Alex, Brett and Chloe survive him.

Steven F. Wells



SOUTH BERWICK — Steven F. Wells, 45, of South Berwick, died suddenly on Aug. 9, 2007, at Frisbie Memorial Hospital in Rochester after a valiant battle with lyme disease and ALS.

He was born May 14, 1962, a son of Joseph and Bernice Wells, in Warren, Ohio.

He is survived by his loving wife of 17 years,

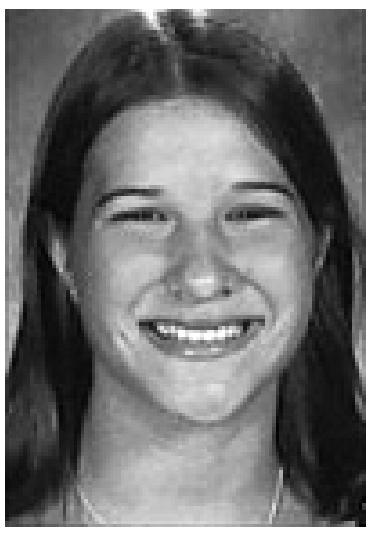
Jennifer (Arambasick) Wells

Hiram College in Hiram, Ohio, with a degree in business management. He continued his studies throughout his life and earned an M.B.A. from Franklin Pierce College in 2004. For the past 10 years, he has been an executive director for the Cooperative Alliance for Seacoast Transportation (COAST). Previously he had worked in public transportation for the RTA in Dayton, Ohio; for Apple Line Transportation in Gettysburg, Pa.; at the Geauga County Transit System in Chardon, Ohio, and as the county airport manager for Geauga County, located in Middlefield, Ohio.

He was a devoted communicant of St. Mary's Church in Dover. He enjoyed spending time with his family, snowmobiling, flying and working to restore his house.

In addition to his wife, he is survived by two daughters, Stephanie, 16, a student at Marshwood High School, and Alexandra, 8, who will be entering the Great Works School in South Berwick. Also, his parents, Joseph and Bernice Wells; brothers Gary Wells of Burlington, Iowa, and Mike Wells of Cortland, Ohio; sister Nancy Wheelock and her husband Bob of Parkman, Ohio; and sister Susan Wells of Northfield, Ohio; brother-in-law Christopher Arambasick of Portsmouth; mother and father–in-law Ron and JoAnn Arambasick of Garretsville, Ohio; niece Erica Wells, niece and goddaughter Amy Wheelock, nephews Matthew Wheelock and Seth Wells. Also, longtime best friend Tim Sheahan and goddaughter Emily of Gettysburg, Pa.; and uncle, Fr. Dennis Arambasick, whose spiritual support has been invaluable.

Emily Powell



Emily Rose Powell, 15, of Centralia, Missouri passed away Wednesday, Aug. 29, 2007, at University Hospital from a tick-borne disease, erlichiosis.

Friends and family are invited to celebrate Emily's life at the visitation from 10 a.m. to noon Saturday, Sept. 1, at Chester Boren Middle School, 110 N. Jefferson St. in Centralia, with Jed Angell of Friendship Christian Church officiating.

There will be no graveside services.

She was born June 3, 1992, in Osage Beach, the daughter of Michael R. and Angie K. Findley Powell, and they survive.

Emily attended First Baptist Church and Friendship Place with the youth group, both of Centralia.

She graduated from eighth grade in May 2007 at Chester Boren Middle School and attended one day as a freshman at Centralia High School, the day she became ill.

Her inspiration was listening to music and enjoying her friends. Her charming personality and winning way endeared her to family and friends.

She will be sincerely and sadly missed.

Survivors with her parents of Centralia are one sister, Elizabeth Ann Powell of Centralia; two brothers, Justin Powell of Albuquerque, N.M., and Nick Powell of Osage Beach; grandparents Linda Shankles of Camdenton and Laddie and Sue Findley of Centralia; great-grandmother Naomi Findley of Lee's Summit; four aunts, Lisa Gramke and husband John of Centralia, April Shankles of Camdenton, Tammie Harshbarger of Bethalto, Ill., and Lori Welborn of Buffalo, Mo.; two nephews and many cousins. pha

Emily Powell is the third child in recent months to die of a tick-borne illness in the state of Missouri.

IDSA claims tick-borne diseases are "easy to diagnose and easy to treat" and are rarely seen away from the east coast, yet new cases of Lyme in the mid-west and southwest are rapidly growing.

After a Decades-Long Search, Scientists Identify New Genetic Risk Factors for Multiple Sclerosis

by NIH News

A pair of large-scale genetic studies supported by the National Institutes of Health has revealed two genes that influence the risk of getting multiple sclerosis (MS) – data sought since the discovery of the only other known MS susceptibility gene decades ago. The findings could shed new light on what causes MS – a puzzling mix of genes, environment and immunity – and on potential treatments for at least 350,000 Americans who have the disease.

"These studies describe the first genes conclusively linked to MS in more than 20 years," said Ursula Utz, Ph.D., a program director at the National Institute of Neurological Disorders and Stroke (NINDS), a part of NIH. "This breakthrough was made possible through persistence, an elegant search strategy, and genomic data and techniques that were not available until recently."

Both studies involved scanning DNA samples from more than 20,000 MS patients and unaffected individuals in the U.S. and Europe, and looking for single nucleotide polymorphisms (SNPs), which are single-letter variations in a gene's DNA code. Published simultaneously today in the New England Journal of Medicine* and Nature Genetics**, the studies demonstrate an association between MS and SNPs in two genes that encode interleukin receptors, proteins that serve as antennae on the surface of immune cells.

Both studies were supported by NINDS and the National Multiple Sclerosis Society. The Nature Genetics study received additional support from the National Institute of General Medical Sciences (NIGMS). The NEJM study was also supported by the National Institute of Allergy and Infectious Diseases (NIAID), the National Center for Research Resources (NCRR) and the Penates Foundation.

They were conducted by overlapping teams of scientists that used different gene-hunting strategies. One team, which scanned the entire human genome for MS risk factors, was co-led by David Hafler, M.D., Professor of Neurology at Harvard Medical School and Brigham and Women's Hospital in Boston, Stephen Hauser, M.D., Professor and Chair of Neurology at the University of California in San Francisco, and Alastair Compston, FRCP, Ph.D., Head of the Department of Clinical Neurosciences at the University of Cambridge, U.K. The other team, which focused their search on a set of genes they considered potential risk factors for MS, was co-led by Jonathan Haines, Ph.D., Director of the Center for Human Genetics Research at Vanderbilt University Medical Center in Nashville, Tenn. and Margaret A. Pericak-Vance, Ph.D., Director of the Miami Institute for Human Genomics at the University of Miami. Drs. Hauser, Compston, Haines and Pericak-Vance participated in both studies.

MS typically causes limb weakness, vision loss and problems with coordination, and is the most common disabling neurological disorder of young adults. It's an autoimmune disease, occurring when the body's immune system mistakenly attacks a protective sheath around axons – the delicate cables that nerve cells use to connect with each other. Various immunosuppressant drugs can reduce symptoms and slow the disease's course, but most MS patients become increasingly disabled with time.

The trigger for MS is unclear, though there's strong evidence for an interplay between genetic susceptibility and some type of environmental factor. Having a relative, especially an identical twin, with MS increases one's risk of developing the disease. In the mid-1970s, researchers discovered that human leukocyte antigens (HLA) account for some of this genetic susceptibility. HLAs are proteins displayed on all the body's cells to help the immune system distinguish self from non-self. A variant of the HLA-DRB1 gene, now widely accepted as the strongest genetic risk factor for MS, increases the likelihood of getting the disease up to four-fold.

Still, HLA does not fully explain the genetic basis of MS; scientists have long realized that other genes must play a role that has been difficult to detect. Some studies have pointed to other HLA genes, but neither of the two genes reported today belong to that category. Both genes encode receptors on the surface of T cells – the immune system's mobile infantry – that enable the cells to respond to regulatory, secreted proteins called interleukins.

"These are the first non-HLA genes to be unequivocally associated with MS," said Dr. Pericak-Vance. "They give us a new way of looking at the biology of the disease, and could be targets for therapeutic development."

Both studies searched for a link between MS and SNPs that were previously identified by the HapMap, an NIH-supported project to catalog genetic differences in human populations.

In the genome-wide association study, the first of its kind in MS, the researchers used gene chip technology to scan more than 500,000 SNPs. In total, they analyzed more than 13,000 DNA samples, many of them collected and stored by the Center for Genetic Studies at the National Institute of Mental Health (NIMH) and the U.K.'s Wellcome Trust Case Control Consortium. In the candidate gene study, the researchers scanned DNA samples from four large groups in the U.S, U.K. and Belgium, totaling more than 10,000 people.

Both studies revealed an association between MS and a single SNP in the gene interleukin 7 receptor-alpha (IL7R-alpha). The genome-wide scan also found two SNPs in the gene for interleukin 2 receptor-alpha (IL2R-alpha) associated with the disease. Both receptors are known to influence the way that T cells patrol the body for pathogens. IL2R-alpha has previously been implicated in other autoimmune diseases, including type 1 diabetes.

Each of the SNPs associated with MS appears to increase the risk of developing the disease by about 20 to 30 percent. Although that number might seem small, "it's the size of effect we expect to see for genes outside of HLA," said Dr. Haines. Multiple genetic variations, each carrying a small risk of MS, could combine with one another and with environmental factors to create a large risk, he said.

Finally, the genome-wide scan identified nearly a dozen other genes that could represent risk factors for MS. Some of the associations were relatively weak and some of the genes' functions are unclear. pha