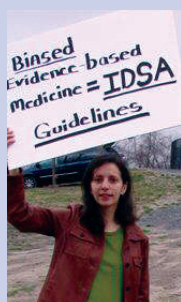


## In This Issue



United We Stand...  
A personal look  
at the Lyme  
Rally in NY...  
pg.2



Donna Reagan  
The Big Top:  
Part 3  
Intermission  
p 3



Marjorie Tietjen  
Munchausen  
By Proxy:  
Blaming the  
Victim  
pg. 3



Sue Vogan  
interviews Dr.  
Garth  
Nicholson,  
M.D.  
p. 4



Scott Forsgren  
interviews  
Amy Derksen,  
ND  
pg 6



Susan Williams  
Lyme Memorial  
Park in the  
making...  
pg 1



Laura Zeller  
Climbing your  
Mountain...  
p. 7

Photos from the Lyme Rights  
Rally in NY..  
photos by Lynn McCabe  
p. 8 & 16



Ginger Savely  
The ALS / Lyme  
Conundrum  
pg 10

## Congressmen Give gift of Hope to Chronically Ill Lyme Patients

Centreville, MD-

Shortly before returning home for the holidays, Maryland's Congressmen Gilchrest, Wynn, Bartlett, Van Hollen, Cummings, Ruppersberger, Cardin and Hoyer signed the Lyme Disease Member Letter, sponsored by Congressman Christopher Smith from New Jersey.

Chronically ill Lyme patients across the state were encouraged and very thankful for the unanimous support from their state Congressional delegation.

The Lyme Disease Letter, addressed to Dr. Julia Julie Gerberding, Director of the Centers for Disease Control and Prevention (CDC), expressed concern about the posting of the new Infectious Diseases Society of America (IDSA) guidelines on the CDC's website without adequate review by the CDC.

The IDSA guidelines limit a physician's ability to clinically diagnose patients, limit adequate preventative and curative treatment protocols, and provide insurance companies a basis for the denial of services. In addition, they promote reliance on lab tests that have repeatedly been demonstrated to be unreliable and concentrate on

*"Hope"...cont'd on pg 5*



*Individual Lyme sufferers and national patient support groups protested the IDSA guidelines and got the attention of congressmen to help in the fight to keep their treatment options available.*

*Photo by Lynn McCabe*

## Memorial Park Project To Honor Victims of Tick-Borne Illnesses

by Susan Williams

A group of Lyme Disease sufferers all across the United States have taken on a project of untold proportions. Discouraged by widespread ignorance that Lyme Disease and other tick-borne illnesses can be fatal, several LymeNet.org members have united to create the National Lyme Disease Memorial Park Project.

Aware of the conflicts between various Lyme organizations, the group hopes to stay entirely neutral while emphasizing that Lyme and other tick-borne illnesses are truly a national problem. They envision an easily-accessible place where people can gather, with a central facility for meetings, research, and education. The building will be made of recycled mate-

rials and be patient-friendly in all aspects. There will be plenty of sheltered areas to stop and rest or contemplate, and some water features. The Park will offer a place not only to grieve, but also to be educated and to come together with others experiencing the same loss.

"Imagine a field of trees - a forest really - that springs up from the heartland, but with a precision in layout and geometry and color that is obviously different from the rest of the land. Obviously planned, and obviously filled with some sort of meaning and purpose that can be understood even by those who have no clue as to what it is all about," describes Melanie Reber, a landscape architect and Lyme patient in California who is heading up the project. "Each tree will have some sort of signage indicating the indi-

vidual that it represents. Each area underneath each tree will be 'given' to family members who may use it for their own sort of memorial area. This could be as simple as a bench, a bed of flowers, a personal memento, or it could be left pristine."

Reber continued, "As you pause to soak in all that nature has to offer the senses, you realize why you are here, and why this place exists. Each tree has meaning, each tells the story of a life that had meaning, but ended far too soon. Each symbolizes the individual that was only one of the many who succumbed to the fate of associated Tick Borne diseases. As you move down the wide circular pathway from tree to tree, the magnitude of this loss begins to settle in."

*"Memorial"...cont'd pg 7*



EDITORIALS & OPINIONS

United We Stand: Lyme Rights  
Protest IDSA Guideline Authors

The morning of November 30, 2006 was windy and overcast in Valhalla, NY. Little did the local residents know several doctors in their community were about to receive a well-deserved public lashing they wouldn't soon forget.

Like an electrifying bolt of lightning, hundreds of spirited people suddenly appeared just outside Westchester Medical Center and New York Medical College, home to three authors of the Infectious Disease Society of America (IDSA) Lyme Disease Guidelines. Patients, hundreds of them, dressed in bold lime green adornment and big 'grateful-to-finally-be-there' smiles assembled at a nearby intersection to take a stand for patients' rights. Together they planned to confront some of the most loathed doctors in the Lyme disease community, some of IDSA's own medical misfits, Wormser, Dattwyler and Nadelman.

"TICK-TAC-TOE.... WORMSER'S GOT TO GO!", they cried out over the traffic noise. Traveling from near and far to gather on that otherwise cold and dreary day were the young children, many who were born infected with Lyme, as well as the older patients who have suffered, some for decades, with severe neurological, arthritic and heart problems caused by improperly treated Lyme disease. Patients in various stages of recovery crowded the protest grounds, many supporting themselves with canes and walkers. Some traversed the rocky ground in their wheel chairs and some forcefully dragged their IV poles and life saving medications with them, but one thing was for sure, in spite of all the obstacles, they made it!

The brightly colored signs they waved in the air echoed what their hearts were feeling and what the medical literature and their experiences had proven many times over. "LONG TERM TREATMENT SAVES LIVES!"

For those deciding to make the trip, the blatant attempts by a handful of unscrupulous IDSA authors to sweep growing numbers of chronically ill Lyme patients

under the rug or simply wish them away, was the proverbial straw that broke the camel's back. The patients decided they had heard enough chin music from those who were blocking their ability to get treatment! They were demanding action! Their hand written messages on poster boards, which have been supported by



The Lyme Memorial Project displayed a 14 foot parchment scroll of patient names who have died from Lyme Disease and related tick borne infections.

countless pages of medical documentation, were extremely powerful and unbending. Patients made it clear they were determined to break free from the ambiguous and domineering IDSA chains! "LYME TREATMENT- THE RIGHT WAY OR WORMSER'S WAY!"

People, whose lives were shattered when doctors wholeheartedly embraced the previous IDSA guidelines and turned a deaf ear to their chronically ill patient's continued pleas for help, have no choice now but to publicly demand adequate treatment for this insidious complex disease, even if it means going to the streets to make their points.

The gigantic neon lime-colored signs, which were strung along a nearby fence, blasted the

IDSA authors and the derelicts in the community who have been supporting them. Chronically ill Lyme patients, who have been compared to the survivors of the IDSA's modern day 'Tuskegee experiment', are now shouting from the rooftops, "IDSA LIES, PATIENTS DIE!"

This shocking claim was validated in part by the testimonial scroll created by Melanie Reber of Redwood City, CA, the Executive Director of the National Lyme Disease Memorial Park Project. Reber provided a list with hundreds of names, which had been inscribed on a 14 foot long roll of parchment paper. It was to honor those who have lost their battle with chronic Lyme disease.

The touching memorial served as a sobering reminder of the seriousness of tick borne infections. As it gently rested on the grassy hillside, it spoke loudly for those whose voices could no longer be heard.

Grandmothers and doctors, authors and farmers, teachers and ministers were among those carrying signs of protest. Lawyers, fire fighters, pilots, nurses, bankers, clerks and secretaries from NY, CT, MD, NJ, DE, MA, RI and VA came to rally for patients' rights.

Some traveled thousands of miles from California, Texas, Washington, Florida, South Carolina and Vermont to support their chronically ill family members and friends who couldn't make the physically exhausting trip. "I AM HERE TO REPRESENT 100 PEOPLE WHO COULDN'T BE HERE TODAY," boasted signs from various states being represented.

"DON'T TAKE AWAY MY CHILDREN'S MEDICINE!"

Laurie Patrick made her way south from northern New Hampshire, a very strenuous journey indeed. For more than 10 years she was misdiagnosed. "I may die trying to get to the protests, but I will do anything I

"United"...cont'd pg 10

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.

PHA Staff

Editor: Dawn Irons  
Assistant Editor: Brad Irons  
**Contributors:**  
Donna Reagan, Barbara Gerami,  
Ginger Savely, FNP, Marjorie Tietjen  
Scott Forsgren, Dr. J David Kocurek,  
Susan Williams, Laura Zeller, Sue Vogan,  
PJ Langhoff

**Website:**  
www.publichealthalert.org  
**e-mail:**  
editor@publichealthalert.org

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

**donations@publichealthalert.org**  
We cannot accept credit card payments.

You may mail your donation to:

**Public Health Alert**  
**821 Sansome Drive**  
**Arlington TX 76018**

PHA is a free monthly publication. We function on the sale of advertising space and donations from the public. We are have nationwide distribution.

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

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

Letters to the Editor

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

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



## Munchausen By Proxy - Blaming the Victims

by Marjorie Tietjen  
Daystar1952@yahoo.com

There is an alarming trend emerging, involving our medical system and child protective services, to label many very well meaning parents with a behavioral disorder called *Munchausen By Proxy*. This accusation towards the parents or parent often results in the removal of the children from their homes.

The basic definition of Munchausen By Proxy (MBP) is when a caretaker intentionally causes harm to a child in order to gain attention for themselves. Some of the symptoms or identifying characteristics of this syndrome which I would like to address are:

1. Perpetrators are usually mothers and most often are considered well intentioned normal parents.
2. They are usually liars and deceivers and are extremely convincing.
3. They usually deny any maltreatment of their children.

4. They change health care providers frequently.

5. Perpetrators may have a history themselves of malingering.

6. Relationships between caretakers and child appear to be excellent.

7. Alleged perpetrators often have no history of child protection intervention.

8. Often seek attention from a variety of people

9. Must be considered more dangerous once they are suspected.

10. Perpetrator causes harm to child to gain attention. This can also mean psychological harm which can be very subjective.

The above are only some of the requirements for a MBP diagnosis, which I found at the MBP Basics website. <http://www.mbexpert.com/definition.html>. The following are two factors this website lists in order to confirm a diagnosis of MBP.

"1.) Proof through direct or circumstantial evidence that the

suspected perpetrator has deliberately exaggerated and or fabricated and or induced a problem ( physical and or psychological - behavioral - mental health) regarding another person and... 2. rationale that the behavior is consistent with MBP maltreatment rather than something else." This doesn't sound very scientific to me. It sounds like guessing and opinion.

This website also mentions that there is no mental health test or evaluation which can rule out MBP. This statement could be very useful for those who are pushing for an MBP ruling.

MBP is an extremely rare disorder but is currently being greatly overused as an excuse to promote different agendas.

Recently I attended a Hearing which involved Lyme disease. The possibility of MBP was brought up and the witness for the defense, who happened to be a prominent psychiatrist, testified that MBP is indeed very rare and that great care should be taken when labeling people with this diagnosis.

We need to look at what segments of the population are being selected for the diagnosis of MBP.

Parents who are going through divorce and parents who have children with the ill defined or misunderstood diseases, such as Lyme disease, Chronic Fatigue Syndrome, Fibromyalgia (among others) appear to be especially targeted.

Many of these diseases have no objective signs that a doctor can put his finger on. How can one prove that they have a headache, that their stomach hurts, that bright lights and loud noises really bother them? How does one expect a doctor to take you seriously when you tell them that you have what feels like brain cramps or that your brains seems as if it is sloshing back and forth within your skull?

I would just like to interject here ...that Lyme disease has been officially mentioned as an excellent candidate for a biowarfare agent and is currently being studied as one by the University of

*"Munchausen"...cont'd on pg 5*

## Reagan's Ramblings Rants & Raves

by Donna Reagan

### The 3 Ring Circus Part 3: Intermission

Historically, an intermission was usually intended as a break for speakers or actors in a performance, but eventually developed into an opportunity for patrons to socialize, purchase refreshments, souvenirs, and most importantly, go tinkly winky.

I personally think we all need various kinds of 'intermissions' in our lives from time to time - even from those good things like the circus, a theatrical performance, and other such things that call for an intermission, but for which I cannot recall because my memory is apparently on an extended ...intermission.

With regards to any disease process, I think most people want, besides a cure, just to take a 'time out' or an intermission away from dealing with the daily routine of medicine, supplements, doctor appointments, research, and very necessary advocacy. Some days I just want to cry: "ENOUGH!" I also think there are plenty of other things that definitely need an intermission - such as a fight between spouses, deadlines from an editor, and from unsavory subjects such as the Infectious Disease Society of America (IDSA)'s guidelines for

Lyme disease, for which I have been providing commentary for the last couple of months.

Last month, I told my editor: "I need a vacation." As I am not a paid freelance writer, which of course, makes me a free freelancer, I didn't feel like this was such an unrealistic request. As I recall, I believe dear editor said, "No problem" or something of that nature. But looking back, I'm sure dear editor would have promised me anything to get my last column in before it was time for her to actually send it off to press.

I don't want to be a bad influence on all the other unpaid freelance writers of this publication, but I have this overwhelming inability to get my columns in on time. Sure, the first column was probably in on time, or even early; no doubt because of the novelty of the situation. However, as time has marched on, and my other responsibilities have grown, my ability to juggle all my daily tasks and prioritize have become more challenging than I feel capable of handling on most days.

While attempting to juggle my variety of daily volunteer duties, I am often reminded of

how my mother feels when she's paying bills via her ever-popular philosophy of "robbing Peter to pay Paul". In order for me to write my "normal" not-ready-for-Pulitzer-prize-consideration-column, it means I must postpone answering 200 emails, forgo doing laundry, and forget about any substantial personal grooming. The free freelance writing life is not glamorous...at least not at my house.

Yes, I realize many of you have fantasized about me writing my fascinating columns while decked out in fine Italian silk, with my lime green feather boa dramatically wrapped around my neck, disguising my triple chins. But no. I'm barely dressed at all because...as I mentioned awhile ago...I haven't the time to do laundry. Nor is the fact that I am scantily clad an exciting thought for anyone because, as I also mentioned...I haven't the time for much personal grooming.

I recently reminded dear editor of my overwhelming need to vacation from some of my volunteer activities to which she replied: "Oh, I don't remember you giving that request to me in

writing."

What? I'm taking a vacation from writing, why should I write to say I'm not writing this month? Dear editor and I are great friends (except when she is editing all the obscenities out of my columns that make my writing the extraordinary drivel it is) - so why does she need my request in writing? Has she become delusional? Furthermore, I already told her that I've got oodles of laundry and personal grooming to tend to - how could she forget? Although she's probably not seen the braid-length hair on my legs, I know she's most certainly seen my need for an eyebrow wax because I'm not the kind of gal that can carry off the Brooke Shields' eyebrow. I feel like I'm starting to look like the caveman on the Geico commercial. How can anyone work under such conditions?

So dear editor said to me: "OK, well you can certainly take a break....but will you just write a one page 'rant' about anything to keep your space in the paper?"

Huh?

*"Intermission"...cont'd on pg 5*

FEATURE

Bacterial Co-Infections in Chronic Diseases:  
An Interview with Garth Nicholson, Ph.D.

by Sue Vogan

Professor Garth L. Nicholson is the President, Chief Scientific Officer and Research Professor at the Institute for Molecular Medicine in Huntington Beach, California. He received his B.S. in Chemistry from University of California in 1965 and his Ph.D. in Biochemistry and Cell Biology in 1970. He has published over 500 medical and scientific papers, edited 14 books and served on the Editorial Boards of 20 medical and scientific journals. He's a busy man, but found time to answer a few questions about Lyme disease.

Why is Lyme disease so difficult to diagnose and treat? The new Infectious Disease Society guidelines say, in essence, that it's a piece of cake.

Nicholson responds, "Lyme Disease is not just about *Borrelia burgdorferi*. Lyme Disease is a collection of infections, often called Lyme co-infections. In the case of chronic Lyme disease, the most commonly found co-infections with *Borrelia burgdorferi* are bacteria: *Mycoplasma* species (found in 60-75% of Lyme cases), *Ehrlichia* species (found in 10-35% of cases), *Bartonella* species (found in 25-40%) and the protozoa *Babesia* (found in 10-20% of cases). There may also be other co-infections that we don't know about." He explains, "Diagnosis of any infection is usually based on signs and symptoms and confirmed by laboratory tests.

Once *Borrelia burgdorferi* and its co-infections become systemic and chronic (causing system-wide chronic signs and symptoms), they are very, very difficult to diagnose by laboratory tests. The reason for this is that these microorganisms hide at intracellular sites in tissues where they can become metabolically inactive or "persistent" (sometimes called cyst-like). When they are in a relatively inactive form, they are not synthesizing large amounts of their surface components, the same materials that are the targets of most diagnostic tests. Since they are not making large amounts of these materials, the host is also not making large amounts of antibodies against them. This is why they are so hard to find with antibody-based tests (RIA, EIA, Western immunoblot, etc.) or microscopy tests (IFA). They are also very hard to find by gene-based tests, such as Polymerase Chain Reaction or PCR, because this

type of test requires the presence of the microorganism in the blood, and in their persistent forms they are rarely released into the blood circulation.

Lyme Disease also cycles, and patients have good and bad periods when they are more and less symptomatic. This can cause tests to be positive or negative, depending on when the test was performed, making confirmation by multiple tests often difficult."

Nicholson adds, "In addition to being difficult to diagnose by laboratory testing, the chronic stage of Lyme Disease can be relatively insensitive to treatments like antibiotics that for the most part target the metabolism of *Borrelia b.* and its co-infections, which can be different; requiring different anti-microbial treatments for the different co-infections.

When the Lyme *Borrelia* and co-infections are not active, they are not very sensitive to such anti-microbial treatments. This is one of the reasons why long-term antibiotics are often necessary to treat chronic Lyme disease-to capture the microorganisms when they are most active. Other reasons are the intracellular locations where some antibiotics don't penetrate well and others can be inactivated or sequestered away from the infections, but probably the most difficult part of treating Lyme Disease is deciding which co-infections are present so that the correct drugs and treatments can be applied."

Nicholson goes on to add, "The NIH guidelines adapted from the Infectious Disease Society are completely wrong for treating chronic Lyme disease. The NIH claims that their funded studies show that Lyme disease can be effectively treated with a few weeks of oral antibiotics. This may be true for the initial stages of Lyme Disease, called the acute stage by NIH, before the Lyme *Borrelia* and co-infections become systemic or system-wide and

invade multiple tissues and cause chronic signs and symptoms, but such treatment is completely inadequate for the chronic phase of Lyme disease."

Dr. Nicholson continues, "Lyme Disease physicians who have been treating Lyme disease for years know that the short-term antibiotic treatments are not effective. This was especially apparent at the meeting of the International Lyme and Associated Diseases Society (ILADS, <http://www.ilads.org/>) in October, 2005 where speaker after speaker indicated that short-term antibiotic treatments were completely inadequate to treat chronic Lyme disease." He adds, "Reasons why most Lyme disease patients are not easily cured of their disease are likely due to the difficulties in treating the multiple co-infections in Lyme disease, the difficulty and timeliness in obtaining a proper diagnosis, and possibly poor treatment decisions along the way."

Dr. Charles Engel, who is with the US National Institutes of Health, Bethesda, Maryland, stated the following at an NIH meeting on February 7, 2000: "I am now of the view that the probable cause of chronic fatigue syndrome and fibromyalgia is the mycoplasma..." Some say that fibro, CFS, GWI, and Lyme disease are caused by the mycoplasma--" What do you say about this, Dr. Nicholson?

"Dr. Engel is an Army Lt. Colonel and psychiatrist assigned to Walter Reed Army Medical Center in Washington D.C. where he was, at the time, director of the Gulf War Referral Center. His view was likely based in part by information from his Army colleague, Dr. Shyh Lo, who has published extensively on *M. fermentans* and other mycoplasmal infections and their role in chronic diseases. If asked, Dr. Engel would probably take back his comments, because they ran against official policy of the Department of Defense that denied that any

chronic infections are involved in chronic illnesses like Gulf War Illness." Nicholson states, "Our position is that multiple toxic events likely cause Chronic Fatigue Syndrome, Fibromyalgia Syndrome, Gulf War Illnesses and other chronic illnesses-but an important element in these chronic conditions is the presence of chronic bacterial and viral infections. Whether such infections cause the condition, are a co-factor in the condition, or they are simply an opportunistic infection(s) that causes a co-morbid state remains to be proven.

However, we do know that such infections are important, because their successful treatment reduces, or in many causes, eliminates the condition. Such chronic bacterial infections can include: *Mycoplasma* species, *Chlamydia* species, *Brucella* species, among others, and *Borrelia b.* and the co-infections found in Lyme disease."

Are the CDC and FDA working with our best interests in mind?

"I am not sure how to answer this question. On the surface, it does not appear that U.S. government organizations have the best interests of our citizens in mind when it comes to Lyme disease and other chronic illnesses. Whether this is due to some hidden agenda, such as hiding the origin of diseases like Lyme disease from the American public, or whether there is a genuine disagreement on how to most effectively diagnose and treat chronic infectious diseases remains to be seen."

It is fact that Willy Burgdorfri worked with transmitting disease to ticks -- why and what use could ever come from infecting ticks?

"Ticks and other insects (fleas, mosquitoes, and other biting insects) are excellent vectors of disease. Look at what hap-

*"co-infections"...cont'd pg 13*

May be useful for:

■ Heavy metals

■ Liver detoxification

■ Weight loss

■ Cholesterol

■ Lyme disease

■ Arthritis

■ Fibromyalgia

■ Crohn's disease

■ Fatigue

■ Diabetes

■ Headaches

■ Double vision

■ Cancer

Detox Foot Pads

Detoxify While You Sleep!





Before use

After use

<http://www.HealthMarvels.net>

Live healthier. Live Happier.

Order online or contact Moira at (562) 803-3723

I have nasty Lyme arthritis in my knee, and the pads are helping to decrease the swelling and flexibility. It was my Lyme doctor who first told me about the pads...she swears by them!

-Satisfied Customer

■ Eight editions

■ Highest quality

■ Lowest prices

■ Imported from Japan

■ Real bamboo vinegar



# “Munchausens”...cont’d from pg 3

by Marjorie Tietjen

Texas in San Antonio .

Biowarfare documents tell us that effective biowarfare agents are microbes which cause symptoms in many different parts of the body. This is considered an important attribute because it makes the patient seem as if he is malingering or faking. The patient is not taken seriously, the disease is ignored, most of the time left untreated, and allowed to pass through the population unchecked. Another admired attribute would be the lack of accurate testing for the disease. Lyme disease, and what we call Chronic Fatigue syndrome and Fibromyalgia fit this criteria extremely well. A certain strain of mycoplasma, called mycoplasma fermentans, was patented by the U.S Army. The patent discusses the diseases which this microbe will be found in.....such as Chronic Fatigue Syndrome, Sarcoidosis, Alzheimer's, etc.

The point I want to make is that the Army knows that this mycoplasma is pathogenic, they know what syndromes it is found in, and they realize very well the symptoms involved. Why are these symptoms not being taught to our doctors? Why are patients who have these symptoms being told it is all in their heads or that the children ill with these symptoms are being made sick by their mothers?

I have spoken to several psychiatrists who feel that MBP is a wastebasket diagnosis and is being attached to patients by doc-

tors who are ignorant of the diverse symptoms which present in these emerging diseases. Doctors are not encouraged to find a "real" diagnosis. The medical system appears to be training the doctors to see these symptoms as a form of depression, hypochondriasis, MBP, etc.

Ask yourself....why is this epidemic of MBP suddenly sweeping the nation? If one subscribes to the idea that this state of affairs is actually occurring then what is the reasoning behind it? I don't believe the explanation that is often glibly given, which says, “Oh that problem was always around, it was just that nobody recognized it.” Maybe it is a fast spreading contagious microbe causing this alleged rampant psychosis? Of course it is mostly women who seem to contract this possible causative agent. Men appear to be mostly immune.

I often think that we are actually experiencing the cover up of a silent epidemic, an excuse to take children away from their homes in divorce and child custody cases. There may also be profits and vested interests involved. Some people believe that the government is trying to create more of a socialistic regime where children are more or less raised by the state. The Federal Government gives states extra money for each child who is removed from their homes. It's also known that schools are given extra money for each child that is labled ADHD and or put on Ritalin.

I would like to leave you with some thoughts in regards to the list of identifying characteristics of MBP. Perhaps the suspected perpetrators are often considered well intentioned and normal because they are well intentioned and normal. What normal parent would not fight for an organic diagnosis of their child and go from doctor to doctor trying to get help...to get someone to actually listen to them? Many parents also have lyme disease or one of these other labels and know that the physical symptoms their child is experiencing are real and perhaps they are suffering from the same disease as their parent or parents. It was said that sufferers of MBP are often liars and deceivers. Perhaps that is just the perception of the doctor who can't find anything wrong with the child through lab testing. The parents probably deny maltreatment of their children because they do not maltreat them. The MBP suspect may also have a history of malingering because as I mentioned they may have the same disease as their child. The website also mentioned that the relationships between parent and child often appear to be very healthy and normal. Well, again, maybe it is because they do have a healthy relationship.

Concerning the characteristic of the perpetrator seeming more dangerous after supposedly being found out.....If you were a mother and you knew your child was ill with a degenerative disease, you

tried to get the child help and then was told you were causing your child to be sick...wouldn't that make you very angry and perhaps even hysterical? What a position to be in!

The seventh characteristic in the list describes how alleged perpetrators often have no history of child protection intervention. Why do you suppose that is? I would say it was because child protection was never needed.

In one article it was mentioned that 9 to 37% of children involved in suspected MBP die. Doctors who are knowledgeable about these emerging and hard to test diseases have witnessed children die due to lack of treatment for the disease the mother was trying to get help for. Once the children are removed from the home, they no longer have an advocate to push for the medical treatment that they often so desperately need.

I think it is about time we investigate and start blaming the corporate perpetrators instead of innocent mothers, many of whom are also sick with the same disease that their child is afflicted with. How tragic and shameful it is to blame the victims.

Comprehensive list of Lyme Disease symptoms  
<http://www.timeforlyme.org/TFLWebDone/SignsSymptoms.htm>

pha

# “Intermission”...cont’d from pg 3

However, when I think about the heavy duty subject matter which I've been tinkering with over the last couple of months, I could write about the national debt and feel like I'm on a break. But never fear sweet readers - I won't write about the national debt because my solution is simple: Print more money.

So here it is. I am hereby giving myself and this series an official intermission, and this is my official intermission 'rant' although I can't determine what it is I'm ranting about other than the need for an intermission, and some personal grooming.

You may now purchase a large bag of popcorn, provided you don't have irritable bowel syndrome; of course you may go tinkly winkly if nature so calls; and if I only had the foresight to make them - now would have been the ideal time for you to purchase your "I loathe the IDSA" t-shirts. So

for now - just make your own.  
pha

Donna Reagan is the local DFW Lyme Disease Support group leader and president of the Texas Lyme Disease Association.

**Texas Lyme Disease Association**



*Giving Lyme the boot!*

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

# “Hope”...cont’d pg 1

short-term treatment protocols deemed "cost-effective" rather than necessarily curative or supported by solid science.

The letter follows a Civil Investigative Demand issued by the Attorney General of Connecticut to the IDSA, initiating an investigation of the IDSA's use of exclusionary tactics in developing their guidelines. Both the national non-profit Lyme Disease Association representing patients and the International Lyme and Associated Diseases Society representing treating physicians requested input into the guidelines process and were denied.

Lyme disease is currently the most prevalent vector-borne disease, with over 230,000 new cases in the United States annually. The CDC estimates for every case reported in Maryland, 7-12 are being missed (CDC- Surveillance for Lyme Disease, United States,

1992-1998, Division of Vector-Borne Infectious Diseases, National Center for Infectious Diseases).

According to their estimated calculations, if current trends continue, by the year 2020 approximately 1/5 of Maryland's population will have been exposed to Lyme disease. If Lyme is not properly diagnosed and adequately treated in the early stages, the spirochetal organism can affect every organ and system in the body. Arthritis, encephalopathy, neurocognitive disorders, facial paralysis, muscle involvement and heart problems are some of the manifestations of chronic Lyme disease.

Maryland Lyme Disease Support Group leaders believe the IDSA guidelines are grossly inadequate and have the potential to severely affect those who are bitten and require rapid diagnosis and treatment, as well as those who are already chronically ill with tick borne infections. pha



## Holistic Approaches to Lyme Offer Hope:

### An Interview with Dr. Amy Derksen, ND

by Scott Forsgren

Scott@BetterHealthGuy.com

Throughout the past year, I have investigated many different options for improving my health after having been diagnosed with chronic Lyme disease. One of the more exciting developments has been the incorporation of a number of natural and integrative therapies. My journey to continue putting together the pieces of what often seems like a complex puzzle has brought me to the realization that Lyme disease is more than just an infection with *Borrelia burgdorferi*. It is a complex, multi-faceted illness that often requires one to address many different issues in order to attain wellness. A holistic evaluation is often a key to marked progress.

I recently had the opportunity to sit down with Amy Derksen, ND and ask her a number of questions about how she approaches Lyme disease diagnosis and treatment as part of her holistic practice in Bellevue, Washington. I hope you enjoy our discussion as much as I did!

#### Tell us a little bit about your background?

I have a Bachelor of Science degree in Biochemistry from Western Washington University. I did research on myoglobins in an effort to find alternative ways to carry more oxygen to the body and doing so in a safer way than having a blood transfusion. I then worked at a conventional medical clinic for a year doing work with blood and urine cultures. I graduated with my ND from Bastyr University in 2003. I was then fortunate to have had the opportunity to pursue an apprenticeship with Dr. Dietrich Klinghardt, a well-known and highly respected expert and teacher in the field of Lyme disease.

#### What led you to alternative medicine?

I was "Athlete of the Year" at my university and won the national championship in hurdles. As a result of repeated injuries and limited relief from conventional pain management options, I turned to alternative medicine. I quickly discovered how something as simple as correcting a mineral deficiency can impact healing.

#### What is ART?

ART is Autonomic Response Testing. It was developed by Dietrich Klinghardt, M.D., Ph.D. and Louisa Williams, M.S., D.C., N.D. It is essentially an advanced form of kinesiology that utilizes the autonomic nervous system as an indicator of stress on the body. It screens everything against a weak arm and this is where the majority of the infections typically appear. I find in my experience that testing with traditional kinesiology, important information is often missed. This is because the body is so stressed by Lyme and other microbes that the autonomic nervous system is not responding and will not allow the strong arm to go weak. This is what we call "blocked regulation".

ART can be a useful indicator of toxins within the body, nutritional deficiencies, structural problems, energetic disturbances such as scars, food intolerances, geopathic stress, unresolved psycho-emotional issues and more.

#### How is ART used to help guide patient diagnosis and treatment?

ART helps to reveal organ stress often before physical damage has occurred. You can determine whether or not that stress is related to microbes, metals, or is simply an indication of a need for more supportive therapies. ART can help to highlight where to start treatment and whether or not the primary issue is related to Lyme, parasites, viruses, bacteria, or fungal/mold issues.

As an example, ART might reveal that one's liver stress is caused by a fungal issue. It can reveal parasites much more effectively than traditional labs which often miss them entirely. It can show a hierarchy of what is undermining one's health. It can answer questions such as whether or not the health challenge is entirely caused by Lyme disease or if there are other factors involved such as those of bacterial, parasitic, viral, or fungal origin. It is an excellent tool for determining whether or

not heavy metals are playing a role in suppressing optimal health. It can be used to help determine whether or not a worsening of symptoms is due to a negative drug reaction or allergy as opposed to a die-off effect (Herxheimer reaction).

#### What co-infections are most commonly found in people with

##### Lyme disease?

We often find parasites, fungi and mold, viruses such as Epstein-Barr and CMV, and bacterial infections. In terms of the more common Lyme-related infections, we see Babesia, Bartonella, Ehrlichia,

Rickettsia (Rocky Mountain Spotted Fever) and others. We also commonly see Chlamydia and Mycoplasma infections.

#### How prevalent are parasites in your experience?

Parasites are very common, especially if there has been any foreign travel. I would estimate that 50% of those with chronic Lyme disease also have some parasitic infections that need to be addressed. This is often the first thing that needs to be addressed before moving on to other issues. Treatment does not always require prescription medications to resolve and in many cases, an appropriate herbal protocol can be quite helpful.

#### What are the more common parasites that you observe?

We see Ascaris (roundworm), Blastocystis, tapeworms, Giardia, and liver flukes most commonly. There are a large number of other parasitic organisms that often are part of the picture as well.

#### Do you see heavy metals as a complicating factor? Which metals appear most frequently?

Oh definitely. Metals are a significant issue for many people. Mercury, lead, and aluminum are the most common. People that react to metals often react to several different metals at a time. It is

important to look at mineral deficiencies and even absorption of minerals when investigating metal issues. A provoked urine test can be very useful in diagnosing heavy metal toxicity. When interpreting the results, it is important to look both at the toxic metals as well as the balance of essential minerals in making a diagnosis.

#### Are mold and fungal issues common?

Yes, very much so. They are especially an issue along the West Coast, including California. Mold and fungal issues are more prevalent when there is chronic sinusitis, especially if Babesia is present.

#### What are some of the more useful treatment options?

For *Borrelia* itself, Samento and Noni can both be very helpful. We are also becoming more aware of the promise held by the rizols which are ozonated oils that may have antimicrobial effects. Samento can be useful for Ehrlichia and Bartonella. For Fibromyalgia or joint pain, Samento can be very helpful. I prefer Samento tinctures over capsules in general. I have seen dramatic differences with Samento.

Japanese Knotweed can be quite helpful for those with Lyme and is also very useful when there are viruses or viral tendencies, including Shingles. Smilax can be useful as an option for supporting the liver. If burning pain exists or there are jaw and neck issues, Noni can be very helpful as these may be related to Babesia.

Andrographis can be important if *Borrelia* is present and is helpful for Ehrlichia and Bartonella. For Babesia, Artemisinin is often effective. I prefer the pulsed dose approach more than a daily dosing. Noni is one of the few options that has been highly beneficial for Babesia. Salt/C can also sometimes help.

Colloidal silver may be beneficial for those with Babesia and fungal issues. For sinus problems, it can be sprayed into the nose or gargled with. Gargling with colloidal silver may also help the tonsils and lymph system.

#### What are the more common parasitic treatment options?

Freeze-dried garlic is a fabulous option. Artemisinin can be

*"holistic"...cont'd on pg 12*





## “Memorial” ...cont'd from pg 1

by Susan Williams

It was the loss of 41-year old William Henry "Billy" Boesché of Maryland that sparked the idea. In an earlier discussion with friends, Billy had commented, "I tend to plant trees in honor of those I love that pass away. There's something symbolic to me about trees, whether it be the branches reaching toward heaven, or just the growth year after year - signifying strength throughout all kinds of weather."

With Billy's death this June, the group decided that the time was long overdue to create a living memorial in honor of those whose life has been taken all too soon by this dreaded illness.

"It is my way of dealing with the fact that the person is gone but their memory will still live on. I also like to know the tree will give pleasure to many, for years to come," reflected Lucy Barnes, a Lyme patient and Director of the Lyme Disease Education and Support Groups of Maryland who is collaborating on the project. "We are having increasing numbers of deaths from Lyme. There is no 'quilt' or memorial way to remember these folks and celebrate their lives. We are hoping maybe we can set up some way to remember Lyme patients after they pass. It will also make people take note of the fact that we are losing folks to this disease that is said to not be serious... and rarely fatal."

"I think some kind of memorial is definitely in order, and trees are the perfect metaphor to represent us," affirmed Paula Halbur, a Registered Nurse and Lyme patient in Iowa whose daughter also has Lyme. "Sadly, this could end up to be a forest."

While the exact location of the Memorial Park is not yet decided, project organizers would like it to be in the heartland of the country, where TBDs are the least understood. This location would be symbolic of all Americans, from north, south, east, and west, coming together at the heart of a difficult issue. The group hopes to set the park within acreage devoid of trees, which would cause the park to visually stand out and symbolize that these diseases happen everywhere and no place is "safe".

Planned facilities include a covered stage, amphitheater, open plaza, comprehensive library, research center, TBD database, gift shop, cafe, and meeting rooms. The Park will have on-going events scheduled such as concerts, conferences, presentations, and rallies.

Organizers already have the project well underway. In addition to developing a preliminary conceptual design, the group is in the midst of researching appropriate site locations, along with existing memorial proposals, site development issues, and design criteria. Volunteers have

been verifying names to add to the growing list of TBD fatalities, which now tops 200. A Board of Directors, consisting entirely of Lyme Disease patients, has been formed and is going through the tedious process of establishing non-profit status.

The Memorial Park has a website at [www.LymeMemorial.org](http://www.LymeMemorial.org) to serve as an informational hub. The website will also have memorials online for each person who has passed away, with a short biography and any other information that the patient's family wishes to add.

"It is very difficult work, but so necessary for all of us to make our voices heard, and the voices of the departed counted for," explained Reber. "I know this is sad and sobering, but it is our reality. And until we can show that TBD associated deaths do indeed occur everywhere, we will continue to be dismissed and uncounted as having a serious disease."

"We are also aware of several suicides," Reber stated, "and they, of course, were TBD associated. Those people need a voice too."

Project organizers are asking anyone that has information to please contact them to ensure that no names are missed. "It takes a lot of research to find the families and verify each name. We do not want to include names without a

family's permission, but we also don't want to shorten the list just because we can't reach anyone to verify and gain permission. This is a dilemma that we are working on," Reber acknowledged.

"We want all Lyme patients to feel that this Park belongs to them and their loved ones," Reber emphasized. "This will in no manner be a static environment. It will be full of life -- a living memorial."

Some Lyme patients have taken the idea a step further in regards to their own mortality. "I know this is a morbid subject, but I think we need to tell our loved ones that, if we should perish as a result of something related to this disease, we want the obituary to clearly say 'Lyme Disease'," added Jeannine Phillips, a Lyme patient in New Jersey. "It might be going too far to write one or more paragraphs in advance when we are still able, and it might be too difficult. On the other hand, many people do sit down and write what they want their obituary to say."

Anyone interested in working on this project in any capacity may contact the organization at [LymeMemorial@netscape.com](mailto:LymeMemorial@netscape.com). The organization also appreciates and accepts monetary donations.

pha

## Sharing Our Stories...SOS

by Laura Zeller [laura@wildcondor.com](mailto:laura@wildcondor.com)

*Laura Zeller's story and website can be found online at [wildcondor.com](http://wildcondor.com)*

Many of us have struggled for months to years in our search for our diagnosis. Once we receive a diagnosis, whether it is Cancer, HIV, or Lyme disease, the shock can be overwhelming. Fear is often our first reaction, and often it does not subside quickly. How do you hold it together emotionally, while searching for a way to treat the disease? People frequently ask me how I managed to beat Lyme disease and keep a positive attitude. I receive daily emails from sick people searching for reassurance and hope. Most of the people contact me after reading my Lyme disease story online, and want to know how they can get better too. I am not a doctor, nor do I claim to know what is right for these desperately ill people. So how do I help them? Well, I share my experience,

and how I have gone on living happily while having chronic Lyme disease.

My family raised me to be independent and determined. I was

a mountain climber, and I was familiar with challenges. For the thrill of adventure in

the outdoors, I used to risk my life on purpose before I got sick. Rock climbers, whitewater kayakers and skydivers know what I am talking about. It is our choice to risk our lives to make our lives fuller and richer by living wild, and on the edge as an adrenaline junkie!



During my darkest days, I remembered the lessons I learned while mountain climbing.

Mountains are beautiful, almighty and powerful. Reaching the summit requires physical strength and mental perseverance.

You cannot give up if you want to conquer the mountain's majesty. My journey with Lyme disease taught me both patience and gratitude, while strengthening my already fierce and determined spirit. Although I am still alive, not having my dreams come true has been a death of sorts. My identity and my freedom were lost for a while. I learned that no matter how

challenging mountains are, the hardest mountains to climb in life are invisible. My love for life kept me alive, and fighting for survival. It has been a long and tortured climb, although beautiful at the same time.

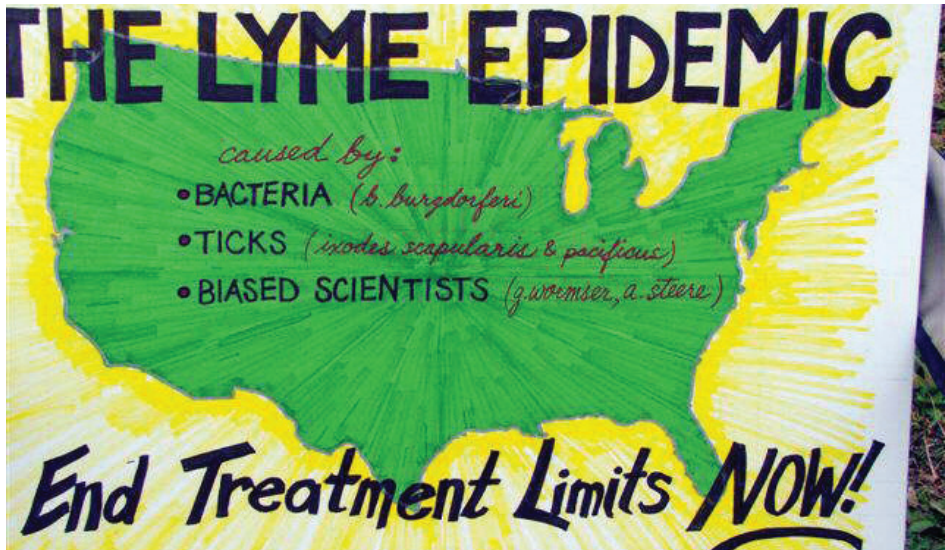
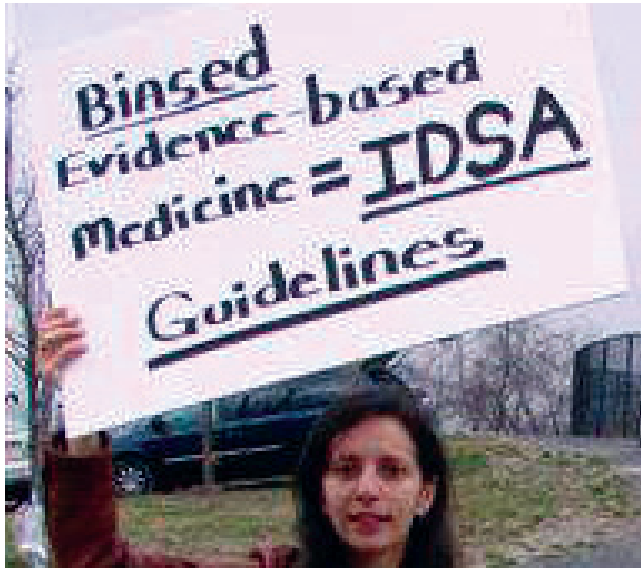
Depending on how sick you are and how long you have gone untreated, you need to prepare yourself emotionally for the long haul. Chronic illness will zap your strength, wipe you out, invade your life, ruin your schedules and routines, and truly test what you are made of. Be prepared for things to get worse before they get better. In my case, Lyme disease changed my life, but I have come out of it stronger and wiser. Your attitude has to be tough, you cannot give up, and you have got to look out for yourself. Please do not act like a helpless victim and expect the doctors and nurses and

*“Mountain”...cont'd pg 14*



# FEATURE PHOTOS FROM LYME RALLY

Photos by Lynn McCabe







**Blood Donation  
Can Save Lives...  
Or Destroy Them.**

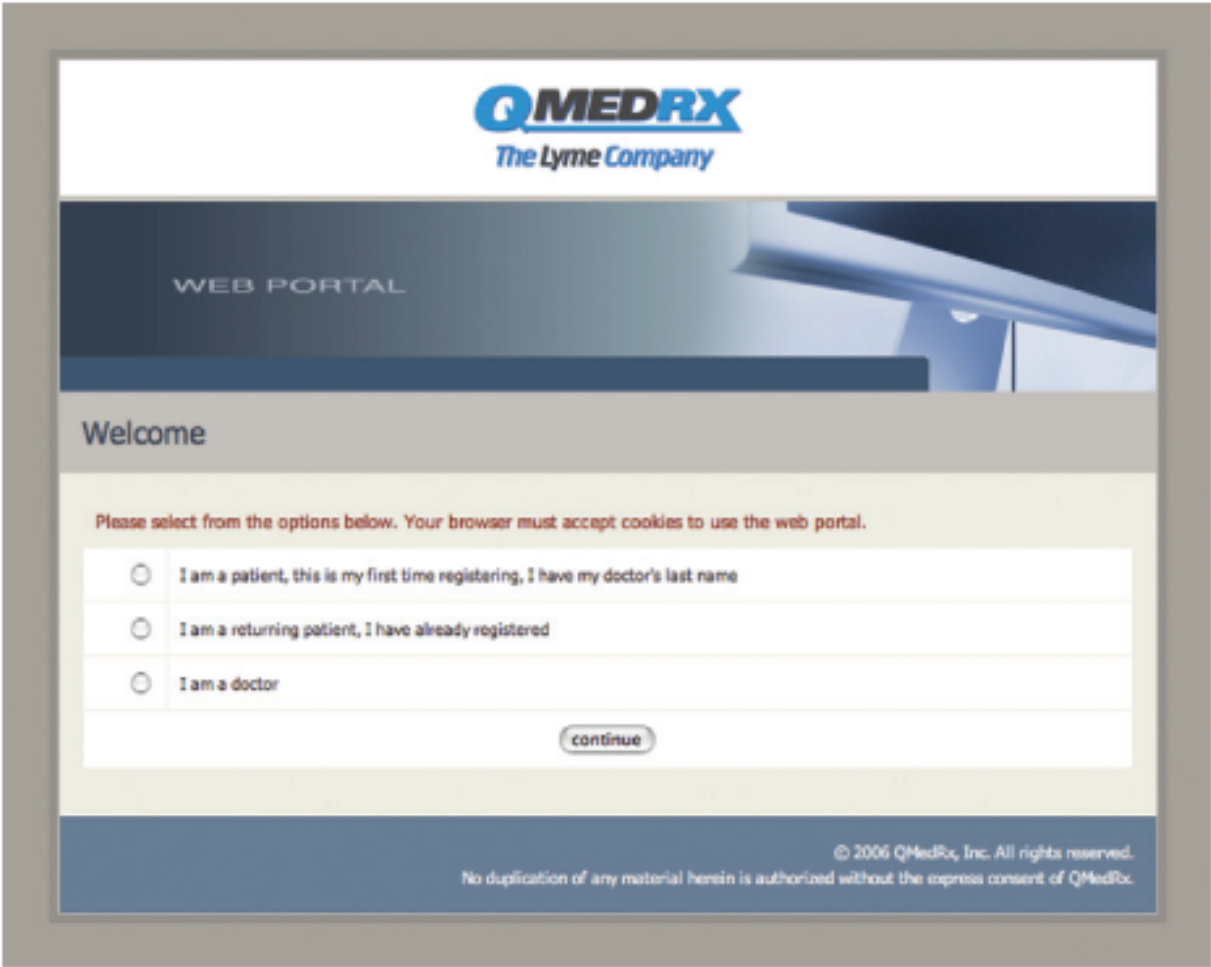
Lyme Disease is the second leading infectious disease in the United States. There is no test currently available to prove that Lyme Disease has been eradicated from one's blood supply.

The Red Cross does not screen the blood supply for Lyme Disease.

**A general rule of thumb if you have ever had  
Lyme Disease:  
Never donate blood or blood products  
Never donate your organs**

**Track Your Progress...**

- QMedRx announces an exclusive online tool that will assist your Doctor in managing your treatment from day one to recovery.
- Developed by the "QMedRx Advisory Board" a committed group of forward thinking Lyme Literate physicians, pharmacists and nurses, with a common goal of simplifying and improving the quality of Lyme patient care.
- Our Website is secure, confidential and user friendly to both Patient and Doctor.
- QMedRx reimbursement team is highly experienced at working with providers and facilitating initial and extended insurance coverage of IV antibiotic therapy.



**For more  
information call:**

**888.273.9820**

**or visit us online:  
www.qmedrx.com**





## “MARNIE”: The ALS / Lyme Conundrum

by *Ginger Savely, FNP-C*

The droning hum of cicadas provides the sound track for a hazy, humid Virginia day. A handsome middle-aged woman, dressed in well-worn 18th century peasant attire, stirs a hefty iron cauldron of beans over an open fire. As she waves away the hovering flies, she smiles, satisfied with the aroma of her simple concoction. It is amazing what a little salt pork can do for a pot of beans! She pushes back the errant strands of hair that are pasted to her perspiring forehead and then slaps her neck in response to the stinging bite of a large mosquito. She settles back down to her knitting, content that the troops at her Yorktown encampment will take pleasure in their midday meal, one of the few bright spots in their daily lives of danger, drudgery and disease. Lamar is her name, but those close to her know her as Marnie. She is well-loved by the

soldiers, who see her as a surrogate mother and a trusted friend. Marnie enjoys her life of service - part-time cook, seamstress, nurse.

The previous scene did not actually occur in the late 1700s but rather in the year 2000. The Yorktown revolutionary war battle-field encampment is one of the few historic landmarks in the United States where workers actually "live" the times, occupying their days exactly as they would have over two centuries earlier. Marnie and the soldiers were state employees performing their daily reenactment of



life in the 18th century Yorktown army encampment. Curious tourists would wander about, intrigued by the extemporaneous theatrical production. In rain and snow, in sweltering summers or freezing winters, Marnie and her co-workers spent their days in the grassy open fields, enduring flea, tick and mosquito bites and the unclean conditions of the times they sought to replicate.

Marnie, who loved the simple things in life, was well-suited to this kind of work. In fact, the job was somewhat of a dream-come-true for her: she was strong, healthy, and a "low maintenance" kind of

woman who also adored domestic crafts. She had obtained a masters degree in textile design in San Miguel de Allende, Mexico and was skilled at batik, weaving, macramé, tie-dye, crocheting, embroidery, sewing and knitting. She also loved to cook and do all other manner of crafts.

Appearing much younger than her 61 years, Marnie approached life with a youthful exuberance. She had a beautiful and kind face, a radiant smile, and a welcoming manner. She looked forward to putting on her white ruffled cap, long full skirt and apron and going to work each day. Makeup and jewelry were out of the question, as she had to be perfectly in tune with her place in history. Since assuming the position of "historical interpreter" some 18 years earlier, she had fallen in love with her work and had never missed even one day due to illness. Despite the modest pay and

**“ALS / LYME”...cont’d pg 11**

### “United”...cont’d from pg 2

can to make sure my children and grand children receive comprehensive treatment when they need it," Laurie stated, after sharing the fact that several of her family members were also affected by Lyme disease.

Headed north from Wilmington, DE, Delores Heintz was able to make the journey by reserving a seat on a charter bus headed to the protest site from Maryland. "When I decided to go I knew that it would take a toll on me physically; but I had to take a stand. Our only recourse in trying to help fix this situation is to create awareness before more people get hurt."

Julia F. Wagner, a Lyme patient from North Wales, PA came to support continuing treatment for her young children and others. "Our pediatrician did nothing," she reported. "Thanks to my Lyme literate physician they are being restored to their normal selves. Had we adhered to the IDSA guidelines, all 3 of these intelligent, enthusiastic children's lives would have continued to diminish, along with mine. We are a complete testimony to the validity of longer-term antibiotic treatment. Our children need to be protected from this insanity!"

Ruth Ann Robinson, a museum curator from PA, whose family has seen first hand the obstacles people face in the Lyme community, shared her thoughts. "The existence of chronic Lyme

disease is being dismissed by a handful of people who admittedly have limited or no experience treating it. They have fabricated an array of self-serving theories, all the while omitting evidence which supports active chronic infection as the key to the chronic phase of the illness."

Parents, who have had to endure years of watching their precious children suffer from multiple Lyme symptoms without proper treatment, plastered their messages on signs for all the world to see, "OUR CHILDREN ARE SUFFERING FROM CHRONIC LYME DISEASE- TREAT THEM!"

As the news cameras focused on the Patients Rights podium, Pat Smith, President of the national non-profit Lyme Disease Association addressed the crowd and said they were "not there because of Lyme disease, but because patients have "NOT Lyme", because the experts said that chronic Lyme does not exist!" She stated that chronic Lyme disease is something that can be recognized, diagnosed, treated, researched, and eventually, even cured. However, she lamented, "NOT Lyme will never be cured. It will consign its unwilling victims to a painful, debilitated existence."

New York Assemblyman Joel Miller, a long time advocate for patients rights, once again stepped up to the plate, continuing to sup-

port Lyme disease patients. He spoke emphatically to hundreds of patients concerning the need to make changes. The crowd came to its feet and cheered, thankful that someone was listening to them and taking them seriously.

Robi Kollendar, a Lyme disease support group leader from Richmond, Virginia attended the protest due to her concern for those who are chronically ill now, especially the children, and for those who will contract Lyme in the future. "This is a battle that must be won to preserve our quality of life", she stated as she questioned if anyone would be treated now due to the restrictive guidelines. "THE NEW IDSA GUIDELINES MAKE ME SICK," stated a poster at the rally.

Dr. Joseph Burrascano, Jr., one of the worlds leading authorities on Lyme and tick borne diseases, has successfully treated chronically ill patients who failed to be cured by the IDSA's recommended treatment protocols for years. As one of the original pioneers in the field, he has personally witnessed the recovery of thousands of patients once they were properly diagnosed and treated. He thanked patients for coming to the protest and urged them not to give up the fight. Dr. Burrascano did what he does so well, he gave them hope, which was backed by solid science and assured them that they would prevail. The delighted audience applauded tumultuously

as he reiterated his battle cry, "We will NOT go away!" Patients were fighting back! Even those too ill to be there in person made their voices heard November 30th. Hundreds, possibly thousands spent the day calling hospital administrators and voicing their opinions about the 'infamous IDSA three' who are responsible for so much destruction. Their phone calls reinforced what the protest signs demanded be done, "RETRACT THE IDSA GUIDELINES BEFORE MORE LIVES ARE DESTROYED!"

As the evening hour approached, individual patients were directed to the podium to share their stories to an understanding and compassionate audience. Hearts broke, tears flowed and patients relived their own nightmares, and yet, spirits rose to the occasion. A small group of people, who were permitted to be directly in front of the Westchester Medical Center, took one final look at the brick walls protecting those responsible for so much destruction, wondering how this could even be happening.

As the shuttle buses returned the brave souls to the parking lots and the weary travelers loaded their signs and gear back on the bus preparing for the long ride home, they all left the scene of the protest with one thing in common. Hope. *pha*



## “ALS / LYME” ...cont'd from pg 10

unforgiving working conditions, Marnie planned to stay on for the rest of her working days, with retirement being the furthest thing from her mind.

Marnie had the kind of sweet and unassuming temperament that no one could dislike. Her fellow workers were protective of her trusting nature and were concerned when they noticed their normally vibrant and energetic co-worker starting to move slowly, tire easily, and require assistance to lift even the lightest tools of the trade. Never one to complain or to worry about her health, Marnie ignored the nagging signs and symptoms that something was wrong. She continued to retain her good humor and appear undaunted, even when her doctor couldn't seem to pinpoint the cause of her sudden decline.

Her weakness worsened to the point where even turning the key to the ignition of her car required both hands and all the strength she could muster. Finally, after a visit to a neurologist, Marnie came home with news that stunned her family, co-workers and friends. The neurologist had told her that there was a strong chance she was developing

Amyotrophic Lateral Sclerosis (ALS), also called Lou Gehrig's disease for the famous baseball player who died from the malady.

ALS is a relentless neurologic disease that affects the nerve cells (neurons) responsible for controlling voluntary movement. It gradually strips its victims of muscular functions, ultimately dooming them to life with a ventilator and feeding tube, unable to speak, the body paralyzed but the mind completely alert.

As many as 30,000 Americans have ALS, and an estimated 5,000 people of all races and ethnic backgrounds are diagnosed with the disease each year in the United States. ALS most commonly strikes people between 40 and 60 years of age, and men are affected almost twice as often as women. There is no known cure and generally life expectancy is three to five years.

In 90 to 95 percent of ALS cases the cause is unclear, with the remainder of cases being due to a genetic abnormality. It has been noted that a high percentage of those diagnosed with ALS had outdoor jobs, spent a good deal of time outdoors, or participated in outdoor athletics. There is also a

higher incidence of the disease in military personnel previously deployed in overseas missions. The only treatment currently available for ALS patients is a drug called riluzole (Rilutek) which at best prolongs life by about two months (but usually only in patients with swallowing difficulties). The medication reduces the levels of the amino acid glutamate, which is thought to be abnormally high, and therefore neurotoxic, in ALS patients. In order to fit the "official" diagnostic criteria of ALS, the patient needs to have abnormal electromyography (EMG) readings in at least three areas of the body. The EMG measures a muscle's ability to contract when the motor neuron is stimulated.

Marnie called me to tell me the neurologist's tentative diagnosis. She said, "He told me that I don't exactly fit the diagnostic criteria for ALS but he thinks I have some sort of motor neuron disease and there is really nothing he can do for me."

As a practitioner who specializes in treating patients with Lyme and other tick-borne diseases my diagnostic antennae go up when I hear words like these.

Frequently, patients with neurologic symptoms that don't quite fit a known diagnosis are misdiagnosed victims of at least one tick-borne infection. Marnie certainly had known her share of ticks. During her 18 years of working in the fields of Yorktown, she had pulled dozens of the blood-sucking creatures from her body. "I'll mail you an IGeneX Laboratories blood test kit," I said, "and let's see what we find out".

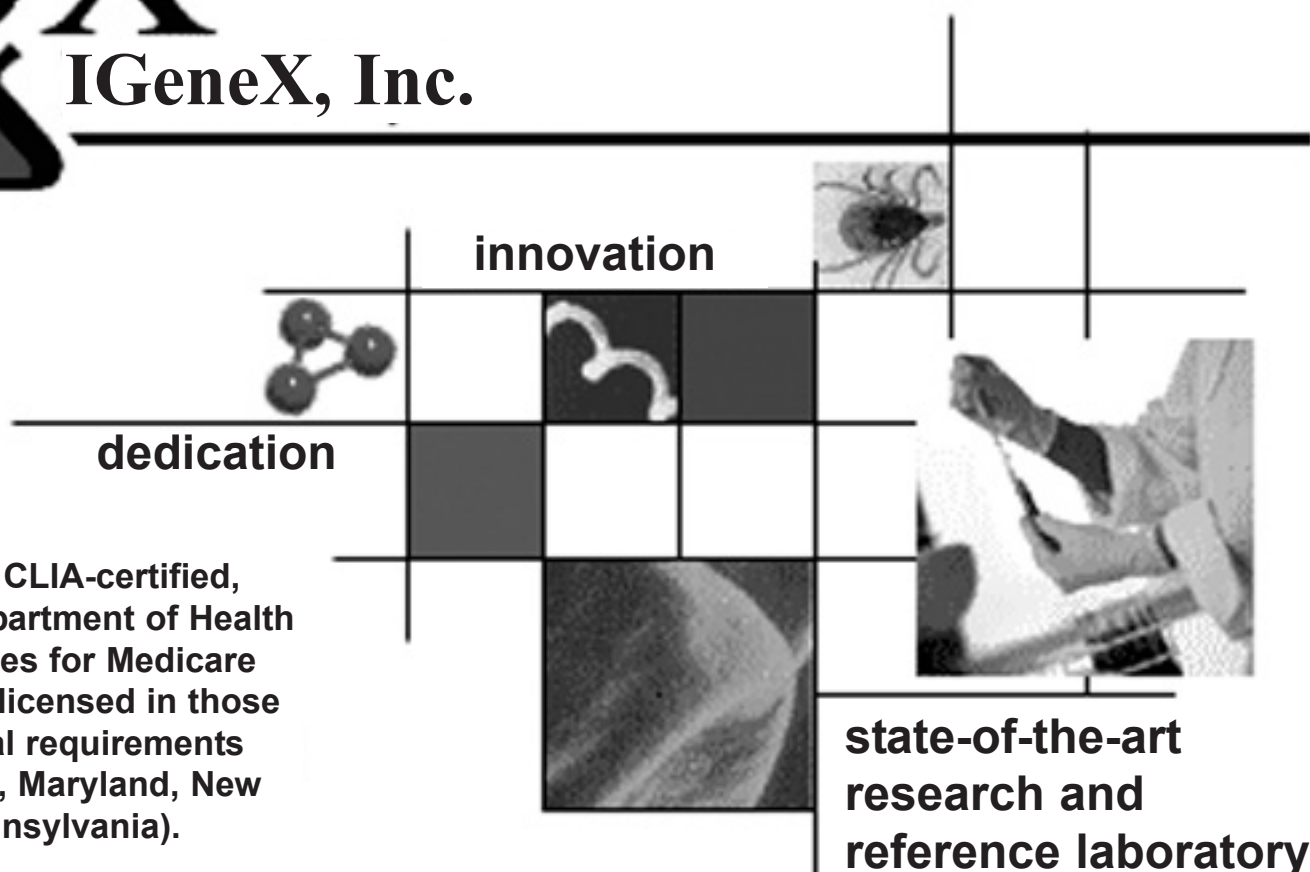
As is often the case in patients with severe or long-standing Lyme disease, Marnie's Lyme Western Blot test results were technically "negative" but highly suspicious for exposure to *Borrelia burgdorferi* (the causative agent of Lyme disease). She was, however, positive for *Babesia*, another tick-borne infection. It was enough evidence for me to recommend treatment. After all, the only other option was to accept the ALS diagnosis and helplessly await certain death. A poll of several of the nation's Lyme experts convinced me that we should not waste another moment but start her at once on intravenous Rocephin, the antibiotic of choice for those with neurologic Lyme disease.

*“ALS / LYME”...cont'd pg 14*

# Igx<sup>®</sup>

## IGeneX, Inc.

Specializing in Lyme Disease  
and Associated Tick-Borne  
Diseases



The laboratory is CLIA-certified,  
inspected by the Department of Health  
and Human Services for Medicare  
testing, and is also licensed in those  
states with special requirements  
(California, Florida, Maryland, New  
York, and Pennsylvania).

795/797 San Antonio Rd.  
Palo Alto, CA 94303  
800/832-3200

# www.igenex.com



“Holistic” ...cont’d from pg 6

by Scott Forsgren

beneficial. Salt/C is another useful option for some people.

Homeopathic remedies can be very useful. I find that this is an essential piece. Generally, I would do either an herb or a prescription treatment and follow that with homeopathy. In children, homeopathy may be enough by itself. You generally won't get rid of the energies of the parasites unless you do some homeopathy. The ozonated oils are often good choices. Prescription alternatives such as Mebendazole or Biltricide can be helpful as well.

What options are useful for dealing with metals?

Chlorella, of course. Cilantro can be helpful. Liquid minerals are often useful. CGF (chlorella growth factor) liquid can be a good mobilizer and can help with metals in the brain. NDF can be a nice option. There is a product called Metal-Free that has been helpful. It may also be necessary to consider conventional chelators such as DMPS, EDTA, or DMSA as part of a metal elimination program.

The KMT (Klinghardt Matrix Therapy) microcurrent device such as the KMT-24 can be helpful here as each of the programs has built-in metal detox frequencies. It can be very useful for patients in dealing with Lyme disease and related infections. It is especially nice if you do the TMJ release and lymph drainage sequences. The most beneficial programs to use can be determined with ART for each individual patient.

Metal detox can be a complex area and should always be done under the supervision of a medical professional.

How do you address fungal/mold issues?

For mold issues, I generally like the prescription options. Amphotericin B orally or Diflucan are useful here. I like Florastor or Saccharomyces boulardii. There is an excellent probiotic from BioImmersion called Beta Glucan Symbiotic Formula. Addressing the fungal issues can often help with liver stress.

Is there value in the Salt/C protocol and if so, what is the likely mechanism of action?

Yes, Salt/C can be valuable for some people. It creates an osmotic gradient that draws water out of the organism and essentially dehydrates it. It can help with chronic constipation by moving

things out. It may be helpful for addressing parasites in some cases. It can be difficult to get patients to comply with the treatment. Stomach burning can be a problem with some types of Vitamin C that are used. I don't like to use a powder for all doses and generally suggest taking a buffered capsule for half of the doses. Pharmax has a nice product called Vital Mixed Ascorbates.

I've seen skin clear up. Patients have seen things coming out of the skin and breakouts may appear. Brain fog often lifts. Stools move. One should watch for edema in the legs as an indication that the dose is potentially too high.

What about concerns over high blood pressure while on Salt/C?

I just haven't seen this as a common issue. It should be monitored closely to be safe. However, many Lyme patients have chronic low blood pressure.

Is the sequencing of treatment important?

Yes, it is very important. If someone is depleted, we have to start with support. Diet, minerals, good bacteria. You have to start with the basics. Each person is different in terms of their readiness or tolerance for addressing the infections. You cannot target just Lyme or just metals. We have to realize that things must be addressed and monitored more holistically. Several things must often be addressed at once. Parasites are often the first things that we have to start with. Fungus should be kept in mind during the entire treatment as it is quite opportunistic. In general, treatment needs to be broad.

What place do antibiotics have in the treatment of Lyme disease?

They have a definite place. My concern is that they are very targeted and co-infections will sometimes not be managed well if someone is only doing antibiotics. They can pull someone out of a severe crisis. Generally, I prefer to use herbs first and then use antibiotics, if required, later. There are people though that have carditis or phlebitis or other symptoms which may absolutely require antibiotics. In many cases, the decision to use antibiotics is dependent on the level of symptoms that the patient experiences.

How does Lyme disease impact the thyroid?

Lyme may attach to receptors on the thyroid gland and interferes with thyroid production. We often see high TSH levels which may respond well to T3 supplementation. Thyroid supplementation may be needed during Lyme treatment. Often with treatment, thyroid function will normalize and the need for supplementation may be reduced or eliminated.

What are the more common organs that you find are stressed when doing ART?

The liver and tonsils are probably the two most common. Liver stress may be due to fungus, metals, or the need for digestive support. Chronic liver stress is often related to a fungal issue. Stress in the tonsils may be related to streptococcal infections or presence of Epstein-Barr or CMV viruses. Issues with tonsils can be very responsive to Pleo remedies. These support the immune system and get the lymphatics moving.

The kidneys may appear stressed and may be helped with products like Renelix or Solidago. Kidney issues may be related to metals or can be as simple as dehydration and the need for electrolytes. Minerals are also important here.

Frontal brain stress with ART may be an indication of metals, viruses, Lyme, or Babesia. Sinus stress may be an indication of mold, Lyme, or Babesia.

What are the more useful diagnostic tests that you employ?

I like IGeneX panels. The Babesia FISH test is nice. I use the Western Blot from IGeneX. Immunosciences also has some very nice panels. I really like their mold panels.

Aside from those, kits are available that contain petri dishes that can be used to test for mold. These can be very helpful in identifying molds in the environment. Often, the results can be correlated back to elevated mold antibodies in other testing that was performed.

For heavy metals, a provoked urine test for toxic metals and essential minerals is important. If a patient is not ready for a provocation test, hair analysis can be of value.

The CD57 can provide useful insights into the severity of a patient's Lyme infection or provide indicators as to the progress being made with the various treatment protocols.

I recommend a thyroid panel and basic chemistry and

CBC. If white blood cells (WBC) are less than 5.5, this is another indicator that Lyme may be an issue.

A Comprehensive Digestive Stool Analysis (CDSA) can provide useful information about parasites, fat absorption, gut immunity, and depending on which lab is used, even provide insight into food allergies to soy, gluten, eggs, and cow's milk.

What dietary considerations are key for someone with Lyme disease?

You must get adequate protein. You must limit sugar. You must rule out food allergies. Allergies to milk, gluten, and corn are common. Electrodermal testing can provide much insight into the food allergies. Blood testing may provide valuable information as well.

How important is exercise in recovering from chronic Lyme disease?

It is extremely important. With chronic infections, the blood tends to be thick. Exercise can be very good to improve circulation and lymph drainage. People often feel better with exercise but it is important not to overdo it. You can set yourself up for a setback if you overdo it. Know your limits.

What are some of the commonly overlooked factors in treatment?

Stress, living in a moldy home, poor diet, and sleep. It is important to remember the basics.

What significance do neurotoxins have relevant to the infections themselves in terms of one's overall symptom picture?

Neurotoxins are often the limiting factor in treatment. They can make you feel lousy even when you are on the right track. A binder is critical for both metals and neurotoxins. If you have burning pains or neuropathies, neurotoxins may be directly related to these symptoms. Chlorella, Cholestyramine, chitosan, beta-sitosterol, charcoal, and numerous other binders can be helpful. It is important to have a good binder in your plan at all times.

What role does hypercoagulation play in Lyme disease?

Hypercoagulation plays a huge role. The key is to look at the color of the blood. It should be red, not dark or thick and black. Look at your blood the next time that you have it drawn. If it is

“holistic”...cont’d pg 13

“Co-Infections”...cont’d from pg 4

pened during the Middle Ages in Europe with Y. pestis infected fleas and other biting insects that caused the Black Plague. Approximately one-third of the population of Europe was eliminated. Insect-borne plagues are an important element in Biological Warfare, and the U.S. and many other countries have been over the years very actively engaged in Biological Defense R & D using a variety of delivery systems."

I had planned to move on with my next question, but I was intrigued. Did Dr. Nicholson believe Lyme disease and co-infections to be biowarfare? Was it accidental, population control, or an experiment? "Sorry, no one outside of the upper levels of the DoD-CIA research organizations can really answer that question. Anyone who does is just speculating. The person who is probably closest to the truth is Dr. Jim Deagle. He actually worked within the system for several years and has good insight into such things," Nicholson replies.

I wondered if he was working on anything now that could help in the diagnosing or treating Lyme disease? Garth responds, "At the Institute for Molecular Medicine we have been actively working on new

diagnostic and treatment strategies for chronic infections. We were the first or among the first to find chronic bacterial co-infections in Lyme Disease, Chronic Fatigue Syndrome, Fibromyalgia Syndrome, Gulf War Illness, Rheumatoid Arthritis, Multiple Sclerosis, Amyotrophic Lateral Sclerosis, Lupus, Autism and other Autistic Spectrum Disorders and other chronic diseases.

The infections that we work on are not widely known in the general medical community, so part of our future efforts will be to educate health care professionals on the importance of chronic infections in a variety of diseases and illnesses and the use of effective treatments against them." Nicholson adds, "Another important area for us has to do with empowering patients to help themselves with dietary and supplement advice for chronic illnesses. We developed Lipid Replacement Therapy and other dietary supplements to help patients with specific problems that were not being addressed in the usual health care settings. In this case damage to mitochondria (the energy system in each cell) and other cellular lipid structures due to toxic substances released or stimulated by intracellu-

lar bacterial infections, such as Lyme Borrelia and other intracellular bacteria, causes fatigue or loss of cellular energy. Lipid Replacement Therapy replaces naturally the damaged lipid structures in cells and tissues and restores energy function and reduces fatigue. Patients can learn more about this from our website, <http://www.immed.org/>."

You've written and just released "Project Day Lily." Briefly tell me what the book is about and why you wrote it.

"Project Day Lily ([www.projectdaylily.com](http://www.projectdaylily.com)) is based on our true story at the largest academic cancer center in the world in Texas when we discovered one of the most insidious incapacitating biological agents ever developed in veterans' blood from their service in the first Gulf War. We found that the modified M. fermentans was hiding inside cells and causing all sorts of chronic signs and symptoms, similar to what one would see with Chronic Fatigue Syndrome, Fibromyalgia Syndrome, Rheumatoid Arthritis, Multiple Sclerosis and many other chronic illnesses. We would find that the weapon that we discovered in veterans had been studied for years before the war in the state prison

system.

Unfortunately, this thrust us into a world of danger and intrigue as we unraveled the mystery of how sinister university and government administrators plotted to keep this hidden from the public, even attempting to murder us to prevent the exposure of their hideous experiments from public scrutiny. Project Day Lily explains what happened to the veterans and their family members after the first Gulf War and what is happening to our Armed Forces to this day. This book is America's wake up call, and it should be particularly interesting to anyone inflicted with a chronic disease, such as Lyme Disease, that involves microorganisms with suspicious origins. It also explains why effective help from government agencies for various chronic illnesses may not be forthcoming until the present climate of secrecy is ended."

Robert A. Heinlein (American writer, 1907-1988) once said, "Secrecy is the beginning of tyranny." It is my sincerest hope that the secrecy ends and healing is allowed to begin.

Sue Vogan is an author, book reviewer and radio show host. Her website is [www.betrayedsoldiers.org](http://www.betrayedsoldiers.org).

“Holistic”...cont’d from pg 12

thick, you may not be getting important nutrients to the cells or clearing away debris.

Helpful tests include fibrinogen levels or the Hemex panels. Some treatment options include Rechts-Regulat (a German enzyme drink), Wobenzym, and Intenzyme Forte. Heparin may be a valuable option.

**What are some of the more critical supplements that someone with Lyme disease should consider?**

Toxin binders, minerals, essential fatty acids, enzymes, and greens. The greens can be helpful with moving metals and are a great source of minerals.

**Do patients get well?**

Patients definitely start to feel better. Symptoms can dramatically improve with treatment. You can become asymptomatic and live a normal, productive, healthful, and happy life.

**What does "cure" mean in your mind when it comes to Lyme disease? Can one forget about this disease after they are "well"?**

"Cure" means that a patient becomes asymptomatic and the immune system is strong enough to

keep things under control. You have to continue to make smart choices. You cannot forget that you had Lyme disease. Remember what worked and continue to consider pulsing of the herbal treatments especially under times of emotional or physical stress.

*I want to extend my personal thanks to Dr. Derksen for her time and for the compassion she shares with her patients as she helps to guide each of them to wellness.*

**Disclaimer:** Though the source of this interview is a medical professional, nothing in this article should be taken as medical advice. Each person is unique and should be evaluated by a knowledgeable medical practitioner. The information contained herein is not intended to serve as medical guidance and is for informational purposes only. *pha*

**Resources:** Amy Derksen, ND can be reached at Holistic Healing Arts in Bellevue, Washington at 425-709-ARTS.

More information on Lyme disease treatment can be found on Dr. Klinghardt's site at <http://www.klinghardt.org> and at <http://www.neuraltherapy.com>.

**Author:** Scott Forsgren has battled Lyme disease for almost 10 years. He can be reached at [Scott@BetterHealthGuy.com](mailto:Scott@BetterHealthGuy.com).

LYME DISEASE AND RIFE MACHINES

In the 1930s, a scientist named Royal Raymond Rife discovered a method for killing microorganisms with electromagnetic frequencies. What resulted was development of the "Rife machine," named after Dr. Rife. Although experimental, and not adopted by conventional medicine, the Rife machine proved to be useful in fighting numerous bacterial infections. In the 1980s, a mechanical engineer by the name of Doug MacLean adapted the technology into a device that he used to heal his case of chronic Lyme disease. Since then, hundreds of Lyme sufferers have followed in his footsteps. Today, Rife machines are considered by many patients and practitioners to be one of the most useful therapies for killing Lyme disease bacteria. In comparison with antibiotics, Rife machines offer several intrinsic advantages:

- they have no known toxic side effects
- they are inexpensive with or without insurance
- treatments can be taken in the privacy of your home, on your schedule
- treatment only takes about 30 minutes, and is needed only once a week

To learn more about Rife machines, read letters from Lyme sufferers using them, and access a free online Lyme/Rife discussion group with over 1800 members, visit:

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

We do not sell rife machines and our only products are books and videos that offer unbiased assessments of various alternative Lyme Disease therapies.

If you'd like to connect with the Lyme disease community, consider joining this free online discussion forum where you can get support, ask questions, make friends, and learn about conventional and alternative treatments:

<http://www.lymecommunity.com>

\*the above statements have not been evaluated by the FDA. Our products are not intended to prevent, diagnose, treat or cure disease.



## “Mountain” ...cont’d from pg 7

by Laura Zeller

loved ones to do everything for you. Become your own detective, and research your illness as much as possible so you will be able to communicate well with your chosen physician. You have to save yourself, and it is going to take a lot of heart and soul.

First, you must organize your materials, and arm yourself with information to educate your family and friends. Let them know how serious this disease is, and how you are going to need their support. Print out information on your disease and give it to your family and friends to read. Find a local or online support group, and feel free to ask questions. *Get copies of all your medical tests*, and keep the folder and health history current.

Chronic illness can result in a vicious cycle of disappointment, anger, grief, chronic stress, and demoralization. I thought of each of the previous stages as mountains I had to climb. Seeking psychological support may be a good idea if you are feeling lost and overwhelmed. Early in my journey with Lyme disease, scared and not knowing where to turn, I got a professional opinion. Psychotherapy, I figured was a tool that could teach me the skills I needed to conquer my mountain, which at that time was fear.

Frustrated by my limitations, and victimized by the medical community, I was desperate for a way to cope. The psychologist I saw told me it was normal to be scared, and that I was going through the normal stages of grief. Although never in denial, I did

experience anger and depression. I was resentful of my body and the limitations of Lyme disease. My life felt empty because I could no longer do the things I loved. Disabled and full of fear, I was desperate for a way to move on, and desperate to climb my mountain. In the end, my psychologist said something that would prove to be the answer I was looking for. My psychologist said "you must accept this disease as your friend, your companion, and be good to it, because it is a part of you." Right there I knew I was finished seeking professional advice. What she said struck right to the core of who I was as a person. Lyme disease was NOT my friend, not my companion, *nor was it or would it ever be a part of me!* The tiny ticks invaded my body and the disease was trying to destroy my life and weaken my spirit. Why should I accept it as my friend?

Her statement fueled my anger, which I instinctively channeled into fierce determination. Although acceptance is a valid stage of grief, it knew it was a stage I would never believe in. My spirituality took over and I knew that I could never accept Lyme disease as my friend. In spirit, I was healthy and full of zest for life. Right then I realized that I already had the tools I needed to climb my mountain of fear. Lyme disease could not touch my spiritual side, nor could it invade my imagination.

My career and my passion for extreme sports were put on indefinite hold, yet I knew that this was a temporary situation.

Nevertheless, my lifestyle changed significantly and I did indeed grieve for my former sense of self. These inner battles are very difficult to explain to others. Often times I tell people to be prepared for your social life to change. In my case, most of my friends abandoned me when I got sick. As odd as it sounds, Lyme turned out to be a blessing in that respect. A true friend is one who walks in when the rest of the world walks out. At one point, when I thought I was going to die, I wrote letters to all of my family and loved ones. Putting my deep feelings down on paper gave me inner peace, and control over a part of my life that had been missing. Luckily, I survived, but the desperation I felt is something that I will never forget.

Finding others in similar situations that can relate to what you are going through is essential. Most of my current friends have Lyme disease, and are the truest friends I could ever ask for. Reach out to others in the same situation, and remember that you always have something to offer, no matter how sick you are. You can radiate energy towards others, and demonstrate a positive attitude, even if you are confined to bed or a wheelchair. Remember that Lyme disease, or any chronic illness cannot take your heart or your spirit.

When struggling with a chronic illness, it is important to find activities to keep yourself occupied. If you are confined to bed, consider a laptop computer to connect to an online support group. Sedentary hobbies have been the key to keeping my own

sanity. I discovered a love for low-key things like scrap booking, aquaria, and fishing. Audio books are a nice solution for those of us who struggle with reading. Keep in mind that meditation and tranquil healing music can be a great help if you are confined to bed. My pets brought me great joy, and were constant companions in during my most frightening days. Focusing on your spirituality can be an enormous comfort on a daily basis.

Midway through my illness, I realized that I could be sick at home, or sick out doing something. Going on with your life as planned is important. Do not forget, you are still alive, and you still can do it if you try hard enough. Do not give up; it is not part of the master plan. Exercise is essential to getting better. You have to start slow, and rest in between, but it makes a huge difference in your stamina and immune function. It is extremely important to laugh as much as you can try to find the humor in your predicament. Plenty of other people are going through the same thing, and you must reach out for support.

My best advice is to continue climbing your mountains, one at a time until you attain peace. Your mountain may be fear, or it may be the lack of support from loved ones. In either case, keep your spirit strong and nourish your determination. Watching the magnificent sunrise on top of your mountain is well worth the long journey. Remember, if you have hope, you have everything. *pha*

## “ALS / Lyme” cont’d from pg 11

But Marnie wasn't convinced that she had Lyme disease. After all, she didn't have the joint pain, malaise or cognitive disturbances that were characteristic of the illness. The intravenous line sounded so drastic and dangerous. She opted to go on oral antibiotics and I referred her to a Virginia Lyme specialist for treatment.

During the following two years Marnie's life went into a gradual tailspin: months of oral antibiotic treatment with resultant nausea and loss of appetite; difficulty adapting to the "sick role" considering a previously robust constitution; gradually worsening weakness; drastic weight loss due to muscle wasting; dealing with family panic and frustration about her unwillingness to try IV treatment; having to abandon the arts

and crafts she loved due to muscle contractures in her hands; and reluctant retirement from her beloved job. In September of 2002, the tentative diagnosis changed to a definite one as she ultimately fit the diagnostic criteria for ALS. When she reached the point of needing a wheelchair, she moved in with her daughter, who could keep her company and tend to her physical needs. There, daily doses of her four year old grandson were welcome medicine for Marnie's spirit. Her beautiful smile never faded, and although each month her condition worsened, she never chose to give up hope.

On September 18, 2003, hurricane Isabel tore through Virginia leaving the state's picturesque landscape cluttered with scattered branches and large

debris. Grand old trees lay uprooted, testimony to the wind's savage wrath. I was hoping to fly east to visit Marnie during that time, but the inclement weather caused flight cancellations and general chaos for travelers.

The first few days after the hurricane were eerily quiet: residents surveyed the damage caused by Isabel's fury and marveled at the crisp, lovely autumn weather, weather so mild and innocent as to be oblivious to the storm's recent mayhem. During Isabel's aftermath, Marnie seemed to exhibit a clarity and tranquility she had not felt for a long time. She commented on feeling better, particularly due to a reprise of the unrelenting nausea that had plagued her for months. The evening of the 21st Marnie even enjoyed a brownie

sundae with the rest of the family. There was still that glimmer of hope.

But the following day she stayed in her reclining chair the entire day and seemed to go in and out of consciousness, her brain reacting to the oxygen deficiency that resulted from her weakened respiratory muscles. It is said that when a brain is oxygen-deprived a morphine-like state is induced. And thus a drowsy euphoria came over Marnie as life's memories flowed randomly through what remained of her waning consciousness. Her daughter stayed close by all day as she tended to housework, while her son-in-law labored diligently in the yard, clearing the storm's senseless wreckage. By evening, delirium drifted in with

*“LYME / ALS” cont’d pg 15*





