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## National LDA President Addresses Maryland Legislators

**Focus on research for Maryland patients who cannot get diagnosed & treated**  
*by National LDA News*

In a presentation before the Maryland House Rural Caucus, 40 delegates heard the President of the national Lyme Disease Association (LDA) provide an overview of Lyme disease, types of research being carried out on the disease in Maryland, and examples of why Maryland patients often cannot get diagnosed or treated.

According to LDA President Pat Smith, whose organization has affiliated groups in Maryland, cases here have drastically increased, and Maryland is now "7th in total case numbers in 2005 (1235) and 9th in rate of incidence (22.1/100,000 pop.). The Centers for Disease Control & Prevention (CDC) states that only 10% of cases that meet its narrow surveillance criteria are reported, therefore about 12,350 new cases of Lyme disease occurred in Maryland in 2005. That number does NOT, in any way, count the number of people contracting Lyme who do not meet the CDC criteria, which are for surveillance, not diagnostic, purposes."

She expressed grave concern for the risk to children, since CDC statistics indicate Lyme is most common in boys ages 5-19 and combined boys & girls, ages 5-9.

Throughout her presentation, Ms. Smith mentioned spreading tick populations, new strains of the bacteria that cause Lyme and new organisms being carried by ticks. The LDA has funded research mapping the genome of different strains of the Lyme disease bacterium, the mapping carried out by The Institute for Genomic Research, TIGR, in Rockville. The research has shown that different strains can mix their genetic material, giving the bacteria better survival characteristics. LDA has also funded a joint NASA/NIH research project taking place at the National Institutes of Health which is looking at the bacterium found in a much more aggressive tick which is expanding its range--traditionally a southern



*Delegate Mary Roe Walkup and LDA President Pat Smith at a presentation before the Maryland House Rural Caucus.*

one, and now as far north as Massachusetts and Maine. The lone star tick carries a bacterium similar to the one which causes Lyme disease but it produces a Lyme-like disease called STARI (Southern tick-associated rash illness)

## Physicians Training Program Brings LLMDs to Communities Nationwide

*by Turn The Corner Foundation*

Turn the Corner (TTC) is committed to ensuring that people with Lyme disease no longer have to go through the painful process of being misdiagnosed and ineffectively treated due to the insufficient training of health care professionals in regard to tick-borne illnesses. With funding from TTC, health care professionals are now being trained around the world to recognize and treat this disease successfully; bringing relief to the many that may have lost hope for a pain-free future because of Lyme disease. The mission of TTC is to support research, education, awareness and innovative treatments for Lyme disease and other tick-borne diseases.

TTC has formed countless programs that address Lyme disease education, diagnosis and treatment since its inception. These innovative programs have significantly impacted the Lyme disease community. An exemplary program that reflects this impact is the Physicians Training Program, which was created by TTC in collaboration with the International Lyme and Associated Diseases Society (ILADS).

This groundbreaking program provides medical practitioners, from Naturopaths to MDs, the opportunity to study with a Lyme-literate health care professional. Through this experience, participants have developed the skills necessary to properly diagnose and treat Lyme disease. These profes-

sionals then bring this skill set back to their community in order to better treat their patients and give relief to the many who suffer from the debilitating effects of Lyme disease everyday. The Physicians Training Program is approximately two weeks long, and trainees become Lyme-literate through watching mentoring doctors in action with patients, reviewing different cases, and learning their individual approaches to diagnosis and treatment.

The Physician's Training Program gained significant recognition in 2006. The number of trainees and mentors increased with new participants learning firsthand about Lyme disease and other tick-borne illnesses. Trainees have

*"Training"...cont'd on pg 4*

## What Ever Happened to Common Sense?

by Dawn Irons



It was a nightmare no parent ever wants to face. My husband and I recently had the frightening experience finding our daughter critically ill after what seemed a simple stomach virus. The first day started out as a typical flu. The second day was when we found her unresponsive and rushed her to the hospital where we were told she was in a coma.

Tests were run and we were told that she had a case of viral meningitis with encephalitis. The doctor warned us that with her level of infection that some people never wake up from the coma. We were immediately transferred to the local children's hospital and assigned an infectious disease (ID) doctor. We spent hours giving very comprehensive medical histories of the entire family to the ID doctor.

Obviously there came the point where we disclosed that both my husband and I were diagnosed and being treated for Lyme disease. As if on cue, the ID doctor said, "We really don't see Lyme disease in Texas, do you ever travel to the east coast?" We knew this would prove to be a point of contention with the ID doctor, so we tried to focus him on our daughter's medical issue at hand.

While we were waiting for blood results to determine if it was viral or bacterial meningitis the hospital put her on IV Rocephin as a precaution. Within in 24 hours of being given antibiotics she was out of the coma, although still quite disoriented. It was during this time that a few of the doctors and medical providers on the PHA staff contacted me and urged me to have Lyme panels run on her since Meningitis and Encephalitis are known illnesses with Lyme. Since both of her parents were diagnosed with Lyme, this was not an outrageous request.

I was not sure how this request would go over with the ID doctor, but I made the request anyway. I was flatly refused. He would not even consider running the blood tests, of which my insurance company would cover 100%. He said Lyme disease is not

known for being clustered in families and our risk of exposure in Texas is almost zero. I guess he had not read the Texas A&M study about the increase of tick-borne illnesses in Texas 4 years ago, but I digress.

The ID doctor further questioned my husband and I on how we came to get the Lyme diagnosis. I explained the bulls-eye rash I had, being fully symptomatic as well as positive lab results. He immediately wanted to know what lab ran our tests. I had personally had a positive test with Quest Diagnostics as well as IgeneX. He immediately explained how IgeneX was not a reputable lab because "their results cannot be replicated by the CDC."

I asked him if he was aware of the Lyme specific bands that were removed from the CDC

**He would not even consider running the blood tests, of which my insurance company would cover 100%.**

**He said Lyme disease is not known for being clustered in families and our risk of exposure in Texas is almost zero.**

**...she was out of the coma within 24 hours of receiving IV Rocephin; a common treatment for Lyme.**

test in order to create a vaccine. The bands were removed because they wanted to avoid false positive results in the people who had received the vaccine...but the bands were so Lyme specific that they were used to create the vaccine (which subsequently caused more damage and injury and was removed from the market.) To this day, the CDC has not added those specific bands back into the mainstream testing because they are hoping to take one more try at a vaccine.

The ID doctor felt that was irrelevant and that IgeneX was not a reputable lab because their results could not be replicated. I sat their stunned. I wondered how an intelligent person could be so...well...DUMB! I knew this conversation was going nowhere! Has common sense completely

eluded the Infectious Disease Society of America's (IDSA) ability to think logically?

Let's put this in elementary terms that we can all understand. Our english language has 26 letters that are very specific to our being able to communicate effectively in the written form. If both the ID doctor and myself were given an assignment to type out the words to the Pledge of Allegiance, yet two essential vowels were removed from his keyboard, OF COURSE he could NOT replicate my typing sample! He would be missing two essential vowels. How difficult is that to comprehend?

I realized I was in a losing battle, but knowing that my daughter's health was at stake, we complied with his wishes while at the hospital, all the while having made an appointment with our LLMD to see her once we got her home. We still do not have those test results back at this point, but the peace of mind knowing that the labs were sent to IgeneX, who uses all of the bands for testing, is a great relief.

I truly have great concern for the Lyme patients in Texas who have to face this kind of ignorance of the disease among the arrogance of the medical community on such a consistent basis. I can tolerate mistreatment of myself..I am an adult. But they cross a line when they start endangering the long term health of my children.

This really is an elementary problem. Are the ID doctors in Texas (and nation wide) smarter than a 5th grader? Even 5th graders know that all 5 vowels are essential to complete and accurate written communication! So it would stand to reason that all available bands for testing Lyme disease would be just as essential in accurate testing outcomes for diagnosis and treatment. But hey, what do I know? I am only a mom using common sense, not an ID doctor. *pha*

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

## Public Health Alert

The PHA is committed to researching and investigating Lyme Disease and other chronic illnesses in the United States. We have joined our forces 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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#### Letters to the Editor

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

# Legal Battles Continue to Plague Pediatric Lyme Specialist Dr. Charles Ray Jones

## A Valiant Hero's Fight to the Finish

Dear Friends,

Your tremendous expression of support continues to overwhelm me. I cannot put into words my heartfelt joy, appreciation and love for you all. The charges against me have provided great challenge, but I remain optimistic. I know that my approach to treatment is sound, and maintain my belief that justice ultimately will be served. I also have tremendous confidence in my legal team, which has been working diligently to enable me to prevail.

We have just entered the second year of legal hearings, however, and my legal defense fund is nearly depleted. My ability to mount an appropriate defense, from a financial perspective, is now in jeopardy (legal expenses have been averaging \$1000 per day), and will depend on my ability to continue to meet the high

cost of this lengthy and complex process. I currently need a fund of \$150,000, to be in a position to fight the charges. In order to achieve this, I need your financial backing, in the form of as generous a donation as your circumstances will allow. It pains me greatly to have to ask this of you, knowing the tremendous burdens that Lyme disease already has imposed on so many. It is critical, however, that I retain my license, in order to preserve timely access

to appropriate, comprehensive treatment for the children who are so very ill.

Checks should be made out to the "Charles Ray Jones, M.D. Legal Defense Fund" (write "gift" in the memo section), and mailed to the CRJMDLDF c/o George Heath, III (CPA), 26 Fairlawn Drive, Wallingford, CT 06492.



Alternatively, credit card donations to the legal defense fund may be made through a PayPal account: [www.DefendLymeDoctors.com](http://www.DefendLymeDoctors.com)

Thank you for your continued support, your prayers and good wishes. Regarding your many letters of encouragement, please know that I read and appreciate every single one.

Sincerely,

Charles Ray Jones, M.D.

Madison Towers  
111 Park Street, 1st Floor  
New Haven, Connecticut 06511  
Tel (203) 772-1123  
Fax (203) 772-0682

pha

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# Should One Reason With Morgellons Cynics?

## Sample Replies to their Doubts

by Dr James Schaller, M.D.



One of the things I learned in my extended college and graduate school experience is that most people, including scientists and

physicians, have core Meta beliefs about what is possible. These are outside their insight and awareness. We see this in religion and psychology pretty clearly. For example, those with terrible parents often are the most passionate about their belief in the absence of God. My point is not whether God exists, but that many with an abusive or absent parent experience core beliefs about parenting and that God is abusive or dead. Another example would be children who have been bullied. Some tend to see the world as more dangerous than others, even after decades without abuse.

Perhaps another analogy is politics. By the time one is 45 years old, it is rare to see a major party change if the original affiliation was strong. Democrats rarely will become strong Republicans and strong Republicans will rarely

become strong Democrats after 45 years of age.

In this setting of our core beliefs, the fact is many scientists and physicians are not worth reasoning with about Morgellons. Why? Their presuppositions and ability to explore this illness cluster is simply not open to this possibility. Some physicians have character rigidity and obsessive personality traits that require extreme amounts of data unavailable for many clinical situations. Obsessive personality traits have some benefits in medical science, because they can help a practitioner attend to important small details, but can also cause practitioners to fear what is not in their "information box"-their finite brain.

Some are also worn, tired and have limited empathy that causes them to see individuals with obviously clear pathological extreme skin lesions as simply folks who "pick at their skin." We also know that some individuals working in the medical sciences or as health care providers have anti-social traits or are narcissistic, which makes accepting a patient's history, over the doctor's medical world view unlikely. Treating Morgellons patients requires physicians to listen very deeply,

have profound humility, and the belief that we have a great deal to discover about human illness.

Furthermore, the abuse of health care practitioners by litigious patients, plaintiff attorneys, state boards, insurance reviewers, insurance companies paying "reasonable and customary rates" which are only customary for the year 1940, makes it hard for practitioners to have the time or energy to learn new concepts and explore new illnesses. Some mean well, but are simply keeping their head above water trying to get all the codes right, and manage their huge insurance processing staff.

Medical illnesses are becoming the source of polar physician positions. These positions are much like the 1990's politics of global warming-some feel it is nonsense and some feel it is as obvious as basic math. Some of these polar medical topics include chronic Lyme disease, indoor mold exposure illness, Babesia, long-term narcotic pain medications, long-term anti-anxiety medications, cash pay vs. insurance pay medicine, the value of organized medicine vs. those who feel traditional medical societies are useless.

So I would suggest that we

take a lesson from politics. Do not waste your time trying to convert those with strong passions for the opposing party. You will waste your time. Instead, first make sure you have fully and clearly stated your position to your own party and that they understand what is at stake and have an understanding of the "platform." In this regard, patients with Morgellons, health care workers with Morgellons, and physicians who believe this is not simply a delusion and treat it, should be educated and included in all Morgellons organizations.

Next, we should reach out to those who do not know everything and are either open to considering Morgellons as an illness, or are too busy and indifferent to oppose Morgellons illness. Both of these groups, over a period of time, might be open to the idea of Morgellons illness, or at least they will refrain from opposing its treatment if they are slightly educated.

Replies to Common Anti Morgellons Criticisms:

**Antibiotics can act as placebos and that is what is happening with "cured" Morgellons patients.**

**"Morgellons"...cont'd on pg 10**

# The "Antifungal Parade"

An option for treating resistant cases of Candida

by Kurt N. Woeller, D.O.

Candida (or similar yeast overgrowth) is a common problem in chronic ill health. I have seen over the years many patients suffer from the ongoing resistance of candida to being eradicated. One problem with these various yeast organisms is the growing resistance to anti-fungal medication. Just like bacteria that develop resistance to antibiotics, candida (and other forms of yeast) can develop resistance as well.

Most forms of Candida (and certain other forms of yeast) live in harmony in small amounts in our digestive system (a.k.a. commensal). They are kept in balance by other natural bacteria (referred to as "natural flora"). However, when our immune resistance is down or the natural flora is disturbed (i.e. prolonged antibiotics) these commensal yeast can start to flourish beyond their normal levels. If left untreated this overgrowth of yeast can become invasive. What this means is the yeast starts to change form and begin to embed into the lining of the gut - in essence it starts to grow roots. The longer it is left untreated the more invasive it becomes. It can be difficult to tell what treatment is going to work the best for a particular yeast overgrowth problem. One common antifungal medication called Nystatin can work very well - many times dramatically at eradicating candida. At other times having to use a variety of antifungal medication is needed.

### Dr. Baker's Antifungal Parade

Dr. Sidney Baker, a well-known and respected DAN! (Defeat Autism Now) and integrative medicine physician coined a phrase called the "antifungal parade" for a treatment approach for chronic cases of yeast overgrowth. This treatment regimen uses various antifungal medications on a rotation basis to determine which one works the best and also to avoid drug resistance. I have been using this approach with good success for patients with chronic, resistant yeast problems. Listed below is an example of my antifungal parade modified from Dr. Baker's original recommendation. The list of therapies is only an example and can be modified based on specific need, availability of medication, and tolerance. I have only listed prescription medications for simplicity sake, but

understand that natural antifungals such as grapefruit seed extract, olive leaf extract, oregano oil, etc. can be used in conjunction as well.

### Anti-Yeast Treatment Program

Most of these medications can be obtained with a doctor's prescription from your local pharmacy. However, the oral Amphotericin B will need to come from a compounding pharmacy. Compounding pharmacies are specialized at making their own formulations of medications from bulk supply. They are more adept at making special formulations of oral suspensions and other blends that are preservative-free. The dosages listed are those commonly given to adults, and the amounts can be modified for children (although some of the dosages are fairly similar). If you are seeking oral suspensions for these medications the use of a compounding pharmacy may have to be employed as only a few medications come standard as both capsule/tablet or liquid.

**Nystatin Tablet (500,000 units)** - one 3x daily for 10 days, then double the dose for 10 days, then switch to:

**Diflucan 200mg** - one daily for 10 days, then double the dose for 10 days, then switch to:

**Amphotericin B 250mg** - 4x daily for 10 days, then double the dose for 10 days, then switch to:

**Nizoral 200mg** - one daily for 10 days, then double the dose for 10 days, then switch to:

**Nystatin Tablet (500,000 units)** - one 3x daily for 10 days, then double the dose for 10 days, then switch to:

**Sporanox 100mg** - one 2x daily for 10 days, then double the dose for 10 days, then switch to:

**Amphotericin B 250mg** - 4x daily for 10 days, then double the dose for 10 days, then switch to:

**Lamisil 250 mg** - one daily for 10 days, then double the dose for 10 days, then switch back to Nystatin.

This program can be

repeated over and over again if needed. Periodic blood work for liver function is warranted, but much less of an issue because you are only taking a systemic antifungal, i.e. Diflucan, Nizoral, Sporanox or Lamisil for only 3 weeks at a time. Usually, if any of these medications are taken for longer than 6 to 8 weeks at a time liver function needs to be checked. The non-systemic antifungals, i.e. Nystatin and Amphotericin B, do not require blood work analysis as they do not get absorbed into the blood supply and only stay local in the digestive system.

The antifungal parade allows for a lot of flexibility. You can start anywhere on the list. The point is you keep rotating from one to the other. A few additional things need to be made clear. If you or your children are getting good results from a particular medication it may not be advisable to switch. If something is working it is okay to stick with it. The last comment is that some of these medications will need prior authorization from your insurance company if going through a standard pharmacy and/or if you are trying to use insurance for co-pay. Usually, Sporanox and Lamisil are the tougher ones to get while I have not seen much problem with Nystatin, Diflucan or Nizoral. Amphotericin B is only available in oral form from compounding pharmacies so this one is usually not available via insurance co pay anyway. *pha*



**Kurt N. Woeller, D.O.** is the medical director for Stillpoint Center for Integrative Medicine in Temecula, CA. He has been a DAN! (Defeat

Autism Now) referral physician since 1998. He can be contacted at 951-693-2267 or email him at [info@mystillpoint.com](mailto:info@mystillpoint.com) Website: [www.mystillpoint.com](http://www.mystillpoint.com)

# "Training"

...cont'd from pg 1

come from coast to coast and even abroad. Word about our unique training program has been spreading, enabling new health care professionals to get involved and go back to their home towns to successfully treat patients with Lyme disease. Many are now the only health care professional in their community, city, or even state that is able to recognize and treat the symptoms of Lyme disease. In 2006 we expanded the Physicians Training Program to also include RN's, DO's, PA's and other health field professionals, enabling as many people as possible to experience this unique program.

Dr. Ann F. Corson, a past participant in the program whose office is in the heart of Pennsylvania Lyme disease country, notes that "Not only have I received grants to study the management of tick-borne diseases with the best existing clinicians, but three other physicians have now come and trained in my office under additional grants from TTC. This charity has done more than any other in promoting the education of practicing physicians in the recognition and management of tick-borne diseases". TTC has trained dozens of health care professionals through this program and hundreds of individuals, who would otherwise be forced to suffer from the effects of Lyme disease, have been properly diagnosed and treated around the world.

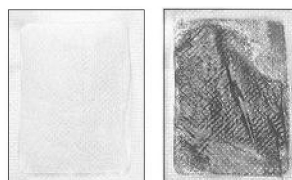
Staci and Rich Grodin founded Turn the Corner Foundation in February 2002. Since its inception, the Foundation has raised nearly \$2 million for Lyme disease research, education, awareness and treatment. For more information about Turn the Corner and their different programs or to volunteer your time, funds or services, please visit [www.turnthecorner.org](http://www.turnthecorner.org). *pha*



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# Peripheral Facial Palsy

## More Than Just a Flat Expression

by PJ Langhoff

You awaken one morning and discover that you cannot smile, have lost your sense of smell and/or taste. You have difficulty speaking, and your face is drooping. Perhaps you have had nonspecific flu-like symptoms, headaches, fatigue, muscle aches and fevers. Have you had difficulty concentrating, or are you sensitive to light or sound? Do you feel more irritable than normal or do you have a stiff neck or ear pain or one or more rashes? Those symptoms may have already come and gone, perhaps multiple times, and years ago. Have you had problems with your heart such as an arrhythmia or heart block? And now you suddenly find your face is affected by "something", or you may have vertigo, difficulty closing one eye, or reduced hearing in the ear on the side of the face that is affected.

That "something" causing a sudden, dramatic change in your face may be the most common neurological symptom associated with Lyme disease, which is peripheral facial palsy (PFP), occurring in approximately 10-30% of patients. It may also be caused by a number of other factors.

You say a routine national laboratory has tested you for Lyme disease in the past and your results were negative-so you "don't have Lyme"? Then please test again. If you haven't been tested before, ask your physician to test you for Lyme disease using a top laboratory such as IGeneX, or Central Florida Research.

Lyme disease testing can provide false negatives for a number of reasons. The patient's results can be affected by a course of antibiotics taken prior to testing. Or the *Borrelia burgdorferi* (Bb) spirochete that causes Lyme disease may have been undetectable in that particular blood sample. Also, the antibody response to Bb is slow, so your body may simply have not made any antibodies, hence they were undetectable. Some Lyme patients never make sufficient antibodies. And last, the test used may have followed CDC surveillance criteria which by definition, misses many cases of Lyme.

The relationship between PFP and Lyme disease is clear. In 1998, the FDA approved a vaccine against Lyme disease called "Lymerix" (SmithKline Beecham, PA). The vaccine con-

tained a recombinant outer surface lipoprotein A (OspA) of the Zs7 strain of *Borrelia burgdorferi* (Bb) spirochete, which was given in 2 double-blind studies with more than 20,000 patients. The results were published in the New England Journal of Medicine at the time. These early OspA antibodies, which occur after infection and are not exclusive to vaccination, are not easily detectable in the early stages of Lyme disease, especially in humans, although they were detectable in animal studies.

In children, PFP was felt to be caused by the direct neural invasion of Bb spirochetes. It was unclear how much impact the vaccine would have on the incidence of Bells palsy, but it was expected to prevent about three quarters of the potential cases of Lyme disease. Studies by Ikeda et al. that were cited during vaccine studies showed that 32% of Bells palsy cases were caused by *B burgdorferi*, and if correct, it was expected that roughly one-quarter of the cases of Bells palsy per 100,000 population might be prevented.

The vaccine was not approved for use in children under age 15, and was subsequently pulled off the market in 2002 after a flare of controversy over its safety and effectiveness, while Glaxo-Smith Kline cited "insufficient demand."<sup>3</sup>

In acute PFP, there is not normally a rash present, but there may be. In the beginning of the acute form of the disorder, simple ear pain, (similar to a mild ear infection), may be the only symptoms present, or perhaps a mild fever or flu symptoms. Over the course of several days, the symptoms will progress into more acute stages.

Facial palsy typically occurs on one side of the face; however, it can rarely present bilaterally (both sides). The external surface of the ear on the affected side may be swollen and/or reddened in appearance. Depending upon nerve involvement, there can also be moderate to severe pain in the face, in or around the ear, and the skin on the face may be painful to touch. Pain may extend from the top surface of the patient's head on the involved side, through the face, neck, and into the shoulder and back. Facial palsy is typically not painful, though extreme forms having inflammation can cause excruciating pain along affected nerve pathways.

There is evidence that the

incidence of *Borrelia*-associated PFP is much higher than reported, and it is postulated that many cases of what is known as "idiopathic" facial paralysis, (Bells palsy) are actually undiagnosed Lyme borreliosis. In many people, acute PFP is the only symptom of Lyme disease, and a diagnosis of Bells palsy is automatically given by the doctor, instead of reviewing the patient's clinical history for positive serological Lyme testing, or other hallmark Lyme symptoms, such as a tell-tale "bull's-eye" rash, or a history of arthralgias (joint pains) and other Lyme-specific symptoms.

PFP in children can be caused by many disorders, including trauma, otitis media (ear infection), tumors or growths, a congenital anomaly, or Lyme borreliosis. Viral infections can also cause facial paralysis, such as a reactivation of the varicella-zoster virus (VZV), which is the virus causing "chicken pox" and "shingles". This virus can also cause in children, what is known as "Ramsay Hunt syndrome", which includes facial paralysis and zoster (eruptions on a nerve path and inflammation) around the outer ear or in the back

of the throat (oropharynx), and affects the eighth cranial nerve, the peripheral nerve dictating inner ear function. VZV reactivation can also cause PFP in the absence of zoster, which is called zoster sine herpete.

In addition, HSV-1 (Herpes simplex virus type 1), EBV (Epstein-Barr virus), CMV (cytomegalovirus), mumps virus and HHV-6 (human herpes virus type 6) have all been reported to cause acute peripheral facial paralysis in children. In most patients of any age (up to 60%), the cause remains unknown and a diagnosis of "idiopathic" peripheral facial paralysis, or Bells palsy is made.<sup>4</sup> If more patients were tested serologically for Lyme disease at the onset of PFP, the number of clinical cases of Lyme disease might well show an increase.

Most people recover from acute PFP, but in approximately 5%, recovery is incomplete and complications occur which include involuntary muscle movements (synkinesis), loss of facial function, or odd or absent sensations.

As a prime example of  
**"Facial Palsy" ...cont'd on pg 12**



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## Sick As a Dog?

### He Might be the Problem, Says Vet

by Texas A&M University

**College Station, TX --** If you're feeling bad and think you're sick as a dog, you might have put your finger on the cause.

There are more than 200 diseases that can be transferred from animals to humans, and even man's best friend can be unfriendly when it comes to staying healthy.

From Petey the parakeet to Roger the rabbit, almost every animal is capable of passing some type of disease or sickness to humans. Dr. Leon Russell, a veterinarian in Texas A&M University's College of Veterinary Medicine & Biomedical Sciences who teaches a course on the subject, says ailments range from near harmless to downright deadly.

The technical term for such a transfer is zoonosis, which means any disease that is communicable from animals to humans."

Most of those 200 or so diseases that can be passed to humans are fairly rare and don't occur much in the United States," Russell says. "But there are a few dozen that are very common and can be even be killers." One of the worst: salmonella. It's a bacterial disease found in poultry and eggs and uncooked meat. Worldwide, it kills thousands of people every year but can be one of the most preventable, Russell says. Its bacterial cousin - campylobacter - can also be acquired from poultry, but young puppies have been known to pass the disease, Russell confirms. "If you cut up chicken and then use the same knife to cut the bread or salad, you're asking for trouble," Russell believes. "And it's best to clean off a cutting board you're using, too. Just one drop can make a person very sick." "Also," he adds, "you must wash your hands after handling raw meat or poultry to prevent transfer of these bacteria to other food items." Snakes and other reptiles are capable of passing salmonella, too, he says. "If a youngster has handled a snake or other rep-

tile and then eats without washing his hands, it gives salmonella an open door to invade the body," he says. Being pregnant is not the best time to be cleaning out the cat's litter box, either. Russell says toxoplasmosis is sometimes passed from cats to humans and can harm a woman's fetus during pregnancy, possibly leading to birth defects. "It's best to let someone else change the kitty litter if you're pregnant," he advises. "Eating uncooked meat, such as pork, mutton or beef, is another way of



transmitting toxoplasmosis," Russell believes. Cows - and dogs - can pass along leptospirosis to their owners. It affects the liver and kidneys and can become very serious. It can be similar to infectious viral hepatitis in humans, Russell points out. Animals urinating in surface water such as ponds, tanks or even small puddles is a hazard, he says. Brucellosis can also be passed from cattle to humans, and although it is not as common in the United States and it used to be, other countries still are dealing with the problem. It often comes from impure raw milk and can cause a high fever and affect bone development. Children who ingest dirt that is used by dogs who have roundworms can get roundworms and can get ill, and hookworms from an uncov-

ered cat's sand box cause skin lesions on humans, Russell adds. Cat Scratch Fever is not a myth - it's real and when kitty's claws come into contact with skin and blood, it can result in flu-like symptoms and swollen lymph glands, Russell says. "Nationally, about 1 percent of all emergency room hospital admissions are due to animal bites or scratches," Russell explains. "That figure may sound low, but it adds up to between 1 and 2 million people a year." The dreaded disease of

rabies has been around for hundreds of years, and skunks and solitary bats are the most frequent carriers, Russell says. The best advice: "Use common sense and stay away from wild animals, and if you see a bat on the ground or a wall, leave it alone. And remember that rabies is transmitted by animal bites, not by skunk scent or flying bats." If you're a bird lover, watch out for histoplasmosis. It comes from bird droppings that are often seen on the sidewalk or on cars, and if you inhale it long enough, it causes conditions that resemble tuberculosis, Russell says, and can become very serious. And parakeets can give humans Psittacosis, commonly called Parrot Fever, which can cause flu-like illness and eventually may affect the heart and

lungs. The Easter bunny can be soft and cuddly, but if it is a wild rabbit it is capable of passing along Tularemia, which causes skin lesions, high fever and swollen lymph nodes, Russell says. Ticks on animals can make them sick and the results can be transferred to humans in the form of Lyme disease or Rocky Mountain Spotted Fever, both of which can be deadly. Russell says Lyme disease starts out as a skin rash, evolves into conditions resembling arthritis and in its final form, can cause serious neurological problems. Deer ticks have been known to pass along Lyme disease and dog ticks spread Rocky Mountain Spotted Fever to humans, Russell notes. Horses can develop Equine Encephalitis and the same mosquitoes can pass it to their owners. Although horses and humans can be victims of mosquito transmitted Encephalitis, horses do not directly transmit the disease to humans, Russell points out. Most moms know a young kitten or dog can have ringworms, a skin ailment that while not usually serious, can be extremely unpleasant. Ferrets can be cute and playful, but some have a nasty habit of biting small children which can cause various types of infection, Russell says. And what about the reverse? Can animals get diseases from humans? "Tuberculosis can be passed both ways - from animals to humans and vice versa," Russell explains. "If people use common sense, they should not have much to worry about when it comes to animal diseases. Washing your hands after handling animals and pets, not kissing dogs or cats near their mouths, treating bites effectively, keeping clean litter boxes and bird cages - all of these things can go a very long way in easing any worries an animal or pet owner might have," he adds. *pha*



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# The Many Causes of Anxiety & Depression

by Marjorie Tietjen

Depression and anxiety are often normal reactions to certain life circumstances that we go through. However, infection, food allergies, chemicals and mold in the food and environment, hypoglycemia, and thyroid conditions can also cause these uncomfortable states of mind. More emphasis needs to be placed on identifying these primal causes rather than simply adding more chemicals to already overburdened bodies. The opinion of a growing number of people is that antidepressants and other brain altering drugs are being vastly over-prescribed.

Antidepressants do help people, especially in acute or life threatening situations, but everyone reacts differently to these drugs. People need to be warned of the possible adverse side effects. These side effects can be very serious, often causing the very symptoms they are supposed to alleviate. Many times when the underlying condition is ignored, and only covered up, the diseased situation continues to simmer and progress, undetected, beneath the surface.

The public should be aware and demand that these basic causes be addressed. We need to be our own researchers and begin to take more responsibility for our health care. The medical system is big business and is set up to make a profit. Pharmaceutical companies prefer that you receive only symptomatic treatments rather than treatments which will cure the disease. Drugs often cause additional symptoms, which require more drugs to cover up the effects of the original drug. This doesn't make sense but we have been conditioned to think of this process as inevitable and normal.

Depression often runs in families, but why is this so? Is it simply due to genetics or are microbes sometimes being passed down through the placenta during pregnancy? A genetic tendency towards depression may require a microbe to bring the full condition into being. The same may be true concerning other diseases such as Alzheimers and Parkinsons. Perhaps certain microbes are passed to family members due to the close living conditions. Infection can incite depression or anxiety directly by causing

encephalopathy (inflammation of the brain). Microbes can also target certain glands in the body, such as the adrenals and the thyroid. These glands produce hormones, which help the brain function smoothly. When there is an excess or deficiency of these hormones, depression, anxiety and other psychological disturbances do occur.

Because I am not a doctor, I am only going to focus on the three conditions, which have affected me, and therefore, I am more familiar with them and able to share what I have experienced and researched. Encephalopathy, severe hypoglycemia and hypothyroidism are the abnormalities I have had to deal with. These can all cause depression and anxiety. Most of the symptoms of these conditions descended upon me, in full force, with the onset of the Lyme disease. However, I did not discover that Lyme disease was the actual culprit until 8 years later. I had been labeled with the waste-basket diagnosis of Chronic Fatigue Syndrome and therefore was left untreated for the basic problem. Due to this misdiagnosis, I am very familiar with the issue

of only treating the symptoms and not the cause.

Encephalopathy of the brain can have several causes. In my case it was the Lyme infection. Some of the symptoms of encephalopathy include depression, impaired visual perception, intolerance to bright light, anxiety or panic attacks, loss of memory and cognitive function, personality changes, lack of concentration, muscle weakness, seizures, muscle jerking, and more. Obviously when a person has several, or many of these symptoms, the cause needs to be determined. Do not stay with a doctor who refuses to investigate, tells you that you are just depressed, hands you a prescription for antidepressants and sends you on your way. If, after a thorough investigation, a cause cannot be found, do not give up on the infection connection. Testing for Lyme disease and other co-infections is very inaccurate. These microbes can hide in the body by cloaking themselves in your body's tissues and by changing into forms that the current testing cannot detect. Many times an adequate trial of antibiotics is **"Depression"...cont'd on pg 13**

## Texas Warning Ignored, Fallout Devastating

TAMU Officials Warned Texas of Growing Problem With Tick-Borne Diseases

by Dawn Irons

There's a storm brewing and Texas is quickly being caught in the eye of the storm. Fortunately, a warning was sounded in 2003 by Texas A&M University (TAMU) that the torrential weather was coming. Unfortunately, no one with the authority to prepare the public and medical professionals did anything to abate the coming downpour.

In May of 2003, TAMU entomologist Dr. Pete Teel, with the Texas Agricultural Experiment Station, shared his concerns of a growing tick problem in an article titled, Officials Warn Texans to Watch Out for Tick-Borne Diseases. Yet his warnings fell on deaf ears. As was foretold, tick-borne illnesses such as Lyme disease, STARI, Rocky Mountain Spotted Fever, Erlichia, Bartonella, and Babesia have been on the steady rise in Texas.

Support groups for Lyme disease have been growing by leaps and bounds throughout The Lone Star State. The Dallas-Fort Worth area support group, led by Donna Reagan, has close to 200

members. The Houston support group, led by Teresa Lucher, was featured in a PBS program about Lyme disease in Texas. A reporter from a newspaper in Victoria also interviewed Houston Lyme patients for a story concerning the growing Lyme disease problem in Texas. The support group in Austin, led by Teresa Jones, has been newly re-established after the group suffered a devastating blow in losing the only Lyme literate medical provider in their area due to harassment by the Texas Board of Medical Examiners.

Patient stories throughout the state are filled with multitudes telling of the devastation of being misdiagnosed and flatly dismissed with the common medical mantra, "We don't have Lyme in Texas. That is an east coast disease." Many more Texas Lyme sufferers tell of insurance companies who deny medical coverage based on the new 2006 treatment and diagnostic guidelines for Lyme disease put out by the Infectious Disease Society of America (IDSA). Still other patients share the horror of battling with the social security office over their disability claims

and Medicare coverage. Yet, the most tragic stories of all are from the numerous patients who have to leave the state to even get medical care. A large majority of the DFW and Houston Lyme support groups travel to doctors in Louisiana and Missouri. Many in the Austin support group travel to San Francisco to see the nurse practitioner that was run out of Texas by the medical board.

The stories are tragic, sad, and financially devastating for the patients. All the while, we should be asking the question... "Why all the fuss?" TAMU saw this coming in 2003 with verifiable scientific data! We were warned! Yet medical professionals who are concerned about threats against their license simply choose not to treat patients with a diagnosis of Lyme. And why is it that the Texas Board of Medical Examiners has such harsh policies for those who have treated Lyme in the state?

Loretta Pressly, of Corpus Christi, has recently felt the full blow of the prevailing medical position regarding Lyme disease in Texas after she was denied continued coverage on her Workers

Compensation disability benefits package.

Pressly received a tick bite on the job and shortly after presented with the classic bulls-eye rash. She was seen by an internist with a specialty in infectious disease. She was diagnosed with Lyme disease based on symptoms, presentation of the bulls-eye rash, and two different laboratory diagnostic tests from separate labs. Workers Comp requested a second opinion and assigned a doctor to review her case. The second opinion doctor also confirmed the diagnosis of Lyme disease.

Pressly has been battling Workers Comp for continued coverage for a while. She recently was given an administrative review of her Workers Comp case to decide if she would remain covered for continued medical care. Pressly requested that a doctor who was experienced in treating and diagnosing Lyme disease review her case history. Workers Comp assigned yet another doctor for a "referee opinion." The doctor assigned to Pressly's case readily admitted that he was not **"Warning Ignored"...cont'd pg 13**

## A Secret Handshake & a Whisper: Part 2

by Sue Vogan

### Are physicians leery about diagnosing Lyme disease (LD)?

We have a situation of governmental disinformation. The same summer that The Wilton Bulletin, our local newspaper, announced that 54% of the families in Wilton had been diagnosed with Lyme disease; the New York Times had a big spread on the front page of the science section and basically said that it was not a big deal. And that seems to represent the official position of the government agencies and they get that information from the experts of infectious disease.

I have great respect for doctors who go thru medical school, internship, and residency to become an internist, passing the examinations all the way along. Becoming a board certified internist is a heavy thing to do. Many of these doctors go on to train in sub-specialties of internal medicine at great personal expense and suffering. They know about infectious diseases that I have

### An Interview with Dr. Warren M. Levin, M.D.

never heard of -- truly they have an area of specialty that is very complicated. I honor them for all of that work, but the educational system has fallen down in terms of LD. There has been an old-boy network that made a stand, took a position and either the network or they refuse to change it. The members of the medical fraternity / sorority have a certain reverence for the professors they choose to study with. And, again, in general it is well deserved. The people who are giving this misinformation are not bad people, I just think they are bad scientists.

### Why have some of these professors/scientists changed their minds? Allen Steere, for example? In your opinion, are there outside influences that encouraged them to change their minds with regards to Lyme disease?

I don't know the answer to that question, but what I do know is that if a physician has gone through the extensive training, examinations and supervision, then they become a specialist in infec-

tious disease. At that point, they have to start earning a living to pay back the debts they incurred while in medical school. Infectious disease tends to be a specialty that is hospital-based, and for a physician to get an appointment at a hospital, it is a BIG thing. But it doesn't give you a practice. Today, we have the HMOs and insurance companies. These physicians can go to any of the big insurance panels and their specialty is welcomed. They have a practice and they get paid!

In the meantime, after having obtained a certificate/diploma and/or board certification, they are able to join the guild. This is the insider group at the Infectious Disease Society of America (IDSA). IDSA doctors have guidelines for diagnosis and treatment. If someone new doesn't follow the guidelines, they are in trouble -- particularly if they work for an insurance company and then choose to give their patient more than four weeks of antibiotics because they aren't doing well at the end of the treatment. The insurance company puts a little

check mark by this doctor's name and when they get too many check marks, they call the doctor to the carpet. They say, "Don't you understand this?" The new doctor will be brought up before the IDSA and the medical board of the state in which they practice, and they will lose their position on the insurance panel. Young physicians can't afford to do this.

Now, if you never do a long-term treatment, because it's against those rules, you never get to see whether it works or not. All you have to base your experience on is what your superiors tell you. The non-specialists, many of whom are family doctors, have families they deal with. They see a patient whose symptoms sound like Lyme disease and the physician treats them with four weeks of antibiotics. Then 4-6 weeks later, the patient claims that he believes the symptoms are coming back -- they begin to hurt and feel tired again, and want some more antibiotics. The doctor says that the patient has had enough antibiotics to get rid of this infection and they don't

*"Dr. Levin"...cont'd on pg 14*

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**By Bryan Rosner**  
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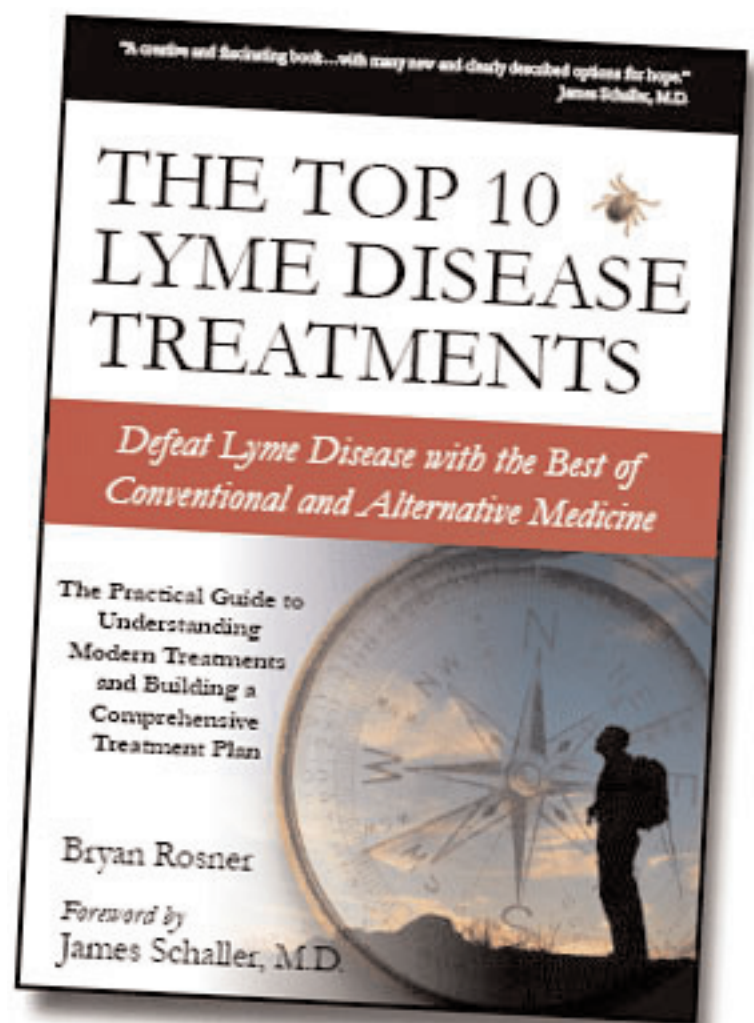
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## “Morgellons” ...cont'd from pg 3

The problem with this argument is two fold. First, these are hopeless people who have had some different treatments and they do not generally expect treatments to work. Second, the rate of eventual cure is higher than the expected rate of placebo for antibiotic medications.

### **Anti-psychotic medications help many of these patients so this means they are delusional.**

It is sad that some health care workers are very simplistic thinkers and forget that all medications have a vast number of "off-label" uses. Indeed, most medications in the USA are prescribed for illnesses never approved by the FDA. Physicians by experience or study have learned that most medications have other effects and benefits beyond the one use approved by the FDA.

One common use for all anti-psychotic drugs is for the treatment of significant agitation. Another common use is for calming inflammation, restlessness and infection of the brain. I routinely use anti-psychotics for agitated people with infections or medical toxin exposure that makes them terribly restless and agitated. If a patient is exposed to a toxic chemical at a chemical plant, and requires an anti-psychotic to be calmed, no one would think this was a cure.

Again, just because a blood pressure medication lowers the blood pressure of Morgellons patients does not mean the underlying trouble is gone. We do not hear from these anti-psychotic promoters that the skin of these patients becomes cured.

It can be unwise to diagnose an illness purely based on the response to the drug used. Phenobarbital given to a person who is vomiting will stop the vomiting. We would not say they had a Phenobarbital deficiency. We would still look for a possible flu, food poisoning or other intestinal illness-the "real cause" for the vomiting.

I do not believe that any physician in the USA has seen a large number of clear Morgellons patients and that they were all cured of their signs and symptoms and abnormal labs by a mere calming anti-psychotic drug. At best, they were made to experience less discomfort by using the drug-one reason I use anti-psychotics for Morgellons' inflammation agitation.

### **These patients are not physically ill.**

Sometimes one looks over the Morgellons work up by an internist, infectious disease physician or a dermatologist and it is clear they are trying to be very careful to limit any testing. Perhaps they are afraid the insurance companies will not renew their contract if they order too many tests. Or they will be wasting healthcare dollars. One can respect this in some cases. Yet I would appeal that Morgellons patients should have very aggressive work-ups. Limiting their lab testing to 3-4 blood tubes is really saying that one has no wish to find abnormalities, and one is only going to look for severe organ failure. I do not know anyone who thinks Morgellons is caused by severe organ failure such as kidney or liver failure, so this is playing at a diagnosis.

### **Morgellons illness is not a medical illness, but simply a specific delusion.**

Simply, this is not credible because 20,000 things can go wrong with the human body. Why then are the 20,000 possible "delusions" all the same in general content? We do not believe in "diabetes delusions," because we often do extra basic lab testing to catch early diabetes and because we see a cluster of people with the same problems. Just because this Morgellons cluster tends to be restless does not mean they are psychotic-most heart attack patients are restless and are often given an anti-anxiety medication to decrease their fear, which also decreases the oxygen demand on the heart.

Again, if you only do organ failure blood testing you will not find Morgellons abnormalities. Of course, you could also miss cancer, very early diabetes and a heart attack because these do not usually show up on basic simple lab tests.

Finally, I have found rare Morgellons advocates who report they know the SINGLE cause of the disorder. Yet I find 15-20 common abnormal findings and Morgellons is not reducible to one thing. Indeed, I usually find about 4 to 8 causes of their Morgellons, which combine to cause the symptom cluster of Morgellons. A small sample of these include the many very severe types of Bartonella skin damage, Babesia, mycotoxin war-like biochemical agents found

in 30% of USA structures, Lyme disease, various bio-toxins and synthetic toxins, parasitic agents, a fully exploded inflammation system in the presence of an impotent anti-inflammation system, and many other causes. In our treatment, we simply list them, and determine what the most important ones are, and just go down the line. Cures never happen in weeks or a few months as a rule, but folks can generally be made fairly functional and comfortable pretty quickly.

### **The skin damage is self-inflicted**

I have a large number of dermatology books, and some show self inflicted skin damage. These images never look like Morgellons' skin damage to me, unless one only looks at very select areas of itching.

Furthermore, as someone who has been around dozens of individuals with large numbers of fire ant blisters and itching, I commonly see individuals very agitated with the residual fire ant blister on their feet and legs. In my attempts to invent a fire ant treatment to prevent damage at the bite site or death in a rare few, I have intentionally allowed myself to be bitten 15 to 20 times as I have worked to design a rapid treatment. The day after the bite, many people want to severely scratch at the bite site due to pain and a severe itch. The worst patients I have seen with massive numbers of bites (30 plus on the feet), followed by itching and picking/scratching the following day. I have never seen lesions that even remotely look like Morgellons lesions.

Morgellons lesions are complex, diffuse, deep and have many types of skin presentations all at the same time. If there is any "delusion" to be found in Morgellons, it is that it looks like the skin organ itself has become delusional and shows a vast array of pathology all at the same time.

As a research clinician who invents treatments in many areas of medicine, one should really be careful about simplistic answers in this age of NASCAR medicine--the physician runs from the intake door to the exit door faster than an INDY 500 race car, just to make payroll. Simple answers are often ridiculous answers. And calling Morgellons a delusion with self-inflicted lesions is something that will embarrass medicine in the coming decades-in the same manner in which HIV was trivialized

and ignored in the 1980's.

### **I go by studies not people's complaints.**

It is very surprising to some physicians to learn just how little of allopathic medicine is supported by quality studies. Most medicines are used for off label uses with limited research. Many medical beliefs are based on studies that disagree. Many positions held in each decade are altered 10-20 years later-this seems to be routine. Medications felt to be safe based on FDA approved studies, are not safe in later studies-usually due to the experience of a few patients. In child psychiatry, major changes in prescribing have occurred based on the bad experience of 1-9 children or adolescents. In other words, massive medication changes have happened based on the report of a few patients and their experience or "complaints."

I once used an enzyme blocker to stop a blood cancer in one patient, and it worked so amazingly, it has become the standard treatment for this cancer and some other related cancers all over the world. One patient changed the treatment of many cancers, years before any studies existed. Many medical problems have very little research to guide us clearly, and we often do not have large, double blinded random studies to guide us.

In modern Lyme disease, it was a mother and artist, who observed that in her Connecticut community a cluster of youth were getting arthritis. She beat Yale to the obvious.

The use of "meta analysis" is common in medicine in an attempt to find out what the very best of the contradictory studies are ultimately saying. Sometimes these conclusions end up being wrong, based on later Metastudies. Much of what I was taught about pathology and especially treatment is already dated.

In conclusion, most physicians have no training in the science of knowing and how to discern their own biases. They believe it is easy to know based on last months journal articles and this is simply not realistic medicine.

Much of medical care is mere symptom relief without a full understanding of the cause or mechanism of the pathology. So much of what we do as allopathic physicians is to treat abnormal

*“Morgellons”...cont'd on pg 16*

# Sharing Our Stories: Samantha's Nightmare

by Laura Zeller

For young Samantha Colter, the horrors of one dark Halloween night haunt her to this day. Wishing to remain anonymous, "Samantha Colter" sat down with me to give a first hand account of her life thus far. I feel very privileged to share her story with you.

When I first met her, I never could have guessed what she was about to reveal, and that our lives were so intertwined. After emailing me to express her gratitude for sharing my Lyme story, Samantha asked if I could meet with her at a local coffee shop to talk about Lyme disease. Sensing the urgent tone in her voice, I agreed to meet her in person, not quite sure what to expect.

At first glance, Samantha looked like a typical teenager, complete with baggy pants, multiple piercings, and bright pink streaks in her hair. As she plopped herself down on the couch across from me, I couldn't help but think to myself "what am I doing here?" Peeking down from underneath her heavy sweatshirt, I saw a large tattoo of a cross, and what appeared to be the name Chris.

Before I could ask her how I could help, her blue eyes glassed over and she started to cry. She took a deep breath, and said, "I need you to listen, okay?" Sensing something deep was coming, I settled in to relax. I will try to quote what she said as best I can. I told her I was happy to listen to her story, and that I had a Lyme support group, and helped people every day. Samantha already knew my personal story, so she felt comfortable that I would understand her story.

After some small talk, Samantha began with "Well, I watched my mother suffer with Lyme disease as a kid. For as long as I can remember, she was super sick." Samantha said. "She was in a wheelchair, and her legs wouldn't work right. My mom had pain in all her joints, and her head always hurt. She always had the flu, and was always pulling off the ticks. We took her to the doctor and she had a dozen pills to take every day. I got the pills for her, and I took care of her. We used to take care of stray cats, feed them milk, even though we didn't have much money. We got a check from the government and food stamps, but we were pretty poor."

Samantha continued on to describe her tortured childhood. We spent 3 hours together talking, as I tried to relate to her story as best I could. In the end, Samantha told me more about her heartbreak than I could have imagined.

It turns out that Samantha was an only child who never knew her father. Instead of playing and laughing like a normal little girl, Samantha was too busy acting as a nurse to her mother. Samantha said her childhood was a blur of washing her mother's hair, getting her pain pills, and cooking Ramen noodles for dinner. For 11 years, Samantha and her Mom shared the same one room apartment, and slept together in the only bed they had.

As she described her youth, it was clear to me that all these two souls had in the world was each other. Samantha remembers her mother "...got lots of tick bites from Ray, a beautiful black lab we had." Her mother had about 10 cats and dogs living and sleeping with them. Samantha remembered ticks crawling all over their apartment, as she used to pull them off the animals and keep the big ones as pets in a jar with grass. Ticks as pets, yes, you heard me right.

Samantha remembered many trips to the doctor's office. She described how they did not like to go because the doctors thought her Mom was a "crazy lunatic" even though she was in a wheelchair and so weak she could not stand without assistance. Even at a young age, Samantha knew her mother was not crazy because she was so strong inside and had a high pain tolerance. Samantha went on to explain, "...my mom's face sagged and people thought she had a stroke, but the ticks did it to her. The doctors gave her pills that helped her pain but made her super overweight. When she realized it was the pills, she asked to stop taking them, but the doctor gave her more fat pills and her pain came back. It was so heartbreaking seeing her go through this, and I couldn't do anything about it because I was just a little kid."

Life was a constant struggle for Samantha and her mother, and it was about to get a whole lot worse.

Samantha vividly remembers a cold, dark, Halloween night when she was 11 years old.

"I remember all the other kids  
*"Samantha"...cont'd on pg 16*



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## “Facial Palsy” ...cont'd from pg 5

PFP, whether caused by Lyme borreliosis or a reactivation of the zoster virus (I have had chicken pox as a child); I would like to share with you my personal experience with this aspect of disease. In 2000, 9 weeks before my second marriage, I awoke with a terrible earache. Over the course of 5 days, and as many physicians later, I was diagnosed with an ear infection, cellulitis, tinnitus, unexplained ear pain, and shingles of the cranial nerve. Unfortunately for me, all of the diagnoses did nothing to alleviate my pain and facial dysfunction on the left side of my face.

Cranial nerves I (olfactory), III (oculomotor), V (trigeminal), VII (facial), VIII (Vestibulocochlear), IX (Glossopharyngeal), X (vagus), XI (Spinal/Accessory) and XII (Hypoglossal)<sup>5</sup> in me were affected. This translates into a very bad, very painful experience affecting sensation of taste, smell, ability to sense or move my facial muscles, shoulder, raise my arm, turn my head in certain directions and it gave me vertigo and double vision. I was unable to blink in the affected eye, and my eyelid drooped and I could not hear well out of the affected ear. An audiologist's test noted approximate 20% hearing loss in the affected ear. My outer ear was horribly swollen and red. I used special eye drops during the day to moisten my eye and goopy cream at night and tape to keep my eye shut so that I could sleep.

I could not feel or move anything in a little over one-half of my face. I was acutely aware that the nerves running along the side of my jaw were being slowly squeezed into dysfunction by the swelling in my jaw and cheek. My doctor told me that if these nerves are cut off or pinched long enough, they will die, and due to the severity of my symptoms, he thought I was in real danger of losing full function in my face. In fact, my physician felt that I was one of the worst cases he had seen in his 30+ years of clinical practice.

Eating and drinking became quite a challenge; and I would pinch shut my lips on the left side of my mouth, holding them tightly closed with my left hand, and tilt my head to the right and do my best to eat and drink without spilling. Chewing was no picnic either, and I certainly appreciated that ability more than one can imagine, when it finally returned.

The pain was so remarkably intense that I took my heating pad to work with me and sat at my desk for the better part of several days with the temperature set on the highest setting possible. I held the heating pad up to my face for the bulk of two weeks—anything to ward off the horrible pain I was experiencing that was unaffected by analgesics.

At the end of most days I cried because I did not know if I would ever find relief from the pain and I worried also that my face might not return to normal. I did not want to be disfigured for life.

When I laughed, my face took on a hideous form that was embarrassing to me and slightly disturbing to others. Knowing this, I would cover my face whenever I had to speak with someone or whenever I was about to laugh.

"All I want to do is be able to smile at my wedding in two weeks," I told the hair stylist. I nearly called off the wedding for fear of looking freakish. I exercised my slack facial muscles with my fingers every day, attempting to increase the circulation or nerve signal function if it was even possible, but nothing seemed to make a difference. All that I could do was ride out the inflammation and hope for the best.

I was unprepared for how the general public would receive my facial palsy, but I found out the first time I walked into a retail store. I asked the clerk a question, and as soon as she heard me speak, she made a comment about being unable to understand me. I couldn't form words properly with my lips and tongue, so my speech was slurred. I had to repeat what I was asking and I noticed that she, along with practically everyone else I would meet over the next 2 months, had a curious habit of averting their eyes when speaking to me. On one occasion, when I and my soon to be mother-in-law walked into a store selling bridal accessories, the clerk took one look at me when I asked her a question, and found it more comfortable to provide my mother-in-

law with the answer, which I found rude.

My last physician had prescribed acyclovir and prednisone, and decided that I was suffering from shingles of the cranial nerves. I had done research and while the diagnosis didn't quite seem to fit, I was glad that he prescribed some kind of medication

that would hopefully deal with this serious problem. After 3 days on the medications, I wound up in the emergency room with a severe reaction to the medication, so it had to be halted.

Over 9 weeks, the basic facial palsy resolved, but I was left with reduced

hearing ability in my left ear, tinnitus, skin hypersensitivity, and permanent nerve damage in my facial muscles to such a degree that I no longer looked, smiled, or spoke quite the same as I had before the affliction. Photographs of me smiling are markedly different post-syndrome than prior. It takes a great amount of effort on my part to smile to a degree detectable on photographs. To me, the feeling in my face is not the same as it was before my affliction. I would smile before, and my face would show the appropriate smile. Now however, when I "smile", little more than a smirk appears on my face, giving me a "mean", "sad", or "flat" appearance.

In fact, in a court trial, a social worker testified that my face had a "flat" expression. She was unaware of the fact that my facial expressions were residual effects of facial paralysis and instead, deemed them a marker of my parenting ability, which contributed in part, to my losing custody of my children. It is interesting to note that psychologists will note in their records that patients with certain mental illness have a "flat" facial expression. I can't help but wonder if those psychiatric patients are manifesting clear signs of undiagnosed neuropsychiatric Lyme disease, as I know Lyme and other tick-borne illnesses have clear psy-

chiatric manifestations.

While most people with PFP won't experience the bulk of what I have, and while PFP can be caused by other factors, be aware that PFP is a hallmark of stage II Lyme borreliosis, and an important signal that the Lyme spirochete has migrated into the central nervous system. If Lyme has been undetected before, step up your efforts to be retested. Left untreated, borreliosis of the central nervous system manifests cardiac problems, paralysis and cognitive disorders, autonomic dysfunction, strokes, blindness, dementia and other serious problems. If you have Lyme disease, the sooner you get diagnosed and treated, the better your overall outcome.

For other causes of PFP, your physician will help you navigate the waters of this disorder which though embarrassing and perplexing, you can take comfort in the fact that PFP runs a relatively short course and is typically not painful, just annoying. Try to look on the bright side of things and realize that with every challenge there comes a greater lesson to be learned. In my case, these symptoms were another indication in my clinical history that I indeed had Lyme disease, and should have been tested for it and treated. Though none of my doctors would do that until many years later, I did learn tolerance and patience with this experience, something that we can all use. *pha*



PJ Langhoff 5 weeks after onset of PFP, in 2000, affecting her left side. Note swelling in outer left ear, cheek and jaw. This case of PFP was due to Lyme disease.

### End Notes

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“Depression” ...cont'd from pg 7

by Marjorie Tietjen Daystar1952@yahoo.com

needed to see how the patient responds. There is no test that can rule out Lyme disease.

Hypoglycemia, along with diabetes, is becoming rampant in our refined carbohydrate saturated society. A carbohydrate laden diet is a very large contributor to these conditions, but I have also personally experienced that infection can target the glands responsible for blood sugar control, which in turn can cause depression or anxiety. In my case the Lyme disease greatly amplified my already mild tendency towards hypoglycemia. I would like to share with you a couple of quotes from a book that I highly recommend Prozac, Panacea or Pandora by Ann Blake Tracy.

Tracy states, "Mental health is so closely tied to blood sugar balances that this is an area that very definitely should not be overlooked. Just how often is hypoglycemia being mislabeled "depression" and treated as a psychiatric malady rather than a blood sugar problem which could be rectified by a good diet rather than a pill? It is absolutely amazing to see how many patients have already been diagnosed as hypoglycemic before their doctors put them on Prozac. Rather than educate the patient, they hand them a pill which only blocks out their symptoms, while it magnifies the original problem and leads many into diabetes."

Although I feel what Tracy tells us here is true, I don't specifically blame the doctors themselves. It is the medical education system that is to blame. Most doc-

tors readily admit it is the drug companies that sponsor most of the education which the doctors receive concerning pharmaceutical drugs that are to be prescribed..

Another important quote from Tracy's book states, "Hypoglycemia is a potential side effect of Prozac and many other drugs. There is a multitude of evidence from patient reports that Prozac is affecting the blood sugar balance and chemically inducing hypoglycemic reactions. According to patient reports it can produce hypoglycemia in a patient who had no apparent blood sugar problems to begin with and diabetes in a patient who previously had hypoglycemia. Ex-patients report that it produced mood swings, confusions, blackouts, even deeper depression, hyperactivity, anxiety, exhaustion, compulsions for sugary foods, alcohol and stimulants, etc. Every one of these symptoms can be directly linked to blood sugar problems. All are known hypoglycemic reactions."

To sum this up, depression, anxiety and other psychiatric symptoms can be caused by hypoglycemia. Poor diet is a main instigator of hypoglycemia, infection can worsen or cause this condition and the drugs used to treat depression can cause hypoglycemia. So, what's the answer? A good start would be to eat a hypoglycemic diet (low in refined carbohydrates). Treat infections, and if at all possible, stay away from antidepressants and certain other drugs that lower the blood sugar. There are many informative books available with good advice on how to

naturally control hypoglycemia. Hypothyroidism is another medically accepted cause of depression. However, one can be afflicted with this malady and have a difficult time acquiring an accurate diagnosis. The current testing or interpretations of the testing are missing a large segment of the population that could benefit from thyroid supplementation or other natural measures to support normal thyroid functioning. A patient can register in the low normal range yet still require additional thyroid hormone to function normally. I had problems with shortness of breath, having to lie down every 20 minutes, inability to squat without becoming faint, the sensation that the heart was not getting enough oxygen, extreme coldness, dry skin, etc. but yet I registered low normal on the testing. Disregarding the apparent normal test, my doctor used clinical judgment, considering my symptoms, which were indicative of hypothyroidism, and prescribed thyroid hormone. Aside from the treatment for Lyme disease, my biggest improvement came from supporting my thyroid gland. Most of the symptoms listed above are now negligible due to the supplementation of thyroid hormone. I had suffered needlessly from hypothyroidism for about 13 years. Doctors need to stand up against the system, not rely so heavily on testing results and begin using their own clinical judgment.

Hypothyroidism can have different causes. Being afflicted with a low functioning thyroid can negatively affect your immune

system...so, hypothetically a patient could more easily acquire infection. Another question we must ask is, can infection, such as Lyme, directly target the thyroid gland, and as a result cause hypo or hyperthyroidism? This brings a classic question to mind. Which comes first, the chicken or the egg?

A good website for more information on thyroid issues is <http://thyroid.about.com>

Last night the T.V was on as I was finishing up this article. The breaking news headlines on ABC resounded in my ears...."Explosion of teen suicide...could it be due to under-concern over the use of antidepressants?" The authorities claim that there has been an 18% increase in teen suicide from the year before. They stated that the warning labels required on the drug information label, might be keeping children from the very drugs they need the most. It is claimed that these warnings, concerning the very real side effects of antidepressants, have caused a 20% drop in their use and increased suicide is the result. I wonder what controlling influence was actually behind this disturbing report? Do we really believe it is natural for this many people in our society to need antidepressants? What is wrong with this picture? In conclusion, I think our need is to always ask, "What is the cause?".... Not how can we simply cover up the symptoms. *pha*

*Marjorie Tietjen is a freelance writer with an interest in public health, education and awareness.*

“Warning Ignored” ...cont'd from pg 7

experienced with treating or diagnosing Lyme disease. This puts the total score board at 2 doctors confirming a diagnosis and now she awaited the official opinion of the "referee" doctor assigned by Workers Comp.

In working to decline her claim for medical coverage, the referee opinion doctor wrote in his report, "Although the environment in question, where this insect bite was alleged, is compatible with a potential for exposure to the Lyme spirochete, the reader is reminded that the annual frequency of new cases of Lyme disease in the large state of Texas is only 0.09 to 0.51 cases per annum.... In other words, the risk of contracting Lyme disease is very low in Texas."

So what's a Texas Lyme

patient to do? Pressly was diagnosed by 2 separate doctors, had 2 separate labs confirm the diagnosis, and she presented with the classic rash and was fully symptomatic for the disease. Then a Workers Comp referee doctor, who has no experience with Lyme treatment and diagnosis, comes along and declines her medical coverage based completely on faulty reporting statistics that even the CDC says are at least 10 times higher than have been officially reported.

This is CRIMINAL.

According to the Centers for Disease Control & Prevention (CDC), when two or more cases of Lyme disease are found in one county, the county is listed as endemic for that disease. Why is

there not one county in the state of Texas that is officially listed as endemic? Since 1990 to present, there have been 1,553 reported cases of Lyme disease in Texas, according to the Texas State Health Department Zoonosis Control Branch. Therefore, according to the CDC, there are probably 15,530 cases or more of Lyme disease in the State of Texas, not including those cases that may have been misdiagnosed as Lupus, Fibromyalgia, Chronic Fatigue, Multiple Sclerosis, and other autoimmune diseases. Now, add into the equation that TAMU had scientifically monitored and verified that a massive increase of tick-borne diseases were on the horizon back in 2003, where does that leave us today?

I still have one nagging

question that haunts me. If Texas has had 1,553 verifiable, reported cases of Lyme, why has the CDC directives of listing an area as "endemic" with 2 reported cases not been enforced? There are 242 counties in Texas...it does not take a rocket scientist to do the math. (Don't forget the actual numbers are more in the range of 15,000 cases, according to the CDC.) Texas Lyme patients are suffering needlessly by not having their Lyme diagnoses reported by doctors and not having the endemic areas classified properly, and officially. *pha*

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

## “Dr. Levin” ...cont'd from pg 8

think more antibiotics will help. They are often told to take some aspirin and rest a little more. Another week goes by, and now the patient can't go to work -- he asks again for more antibiotics. Someone who isn't part of "the guild" now has a patient before him whom he has known for years - this doctor doesn't think the patient is malingering - he wants to see what happens with more antibiotics. The patient is better again! That's not what is supposed to happen, but once you see it happen, the physician begins to think, "Hey! Maybe they're wrong."

I think it's the physicians who are in the trenches who have led this "rebellion" and they are putting the infectious disease people in a very hot seat. I think the IDSA has made some serious mistakes in their new guidelines and it's going to be very interesting to see what happens with the Connecticut Attorney General's probe.

When a physician chooses to go outside the "standard of care," in most jurisdictions, it's considered "professional misconduct." So we are fortunate to have the ILADS standard of care existing on the government's website. It's the one thing that may save a lot of physicians, but it isn't saving the patients.

### What are the top misdiagnoses that you see in your practice?

Chronic Fatigue, fibromyalgia, and arthritic diseases, as a group, are common misdiagnoses for Lyme disease. Every patient with Parkinson's, ALS, depression, anxiety, ADHD, autism, and so on should be tested for Lyme disease.

In 2002, President Bush signed a congressional law saying that doctors and insurance companies should NOT use the CDC surveillance criteria for reporting Lyme disease as a diagnostic standard. That's not what it's for. Many insurance companies are abusing that law.

All Western blot diagnostic tests are not the same -- because the CDC states what bands are to be used for diagnostic purposes, but those bands were only intended to be used for surveillance and reporting standards-not for diagnosis. Quest Diagnostics and Lab Corp are not doing the best test, and their interpretation is incorrect because of the CDC's criteria. So this is really a deep morass. Then we come to the treatment, and the treatment is controversial.

I do see patients with late Lyme disease. It's interesting that the new IDSA guidelines suddenly differentiate between chronic Lyme disease, post Lyme disease syndrome, and late Lyme disease. They do allow late stage Lyme disease patients long-term antibiotics.

### Are herbs and minerals a supplemental option we should be looking into since we may be compromising our immune system with the long-term antibiotics? Should each patient's treatment be individualized?

I don't think there's any question that it has to be individualized, but up until now, as an alternative physician, I haven't seen any evidence that these treatments (herbal, Chinese herbal, homeopathy, electrode diagnosis) have worked on a long-term basis. The only thing that I have seen evidence for effectiveness is a long-term antibiotic.

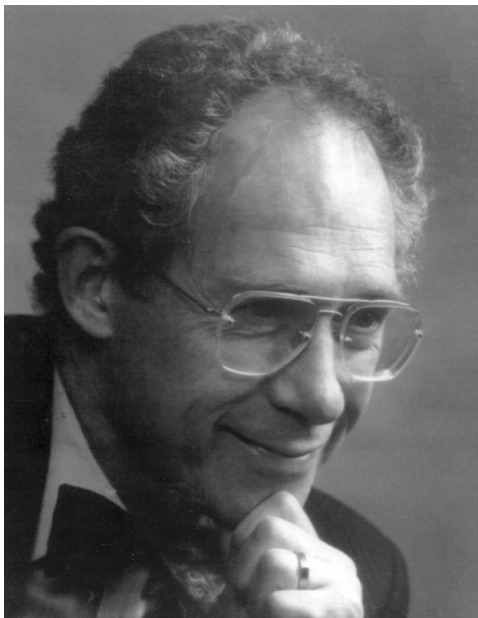
I think the Vitamin C - Salt protocol is really a safe and inexpensive thing to do, but I haven't had any long-term experience with it.

### Are we suppressing our immune systems with long-term medications? This is what we have heard and why it is discouraged.

I have screamed about overuse of antibiotics for more than thirty years. I see people who feel better (on the herbs, etc.), but feeling better isn't long-term success. And no one has done long-term studies with it. We're not getting many studies on long-term antibiotics either, but there are enough studies available that show evidence that it does seem to work in some patients who have been ill for years.

Another thing the IDSA claims is that you shouldn't use more than one antibiotic. They specifically state the fact that the organism can assume a different morphology is not adequate, but that is the very reason you must have two different, simultaneous antibiotics. This is a major example of bad science - the IDSA scientist examines the evidence and denies it, but the metamorphosis that is clearly demonstrable in

Lyme disease is as dramatic as a caterpillars turning into butterflies! IDSA is a much larger organization than ILADS, but scientific truth is not decided by majority vote!



### Are Chronic Fatigue Syndrome and fibromyalgia real diseases?

One of the major errors of American medicine is the naming of the diseases. They take words from another lan-

guage and use it so the patient has something that sounds important. If you're having headaches and the doctor says you have "cephalalgia", well that sounds good, but what does it mean? It means you have a pain in the head. It's just a description -- just like chronic fatigue is a description of the patient's complaints.

Chronic Fatigue Syndrome (CFS) includes many of the symptoms that are also seen with Lyme disease. Multiple Sclerosis (MS) is also a description -- it has to do with plaques that are seen in the central nervous system. Initially it was discovered in an autopsy, but now they see it on MRIs or CAT scans. It's a sclerotic plaque so that's MS -- but some of those plaques can disappear when the patient is treated for Lyme disease.

### What about the treatment for CFS, Parkinson's, MS, and ALS (Lou Gherig's disease)? Are you seeing any improvement in these conditions when you treat for Lyme disease?

When you talk about ALS, that's really a death sentence. So when you ask if we are getting any success with treatment, 10% with ALS would be phenomenal.

### If there is improvement, does this mean the initial diagnosis was wrong?

It doesn't mean the diagnosis was wrong because a diagnosis is just a description. The description does not encompass the cause, and in some cases, it appears that Lyme disease is the thing that tips it over. If you get the Lyme disease under control, even if you don't cure all of the damage, if you

stop the progression, that's a big win.

I had one patient that came in with the diagnosis of ALS. I questioned the diagnosis the first visit because the patient said the diagnosis was made eight years ago and the lifespan after an ALS diagnosis is typically 3-5 years. This patient was progressively worsening. She was very strongly positive for Lyme disease. She was treated for Lyme and responded very well. At one point she was able to feed herself again. Prior to treating the Lyme disease she hadn't been able to do that for years. After treating the Lyme disease, she walked 900 feet. Prior to treatment, she had been confined to a wheelchair. Then the insurance company stopped paying for her treatment.

### What was the insurance company's reasoning for stopping the coverage?

You don't talk about reasons with insurance companies.

### What about other maladies in your practice were misdiagnosed that later turned out to be Lyme disease?

I had a nine-year-old who was diagnosed as autistic, ADHD, and bi-polar who was on four anti-psychotic drugs and he was without communication. He had Lyme disease. He was going to a special school and was so disruptive that he had a special teacher assigned to him alone. He responded to treatment and by the end of the first year, he was the best student in the class. The child's father was also diagnosed as bi-polar and was on multiple drugs and barely functional. He, too, improved. It wasn't genetic - the child was adopted!

Psychiatrists and neurologists are seeing Lyme patients and missing the diagnosis. I think every patient with a psychiatric or neurological diagnosis should be checked for Lyme disease. *pha*

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# NATIONAL SUPPORT GROUPS

## National Multiple Sclerosis Association:

[www.nmss.org](http://www.nmss.org)

### Alabama

3840 Ridgeway Drive  
Birmingham, AL 35209  
Phone: (205) 879-8881  
Phone: 1-800-FIGHT-MS  
Email: [alc@nmss.org](mailto:alc@nmss.org)

[www.nationalmssociety.org/alc](http://www.nationalmssociety.org/alc)

### Northern California

150 Grand, Oakland, CA 94612  
Phone: 510-268-0572  
toll-free: 1-800-FIGHT MS  
Email: [info@msconnection.org](mailto:info@msconnection.org)  
<http://www.msconnection.org>

### Colorado

700 Broadway, Suite 808  
Denver, CO 80203-3442  
Phone: 303.831.0700

1.800.FIGHT.MS

### Georgia

455 Abernathy Rd. NE,  
Suite 210

Atlanta, GA 30328  
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Phone: (407) 478-8880  
Email: [info@flc.nmss.org](mailto:info@flc.nmss.org)  
[www.nationalmssociety.org/flc](http://www.nationalmssociety.org/flc)

### Texas

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

## ALS Association DC / MD / VA

<http://www.alsinfo.org/>  
7507 Standish Place  
Rockville, MD 20855  
(301) 978-9855  
toll free: (866) 348-3257  
fax: (301) 978-9854

### Great Philadelphia ALS Chapter

321 Norristown Road, Suite 260  
Ambler, PA 19002  
Phone: 215-643-5434  
Toll Free: 1-877-GEHRIG-1  
(1-877-434-7441)  
Fax: 215-643-9307  
[alsassoc@alsphiladelphia.org](mailto:alsassoc@alsphiladelphia.org)

### South Texas Chapter

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

### North Texas

[http://walk.alsanorthtexas.org/site/  
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### The ALS Association Upstate New York Chapter

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P.O. Box 127  
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## Lyme Disease Association [lymediseaseassociation.org/](http://lymediseaseassociation.org/) Pat Smith 888.366.6611

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### New Mexico

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### Oklahoma

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[Janet@LDSG.org](mailto:Janet@LDSG.org)  
[www.LDSG.org](http://www.LDSG.org)

### Portland, Oregon

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

### TEXAS: Dallas/Ft Worth

[www.dfwlyme.com](http://www.dfwlyme.com)  
[donna@dfwlyme.com](mailto:donna@dfwlyme.com)  
817-455-8520

### Houston

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

### Washington State

Alexis Benkowski  
WA-Lyme-owner@  
[yahogroups.com](mailto:yahogroups.com)

### WI / IL / MN Regional areas

Contact PJ Langhoff  
(920) 349-3855  
[www.Sewill.org](http://www.Sewill.org)

### www.LymeLeague.com (Intl)

### Lyme Coalition of N. Wisconsin

Pat Jackson (715) 356-3364  
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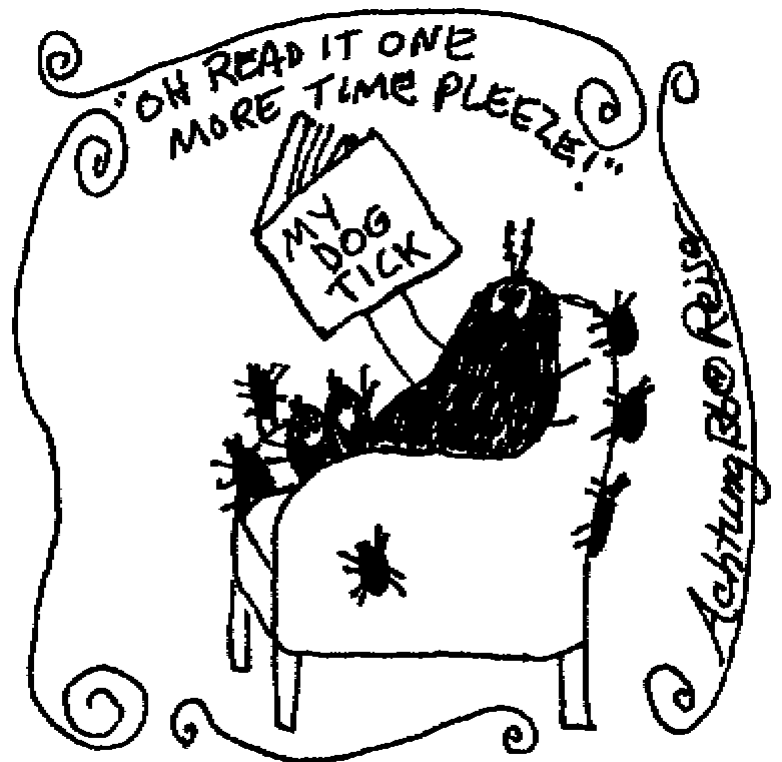
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## Ticktoons



by Terri Reiser

## “Samantha” ...cont'd from pg 11

by Laura Zeller wildcondor@yahoo.com

were out trick or treating." Samantha paused to clear her throat, and then surveyed the room to make sure nobody could hear us. She continued, "I had been always sleeping in the room with my mom to keep her company. She hated being lonely, and in the extreme pain she was always in, she liked me to lie next to her. This night was very different. She told me to make a bed on the floor with covers and sleep on that instead. I agreed (even though it was unusual) I went to sleep having a mysterious dream of her death. Ticks were crawling out of her brain and she was dead. I woke up terrified and tried to get her up. She was very cold. I ran to the neighbors house and told them I can't wake my mommy up!" Samantha put her face in her hands.

The neighbor came over and found Samantha's mother was dead. The neighbor called 911, and it took 2 hours for EMS to respond to the scene. Samantha remembers those hours as the worst in her life, and she is reliving the raw emotional shock as she tells me her story. "When the paramedics arrived, they tried to resuscitate my mom, but she was already gone. The ticks killed my mom. They crawled into our apartment and they killed her." A brief silence followed, as I was speechless.

While I was trying to think of something supportive to say, Samantha wiped her tears away and remarked, "Why can't they cure Lyme disease? Tell me why? Why did she have to die? What is being done Laura? My life is destroyed and nobody cares!" Samantha stood up and walked quickly out of the coffee shop. Shaken, I searched for tissues, and

quickly walked outside after her. Samantha found a secluded bench to gather her thoughts. I waited a few minutes, until she waved me over to come to her.

"Samantha" I said calmly, "this was not your fault, and I am so sorry you lost your mom."

Samantha looked up at me, and we hugged each other for a long while. After a moment, I tried to help her as best I could. I gave her a counselor's name, a support group phone number, and wrote down websites I thought might help her. Is there anything I can do to help you?" I asked her, while thinking to myself how much courage this young woman had to tell me all of this. "I want you to tell my story Laura," she said. "Tell the world, and leave nothing out! People need to know how serious Lyme is, and how it kills people. It will bring me closure to know my story is out there. I need to know my Mom died for a reason. I want her to be a hero, and proof of how bad Lyme disease is. She did not have to die." Samantha pulled up her sleeve, revealing her colored tattoo. "This is a tribute to my mom, her name was Christine." The tattoo was a beautiful cross bearing woman with angel's wings.

I promised Samantha that I would share her story, and I hope I have done it justice. I hope by sharing her story with you that she can gain some closure and peace after such a young and difficult life thus far.

Samantha is now 16 years old. After her mother's death, she was put in foster care. She eventually found a loving home with one of the families who fostered her. Samantha hopes to graduate from high school and go to college for nursing. She is in counseling now,

and is doing as well as can be expected. Amazingly, Samantha never got Lyme disease herself. She attributes that to her childhood habit of looking for ticks with flashlights, and then putting them in jars. Samantha avoids ticks now, and she also does not like to talk about Lyme disease.

She says she is trying to move on with her life, and is working to salvage a normal life with her new family. It is her dream to have her own daughter someday and share happy fun times. Samantha wishes that all Lyme disease can be cured, and that doctors would take responsibility for misdiagnosing and under treating so many thousands of people.

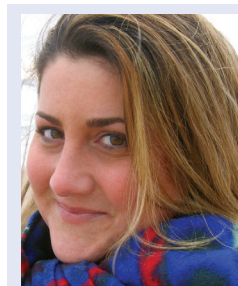
After my visit with Samantha, I was emotionally exhausted. Overwhelmed by the intensity of the day, I tried to reason with the purpose of what I had just shared. Honestly, I was so upset that I drove around in my car listening to Josh Groban's song "To where you are" and I cried my eyes out. I cried not only for Samantha, and her nightmare, but also for the Lyme disease patients around the world.

Samantha hit the nail right on the head when she said "Why did this happen?" She went on to say that "It wouldn't be like this if she had cancer. The doctors wouldn't have told her she was a crazy person. Lyme gets no respect."

Reflecting on Samantha's story, I found myself angrier than I care to admit. It makes me livid that it is 2007 and Lyme disease is still being grossly misdiagnosed and under treated. I did not have the heart to tell Samantha about the recent Lyme disease protests and the current state of chaos involving tick-borne political

affairs.

Lyme disease is a nightmare of an illness, and has become a battleground for political war. The outrageous misinformation set forth by the Infectious Disease Society of America (IDSA), and directed towards Lyme Literate Medical Doctors is proof of how far we still have to go. How many more people have to die before chronic Lyme disease is properly acknowledged? Haven't we lost our freedom as American citizens when we cannot get the health care we deserve? Instead we have a society of self-proclaimed "experts" (IDSA) dictating to the medical community what is right and wrong for us as individuals. I know in my heart that Samantha was right; it is different for cancer patients. Lyme disease sufferers deserve and demand respect. Something has to change, and the time is now! *pha*



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Lyme disease community in her state, and nation wide through her website: [www.wildcondor.com](http://www.wildcondor.com)

You can read Laura Zeller's personal Lyme story at: [www.wildcondor.com/lyme.html](http://www.wildcondor.com/lyme.html)



Extensive Online Resources: <http://www.wildcondor.com/lymelinks.html>

## “Morgellons” ...cont'd from pg 10

findings, not discover the cause of the abnormal findings. We do poorly with illnesses that stump us, and at times annoy us, because we did not study for 20 years to be left struggling, trying to understand something outside our voluminous training.

We have a clear, large group of patients with very similar troubles, diverse and clearly abnormal labs, profound skin diseases which are found in many places, but with areas of higher concentration, e.g., California, Texas and Florida. This sounds like another example of a clear medical syndrome with clusters.

Yet, as of this year, the Morgellons illness is not in the newest "comprehensive" medical textbook. But I guess there is a reason they continually revise all major medical textbooks, because medicine is a lifetime of constant medical discovery. I only wish so many patients did not have to feel rejected and ignored while health care workers come to accept this medical problem.

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Dr. Schaller is working with Dr. Charles Ray Jones on a Pediatric Lyme book which is 50% completed. Dr. Schaller is the author of 19 books including: The

Diagnosis and Treatment of Babesia, Mold Illness and Mold Remediation Made Simple, The Complete Guide to Artemisinin, When Traditional Medicine Fails, 100 Solutions to Out of Control Youth, Suboxone-Pain Treatment with Addiction Relief. He is currently preparing the most up to date textbook on Bartonella, which he feels is the top vector infection in the world--possibly more common than Lyme. Dr. Schaller has 25 National and International Medical Publications in such journals as JAMA, Medscape, and some of the largest pediatric journals in the world. He was the first

to publish a practical cancer cure which blocks a single enzyme for a deadly blood cancer, which has become the standard treatment internationally. He has also designed wholesale nutritional products and published nutrition and herbal purity and potency research. Dr. Schaller is a strong advocate for looking at many treatments and illness causes as can be seen from his main web site, [www.PersonalConsult.com](http://www.PersonalConsult.com). Here he offers over 800 articles in over 10 areas of medicine for free. *pha*