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When a Delusion Is NOT a Delusion: Re-examining "Delusions of Parasitosis"

by *Ginger Savely, DNP and
Cindy Casey, RN*

A Never-Before-Seen Skin Condition

"Oh my gosh.... that looks so creepy!" "What could possibly cause that?" "Have you seen a dermatologist?" "What are you going to do?" With concern and bewilderment in their voices, a group of nurses gathered around the nurse's station and examined their co-worker's arms. They were intrigued yet somewhat frightened by the unusual skin condition that was causing their friend's skin to erupt and produce brightly colored fibers. A 60x-powered, hand-held, lighted magnifier enabled the nurses to visualize the unusual filaments that were intertwined in masses beneath their friend's epidermis. One of the nurses motioned for the doctor on call to come and take a look. It was not unusual at this teaching hospital for staff to gather to assess a patient with an unusual condition, learn about a new monitoring device, or brainstorm about a problematic wound. But what was unusual this time was that the patient was one of their own, a respected and experienced member of their team.

No Help From the Dermatologists

Cindy Casey, RN had worked as a staff nurse and charge nurse in this Medical Specialty Intensive Care Unit for over 15 years. She had already seen four dermatologists for her peculiar symptoms and none of them were even willing to look at the filaments she described. She was hastily dismissed as delusional or self-mutilating and was offered no more than antipsychotics. Despite her disfiguring lesions and debilitating symptoms, Cindy was released to continue working in her job as staff nurse/relief charge nurse in a 21-bed critical care unit. The lesions continued to appear spontaneously and the symptoms intensified. The itching and crawling sensations became unbearable and soon Cindy's entire body was covered with painful, open, oozing, disfiguring lesions. Doxepin, various antihistamines, and medications for neuropathies were all ineffective in controlling the insatiable

itch and crawling sensations. Black specks and bizarre filaments in white, clear, black, red, and blue emerged from unbroken skin and the edges of the open lesions turned black. Cindy's co-workers, friends, and family could see these strange exudates with their own eyes. They knew Cindy as a calm, competent, and well-adjusted woman and certainly not delusional.

The 5th dermatologist Cindy consulted took her seriously enough to conduct a thorough medical work-up including comprehensive blood work, a chest x ray, a series of stool specimens, and a referral to a neurologist to rule out neuropathy as a cause of the unusual sensations. Yet even this dermatologist had no interest in looking carefully at the microscopic debris that was torturing Cindy day and night. Cindy could only guess that the doctor's reluctance to examine her skin had something to do with not wanting to encourage her "delusion". A skin biopsy was performed at Cindy's insistence but the report described the fibers as textile contaminants. All test results were normal and again, there were no answers.

When In Doubt, Diagnose a Psychiatric Condition?

Cindy continued working and was very open about her illness with her colleagues. Her nurse manager became concerned that Cindy's condition might be contagious, putting the unit's immuno-compromised patients at risk. Furthermore, the open lesions that Cindy was unable to occlude would put her at risk for hospital-acquired infections. Cindy's nurse manager consulted the infectious disease specialists in the unit for advice. Initially, these specialists seemed concerned but after making a call to Cindy's dermatologist, they too suspected her problems were neuro-psychiatric in origin.

The dermatologist and his residents had alluded to a possible psychological origin of Cindy's illness but had never come out and said anything definitive. When Cindy's husband Charles asked directly for a diagnosis, the residents became uneasy and evasive. Charles asked again and was told: "It is known as different things in different countries".



The above photo shows a magnified image of the fibers that have been retrieved from Morgellons patients. The inset shows the dermatological irritation many patients have.

Charles replied with "Okay....then let's start with what it is referred to in the United States". In a meek voice and without making eye contact, one of the residents reluctantly replied "Delusions of Parasitosis."

Delusions of Parasitosis

Delusions of Parasitosis (DOP), also known as Delusional Parasitosis or Eckbom's Syndrome, is a psychiatric disorder in which patients mistakenly believe they are infested with parasites. In medical school, physicians learn of the "matchbox sign" of DOP, so named because in earlier times patients would present the debris from their lesions in a matchbox. DOP is actually very rare and oddly those diagnosed with it have no prior history of mental illness. In fact patients seem cognitively intact in every way while insistent that there is something inside of them causing itching and other disturbing sensations. Some of the earliest patients with these symptoms expressed belief that their symptoms were due to a parasite. However, because a known parasite could not be identified on superficial exam, doctors assumed that the patients were imagining things. A recent explosion in the number of patients with this unusual dermatopathology has given rise to a virtual epidemic of

delusions of parasitosis. The sudden prevalence of DOP raises suspicion that these unfortunate people may actually have had a real, unrecognized disease all along.

In Search of Answers

Cindy and Charles were stunned by the DOP diagnosis. Cindy had never mentioned parasites nor did she have a belief that parasites were the cause of her problems. She had no personal or family history of mental disorders and in fact she was a newlywed and the happiest she had been in her life. If the doctors believed she had a psychiatric problem, why had they not referred her to a psychiatrist? Charles asked the dermatologist for treatment recommendations. His reply was: "There is nothing we can do for the condition of her skin. We can only offer medications that may help her to perceive her skin differently." Unfortunately, the medications prescribed caused incapacitating sedation and the horrifying symptoms remained unchanged.

Refusing to accept the DOP diagnosis, Cindy and Charles continued to search for an explanation for Cindy's frightening and debilitating symptoms. Charles created a website and began to maintain a blog detailing the trials and

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Download Dr. Burrascano's Lyme Protocol FREE at:
www.PublicHealthAlert.org

Attention Deficit Disorder



by Dr. Martha Grout

The American Psychiatric Association gave official recognition to attention deficit disorder (ADD) in 1980. The drug Ritalin became widely prescribed to calm the children. Then in 1997 with the epidemic standing somewhere around 500,000 to 700,000 nationwide, the American Psychiatric Association rewrote the diagnostic criteria by adding the term "hyperactivity" to the attention deficit attention deficit disorder. ADD became AD/HD.¹ Mostly.

ADD differs from ADHD because there is an absence of hyperactivity. These children are withdrawn, they display what some might describe as the "lights on, but nobody home" type behavior. Usually, people say ADHD when talking about attention deficit disorders.

Three types of ADHD are diagnosed:²
* 80 % = combined inattentive, hyperactive, and impulsive
* 10%-15% = predominantly inattentive
* 5% = predominantly hyperactive and impulsive

It is estimated that 7%³ of children aged 4 to 17 are affected with ADHD. The Centers for Disease Control estimated in 2004 that there were 4 million cases nationwide in children 17 and under. That is about 1 out of every 10 children in public schools.⁴

There is no physiological process of degeneration or disease that characterizes the disorder. The diagnosis of ADHD is most often made after a doctor or psychiatrist observes behavior and deems the patient has ADHD.

ADHD is characterized by the "inability to marshal and sustain attention, modulate activity level, and moderate impulsive actions."⁵ This results in behavior which is markedly inappropriate to the child's age, and often gets them in serious

trouble in school. These children are typically impulsive, often aggressive. They cannot seem to control their level of activity, and they spend three times as long as other children doing their homework. Even at that, they usually require the presence of a parent or other caregiver to enable them to finish their homework at all. The diagnosis and treatment of ADHD has generated controversy. The DSM-IV (the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders), lists 14 symptoms; the diagnosis of ADHD can be made if a child is found to have 8 of them:

- 1. often fidgets or squirms
- 2. has trouble staying in one's seat
- 3. is easily distracted
- 4. cannot wait one's turn
- 5. blurts out answers
- 6. has trouble following instructions
- 7. cannot sustain attention
- 8. shifts from one activity to another
- 9. does not play quietly
- 10. talks excessively
- 11. interrupts
- 12. cannot listen
- 13. loses things
- 14. does dangerous things

If you're thinking that sounds like you as a child and some adults you know today, you're not alone.

Stimulant Drugs

Drug therapy is the most common form of allopathic medical treatment for ADHD. Ritalin, Concerta or Adderall are the most popularly prescribed drugs. Focalin, another methylphenidate drug, is the latest. There is little doubt that stimulants help to control behavior in many cases. There is much doubt whether they in fact improve scholastic performance.⁶ And concerns about the drugs' side effects are mounting. Prescription drugs for ADHD are almost all stimulants and come with "black box" warnings, meaning they carry significant risk of serious or even life-threatening adverse effects. These drugs have been linked to cardiovascular problems and sudden death. The more common side effects can be so devastating or unpleasant that many kids just don't want to take them.

Long term, drug therapy may turn out to have been a very costly short term fix.

There is evidence that the use of stimulants increase the risk of substance abuse in later life by over 50%.⁷ There is substantial evidence that stimulant drugs increase the risk of hypertension, stroke and cardiovascular disease.⁸ Many parents, and even some researchers, are questioning whether the use of stimulant drugs in warranted, given that other therapies are more effective in the long run.⁹ In April 2009, USA Today editorialized that we need more education, less drugs.¹⁰ The paper reported that according to the government's leading, multi-year study of 579 children¹¹, the

"In some cases, ADHD can be vanquished by eating foods that build strong bodies and learning how to eliminate those foods to which a child is allergic. I call that the power of the refrigerator. You'll love the control it gives you."

effectiveness of the popular drugs for ADHD can dissipate after 14 months of use. By the six- and eight-year mark, across 30 measures of behavior and academics, children still given medication fared no better than their non-medicated counterparts, despite a 41% increase in the average total daily dose, failing to support continued medication treatment as salutary. The drugs can stunt growth. After three years, medicated children have grown an average .79 inches less than non-medicated ADHD kids. They also suffer from more muscle tics. The editors wrote: "Response to what the study itself calls its "failure to find better outcomes associated with continued medication treatment" has been troubling. Psychiatrists who've publicly favored drug over non-drug therapy have downplayed the findings. And the website of Children and Adults with Attention Deficit/Hyperactivity Disorder, a leading ADHD

advocacy and support group, buried mention of the study in a blog without noting any findings. Perhaps not coincidentally, 30% of CHADD's revenue is from drug companies. Such denial risks real harm. It's time for those with ADHD children in their care to recalibrate their enthusiasm for long-term use of the drugs and to engage in some behavioral modification of their own."

School officials are prohibited from implying that medication is a requirement for school attendance but teachers, more than parents or doctors, refer children for an ADHD diagnosis. Drugs are the usual consequence. Yet most teachers surveyed are ignorant about many of the drugs' basic aspects, says a University of Wisconsin-Eau Claire study.¹² California neurologist Dr. Fred Baughman, author of The ADHD Fraud, *How Psychiatry Makes "Patients" Out of Normal Children*, spearheads the arguments against the exploding AD/HD diagnosis and increased drug treatment: "The single, biggest health care fraud in US history-the representation of attention deficit hyperactivity disorder (AD/HD) to be an actual disease, and the drugging of millions of entirely normal American children, as "treatment," is spreading like a plague-still. Once children are labeled with AD/HD, they are no longer treated as normal. Once methylphenidate hydrochloride, or any psychiatric drug, courses through their brain and body, they are, for the first time, physically, neurologically, and biologically abnormal."¹³

Some psychiatrists, including Peter Breggin, worry about the drug therapies too: "...we abuse our children with drugs rather than making the effort to find better ways to meet their needs. In the end, we are giving out children a very bad lesson-that drugs are the answer to emotional problems. We are encouraging a generation of youngsters to grow up relying on psychiatric drugs rather than on themselves and other human resources."¹⁴ We need only look around us at the children today to see that something is clearly amiss. The U.S. government admits that 1 in 6 children is born today with some kind of brain impairment.¹⁵ By age 3, an

“Attention Deficit” cont’d pg 7

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 nationwide support group leaders. These groups include the chronic illnesses of Multiple Sclerosis, Lou Gehrig’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’s attention. We seek to make sure that anyone struggling with these diseases has proper support emotionally, physically, spiritually and medically.

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NVIC Launches Research Fund To Study Health & Vaccination



by Barbara Loe Fisher

“Show Us the Science and Give Us the Choice” was the rallying cry of the 700 parents and health care workers who traveled from 44 states and 11 nations to attend the groundbreaking Fourth International Public Conference on Vaccination sponsored by the National Vaccine Information Center Oct. 2-4, 2009. The historic conference featured presentations by more than 40 world experts in the areas of vaccine science, policy, law, and ethics and raised more than \$100,000 to launch an international fund raising campaign for scientific research to investigate health differences between vaccinated and unvac-

inated children and identify those at risk for suffering vaccine injury.

Families with healthy children and those with vaccine injured children joined hands with nurses, doctors and allied health care workers in a united call for quality scientific research and the human right to make informed, voluntary vaccination decisions. What we witnessed was a celebration of the human spirit and what we affirmed was dedication to truth in science and the duty to protect the biological integrity of our children.

We are not going to wait any longer for government or industry to answer the big question of whether the nearly 70 doses of 16 vaccines that doctors now give our children between the day of birth and age 18 is contributing to the unexplained chronic disease and disability epidemic that is harming far too many of our children. With 1 child in 6 now learning disabled; 1 in 9 asthmatic; 1 in 100 developing autism; 1 in 450 diabetic and millions more suffering with seizures, rheumatoid arthritis, Crohn’s disease, bi-polar disorder and other chronic illness, the National Vaccine Information Center is assembling

a group of independent experts from multiple scientific disciplines to immediately evaluate and act to protect our children’s health.

NVIC’s Children’s Fund for Hope, Health and Healing will raise funds to first create data collection systems and conduct small preliminary studies with a longer term goal of conducting a large 10-year clinical study. The scientific research program will evaluate health outcomes of vaccinated and unvaccinated individuals; identify potential high risk factors for adverse responses to vaccination; and investigate the biological mechanisms for vaccine injury and death.

Vicky Debold, PhD, RN, who teaches health research methods at George Mason University and has served as NVIC’s Director of Patient Safety for three years, has been appointed Scientific Research Director for NVIC’s Children’s Fund for Hope, Health & Healing. She is assembling a steering committee of health research experts and has pledged “to leave no stone unturned in our efforts to understand why so many healthy infants and children are regressing after vaccination and becoming chronically ill.”

NVIC will also raise funds to strengthen informed consent protections in US vaccine laws and support health care workers seeking to protect their right to make informed, voluntary vaccination decisions. Dawn Richardson, co-founder and president of PROVE, has been appointed as NVIC’s Director of State Advocacy. Mrs. Richardson led a seven-year successful grassroots campaign to obtain conscientious belief exemption to vaccination in Texas in 2003. She said “There is too much abuse of executive power taking place at the state level when it comes to mandatory vaccination.”

If you want to support unbiased, scientific research into the health effects of vaccination and be part of this historic grassroots movement to defend truth in science and the informed consent principle, become a donor supporter of the consumer-led non-profit (501c3) National Vaccine Information Center. The world’s largest and oldest vaccine safety and informed consent organization is funded by donations from individual citizens and foundations, including Dr. Joseph Mercola and the Albert and Claire Dwoskin Family Foundation. NVIC takes

no pharmaceutical industry or government funding.

You can direct your tax deductible donation to scientific research or informed consent advocacy – or both. It’s your choice.

Go to www.NVIC.org to learn more about NVIC’s unmatched 28 year record of public service to prevent vaccine injuries and deaths and also learn how to make an informed decision about H1N1 swine flu vaccination. It’s your family, your health and your choice.

A heartfelt thank you to all the parents, grandparents, nurses, doctors, scientists and health care workers who came and made history with us at the Fourth International Public Conference on Vaccination. You are writing a new chapter in the three decade vaccine safety and informed consent movement.

Together, we CAN stand up and protect our human right to make informed, voluntary vaccine decisions based on good science. Because the future is ours to change for the better if we have the courage and believe we can do it.

pha

Healthcare Choices: Paving the Way for Physicians & Patients

Part 2: An Interview with Sandy Yozipovic

by Tina J. Garcia

Tina: I was under the impression that it was either chemo and radiation or natural therapies. I understand now that some natural practitioners acknowledge that chemotherapy is sometimes necessary.

Sandy: We’re not against chemotherapy or radiation. It’s just that if you’re going to put that substance into your body, you better have something to counteract it that really builds up the immune system. So, we only believe in chemotherapy when it’s necessary in certain types of cancers. What Envita’s belief is, and what my belief is, is that every body is different. Every body’s needs are unique with each disease you have.

Envita wants to give the cells of the body what they need in order to function. So, treatment should not be a standard protocol. It should be from the standpoint of, “How are you doing? Let’s see where you’re at and what we can do to give you the right protocol, tailor made to the cause of your disease, not the symptoms.”

Envita is not into treating symptoms; they’re into treating the cause. Why do you have that headache in the first place? Where did that come from? So, you’ve had a headache for ten years? Why? This is in contrast to the traditional way of medicating you. “Here, try this new migraine medication.” Will the medication get rid of the cause? I don’t think so.

Envita has a low-dose, natural form of chemotherapy that they administer. They get

down to the cause. They partner with doctors who are like-minded, because health care should be about treating and healing the sick. It shouldn’t be about just getting by and adding more chemicals in the patient’s body. It should be about finding the cause, so they work with microbiologists like Dr. Stephen Fry.

Tina: Healing the sick goes way beyond putting band aids on the problem, doesn’t it?

Sandy: That’s right, but you understand that the pharmaceutical companies have a monopoly, and the doctors can’t even keep up. The liability insurance is so great. Medicine is a completely different industry than it was fifty years ago. How many doctors do you know today who make house calls? That’s the thing that I learned through what became my worst nightmare in battling cancer. My experience opened the door to advocacy for people’s rights.

To prove that there are other ways to treat disease, whether it’s cancer or Lyme disease, you’ve got to get down to the cause, and you’ve got to be able to get rid of those infections in the body. You’ve got to be able to keep your immune system burning at high octane, so you can thrive.

Tina: Can you explain more about the legislation that mandates treatment for cancer?

Sandy: Well, I didn’t even know that it existed until this happened with this young boy. Then I found out it’s in every state. I’m from Canada and I found out that the laws are the same there, too. They say that you are a bad parent if

you refuse having your child undergo the standard protocol of chemo and/or radiation for that particular cancer. That’s what the doctor is prescribing, and if you refuse, then they say you are neglecting your child. That’s not the case. Why can’t I choose for my child some of the treatment, like maybe we don’t want to do the chemo and we just want to do the radiation or something else instead?

You see, what happens is that insurance companies won’t cover this new advanced treatment. That’s where the crime is. If parents had the choice to do both and have it covered, they would. Patients have to make a life-altering or life-saving decision based on what they can afford. That’s the bottom line. You know, my costs at Envita were a third of my costs at the Mayo. Isn’t that something?

Tina: Yes, that’s incredible! By the way, are there treatment guidelines for certain types of cancer that are written by oncologists similar to the treatment guidelines for Lyme disease?

Sandy: Yes, so for stage three-four colon cancer, the protocol was six months of a chemo-radiation sandwich, which is two months of chemo, six weeks of chemo and radiation and another two months of chemo. I went to two cancer centers, and both of them said they copy what the Mayo does. That’s the standard protocol. I know the Mayo was the one who started it. They used to do twelve months and then they saw that people were surviving, so they tried nine months and then six months.

And when I quit after four months, you would have thought that I just shot somebody, because they thought that with my type of cancer, I was crazy to stop. The cancer I had was so aggressive that the doctors said there was a 99% chance that it would come back in the first two years. They couldn’t believe that I would stop their standard protocol, because no one would do that after four months. Yet, I’ve been completely cancer-free since 2001!

I had gone in for a scope five months after my surgery. This was after I had four months of the chemotherapy and five months of the Envita treatment. I’ll never forget when I was done; the doctor asked me, “Who did your surgery?” I told him it was Dr. Jacque Heppell, a brilliant surgeon I just love. And then the doctor asked, “When was your surgery?” I said, “September 11, 2001.” This was only a few months earlier.

He said he had never seen anything like this. This was when I knew there was a big difference. He said he couldn’t even tell where the cancer had spread to the intestinal wall, where they did the resection, where they had taken out fourteen inches of my colon and had to rebuild two-thirds of my rectum. I also had my ovaries removed, and of fifteen lymph nodes, eight were cancerous.

I’ll never forget when the doctor told me the thirteen-inch scar on my abdomen was healed. It looks like it didn’t even happen. When I had my colonoscopy done after that, my

colon was like that of a brand new baby’s - pink, shiny and clear. Even to this day, my surgeon at the Mayo told me to keep doing what I’m doing, because he is so amazed at my recovery.

Tina: Is the Mayo Clinic open to working with Envita?

Sandy: I attribute the Mayo for the success of the surgery, for I wouldn’t be here if they hadn’t done the surgery that day. That would have changed a lot of the factors, because the cancer would have been everywhere. It took seven months for my husband to get their oncologists and radiologists to talk to Envita. The top radiologist, since retired, became a dear friend, and he knew what I was doing. However, they can’t recommend it, because it’s not in their protocol. That’s what’s sad.

Tina: Are the doors and windows opening to such integrative treatments?

Sandy: I’m going to make sure they do. That’s what my role is. Somebody’s got to speak up. Somebody’s got to let these people know that there are other options. I don’t think you should have to pay out of pocket for them, especially when it could save your life and prevent you from being a hindrance on the healthcare system twenty years from now. We need to teach preventive medicine and educate the public on what their options really are.

I really think that this is the healthcare of the future, and it lies in the new Celebration Centre for Integrated Healing “Choices” ...cont’d pg 13

Communicating with Your Spouse About Your Chronic Pain



by Lisa Copen

"It's as if there are thumb tacks I our bed," I lament to my husband as he crawls in on the other side of our bed. "Logically I know nothing is there, but my body would argue otherwise."

"I'm sorry," he offers with a sympathetic voice, but there is little else he can do.

"I feel a little nauseous tonight too," I respond. "I wonder if I should eat some crackers or something. . . or if that would just upset my stomach more. It has to be the medications. It will probably pass soon." Before I can finish my sentence he is already asleep.

For many of us, we have a deep friendship with our spouse. If we share a good relationship we want to share our deepest thoughts that are running through our brain. And even if our relationship isn't as good as it once was, we may feel that by explaining a bit about the pain that we are experiencing, our spouse may actually understand our moodiness better and be a bit more loving.

Although we don't want to burden them by constantly sharing about our aches and pains, when we are hurting there is a desire to be heard and have our feelings validated. By talking out loud about what we are feeling, it somehow makes the pain real. It's no longer "all

in our head."

"Carry each others burdens, and in this way you will fulfill the law of Christ," says Galatians 6:2. But at some point we need to carry these burdens to the Lord, and even a close friend, rather than just our spouse.

Although your spouse may not be suffering from a physical ailment, there are still many losses that he is grieving. For example, it is an emotional thing to watch someone you love be in pain and not be able to fix it. He may be suffering as he watches you lose the ability to do things you love. He likely misses the couple outings you once took together when you could do physically active events, whether it was skiing, or just taking long walks together on the beach. He may be frustrated that even his hugs can cause you to wince. Counselors have found that there are three major areas where marriages suffer: money, time and physical intimacy.

Your marriage may be having difficulties in all three, specifically because of the role chronic illness has taken on within your marriage. Is it possible to "share our burdens" with our spouse without overburdening him and making him want to run the other way every time we open our mouth to share another symptom of our ailments?

Consider your spouse your partner and the illness the third party

It's easy to think of you and your illness "up against" your spouse, but the illness should be the third party, not

your spouse. Although you will often feel that your spouse is merely a spectator to the pain you are in, he is feeling his own kind of pain due to your illness. Make him a part of fighting this battle to have the life you want to have in a way that he is comfortable with.

It is okay (and wise) to gently educate your spouse on your illness. Allow him to come to your doctor's appointments if he wishes, and ask his own questions about your illness, especially when you are first diagnosed. Don't overwhelm him, expecting him to read all the books you are reading, especially if he never reads. Instead, give him a brochure with the basics or see if there is a podcast he can listen to. Talk openly about how some of the responsibilities or roles may change within your marriage due to the illness. Be open about what you think you can and cannot do, for example, maybe you can no longer scrub that tub. Be forthright about them so you can decide as a team how they can still be completed.

Connie Kennemer lives with multiple sclerosis and she shares, "I am not as mobile as I used to be and often ask more of my husband. I may ask him 'Can you work at home this afternoon?' Or I have asked, 'Why do you have to go to another meeting?' How much should he accommodate me because my body is changing? He doesn't always know when to stop and encourage me to try things myself. This is a constant challenge."

Be reasonable in your expectations

It is quite common that we end up marrying someone who has the opposite personality style as we do. You may want to talk about your illness a great deal and read books of information on it. You may sign up for all the support group meetings to have a chance to talk about it and make new friends that you have your illness in common with. If your spouse doesn't read the books or want to accompany you to your meetings, remember that it is not because he doesn't care, but likely because he is dealing with the diagnosis in his own way within his own personality style.

On the other hand, maybe you take things as they come and don't want to get on the internet and read every detail about the symptoms you may have. Your spouse may wonder why you aren't more interested in finding out how to best treat (and even cure) this disease. He may go as far as to accuse you of being in denial about your illness. He may want to see you be more pas-

sionate about being healed than you are. A wonderful book that will help you smooth out some of your communication is "Men are Like Waffles, Women are Like Spaghetti" by Bill and Pam Farrell.

Have information about your illness readily available

Sometimes we can just talk in circles about our pain and illness, never really getting to anything specific or a topic that can help our marriage grow. Perhaps one of the most effective tools to share something is to place sticky notes on pages of a books you'd like him to review with comments about topics you'd like to discuss. You can hand it to him and say, "There is a great example in this book about what we are experiencing right now. Would you be willing to read it and then maybe we can talk about it later?" Shares Connie, "After ten years of living with MS, I am past the whiney stage, but Rex sometimes holds back; that's when I need to ask him more questions about his feelings."

Find ways to share about embarrassing parts of the illness

There are some parts of illness that are just downright embarrassing. For example, if you attend an event with your spouse, you may end up in the bathroom for eighty percent of the show. You need to let your spouse know this is part of the disease. But if you don't want to talk about all those details it's okay. He probably doesn't really want to hear about them either. Most health organizations have brochures that list the symptoms of the disease. You can hand him one of these and say something like, "I'm trying to cope with some of the more personal matters of this

“Communicating” ... pg 9

Maintaining Marriage through a Correct Life Focus

by Linnette R. Mullin

"Marriage is an adventure, like going to war," says G.K. Chesterton. Is this how you feel - that marriage is a series of battles, one after another? I believe all couples dealing with chronic illness struggle daily just to survive and wonder if life will ever get better. Others don't fare quite as well and their marriage comes to a tragic end. Despite the constant upheaval we Lymies and our spouses face, I believe our marriages can do much more than simply survive. I believe they can thrive." (PHA October, by LRM)

I last shared in an overview some vital things for rescuing and strengthening your marriage. Let's begin to delve into the first main point, "Between you and God."

1. Correct life focus - an intimate relationship with Christ is vital. Without it, there is no guarantee of success.

The first step to building a strong marriage is not

moves impossible mountains everyday for people everywhere. Unfortunately, limiting Him in our minds often renders us unable to see the wonders He displays before our eyes.

I don't always understand the things I go through in life, but I'm learning to trust that God knows what is best for me. To illustrate this, I'll share song lyrics I wrote during a desperate time in my life:

More Than I Deserve

Sometimes I cannot see Your will, or hear Your voice, say, "Peace, be still."

Oh dear Jesus, please guide me, hold me safely to Your side.

I do not always understand all the things that life demands.

Help me trust You and serve You whatever comes my way.

Oh, if I wrote a thousand songs to worship You and You alone,

I could not begin to come to the end of ways to sing Your praise.

“Marriage”...cont’d pg 7

Insights into Lyme Disease Treatment: Interview with Author Connie Strasheim



by Laura Zeller

A powerful new Lyme disease resource is now available! Health care journalist Connie Strasheim has just come out with her latest book, *Insights Into Lyme Disease Treatment:Thirteen Lyme-Literate Health Care Practitioners Share Their Healing Strategies*. It is an extraordinary accomplishment, and an amazing resource that will no doubt help save many lives. It explains in precise detail the Lyme disease treatment protocols used by thirteen of the world's most recognized Lyme disease specialists. I wish that a resource like this would have been available twenty years ago! Connie has compiled a tremendous amount of information and summarized it into easy to understand chapters.

The Lyme disease specialists featured in her book offer a wide variety of treatment options to choose from, including antibiotic therapies, herbal protocols, homeopathic remedies, energy medicine modalities and much more. Most importantly, Connie asks each of the professionals their opinion about who gets better, and who does not, and why. The insight and answers given in her book are bound to bring on a feeling of empowerment. After reading "Insights into Lyme Disease Treatment," you will undoubtedly be armed with the information that you need to help get yourself well. I am very grateful that Connie agreed to share even more valuable information with me in the following interview.

Can you discuss in summary what your new book "Insights into Lyme Disease" is about?

This book discusses, in general terms, the treatment protocol of thirteen "Lyme literate" health care practitioners, as well as insights into the healing process. Included in the book are the following:

- 1) Anti-microbial treatments for Lyme disease and associated infections, including antibiotics, herbs, homeopathic remedies, plant stem cells and biophotons
- 2) Information on how to support the body's systems, which is an integral component to healing from chronic Lyme disease. Particular attention is given to the immune, endocrine, neurological, digestive and musculoskeletal systems
- 3) Treatments for symptomatic relief. Solutions for fatigue, pain, brain fog, depression, anxiety and insomnia are offered, as well as others
- 4) Detoxifying Lyme biotoxins, mold, Candida, heavy metals and other environmental toxins
- 5) Treating food and environmental allergies
- 6) Lifestyle and dietary recommendations for faster healing
- 7) Strategies for healing emotional trauma
- 8) Patient and practitioner challenges to healing
- 9) Factors that influence healing

10) Suggestions for how family and friends can help the sick

11) Which anti-microbial treatments work and which don't

12) How to discern whether Lyme disease is primary in patients' overall symptom picture.

How does your new book compare to your previous book "The Lyme Disease Survival Guide"?

While both books contain treatment information, two-

nent in the first, so I think it is a book that touches the soul more than the mind, while the second one provides valuable treatment information from the professionals. My first book was fun, and therapeutic, to write. The second one was more grueling, since I had to collaborate with thirteen medical professionals, but the research process was interesting and an exercise in enlightenment for me.

Did the Lyme specialists in the book welcome the opportunity to discuss Lyme disease treatment, or were some of them reluctant to share specific information?

Yes, they did welcome the opportunity to share, because they are doctors who truly want to see people get well, and some have even been personally affected by Lyme. Hence, I believe they decided to participate because of their passion for treating the disease.

How open were the medical professionals featured in the book with disclosing specific treatment protocols, doses, testing, alternative therapies, and advice? Did they openly share the information, or were some of them guarded (out of fear of persecution of LLMD's)?

A few of the professionals were a bit guarded, yes, and logically, since LLMD's are being so heavily persecuted these days. Putting a disclaimer in the front of the book, and faithfully adhering to the information they provided me seemed to allay any concerns. They all had a chance to edit and review their chapters

before I finally submitted them for publication.

I noticed a general consensus amongst the physicians in the book that antibiotics do not work for everyone. Would you agree with that?

Based on my experience in speaking with other people who have Lyme, I would agree that this is true. Sometimes this happens because antibiotic regimens are inappropriate and/or inadequate, or because supportive therapies aren't undertaken. Some people have the idea that antibiotics are all that you need to get better, but many with Lyme also require aggressive detoxification, immune and endocrine support, for example. Supportive therapies are vital. Also, I surmise that some people have antibiotic-resistant strains of the infection, or problems with their biochemistry which prohibit antibiotics from being fully effective. I took antibiotics for only two months during my Lyme disease and became extremely weak. Energy medicine and herbs have been more helpful for me, but these strategies don't work for everyone. Antibiotics have the longest track record of effectiveness, in any case.

It seems like the best LLMD's combine the best of antibiotic therapy, with that of alternative therapy. Would it seem logical to you that what we truly need are Integrative medicine LLMD's?

Yes, because I think there is value in both areas of medicine, and the practitioners who have knowledge of both types of medicine seem to have the most success with their patients. Drugs aren't the answer for all problems that happen in the body when a person becomes chronically ill with Lyme. They may be most useful for ridding the body of infections but alternative methodologies may be more effective for supporting and strengthening the body. And when used together for all of the aforementioned purposes,

"Insights" ...cont'd pg 9



thirds of my first book focuses on the lifestyle and emotional challenges of living with a chronic illness, and how to cope with those. It is based on my own experience with Lyme, and as such, is somewhat autobiographical. The second book contains the treatment protocol of thirteen health care practitioners, so my opinion is not reflected in this book, and it contains more comprehensive treatment information. Both books have their own value, but my personal style and "signature" are definitely more promi-

"EXPLOSIVE" – Fox News

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OPEN EYE PICTURES

TURN THE CORNER

“Delusions” ...cont’d from pg 1

tribulations of their quest. Cindy started granting inter-views for television and news-papers regarding her mysterious illness. After her first appear-ance on TV, Cindy began hear-ing from patients all over the United States. It was then that she knew she had done the right thing by going public with her symptoms. At the same time, she realized that her life would never be the same.

A Disease is Born

In 2002, a Pennsylvania mother of 3 noticed unusual fiber-containing lesions on the body of her 2 -year- old son. Unable to find a diagnosis for her son's condition, Mary Leitao coined the name Morgellons disease (MD) for the ailment after discovering a condition resembling her son's in a 17th Century medical text by Sir Thomas Browne. Drawings representing the 'harsh hairs' that were found in the skin of children in France bore some resemblance to the fibers she had pulled from her son's lesions. Ms. Leitao started a not-for-profit organization named The Morgellons Research Foundation (MRF) with the goal of garnering seri-ous attention for the disease. The organization's website, www.mrf.org, began to dissem-inate information and ask those with MD symptoms to come forward and be counted. The website included a database where patients could report their symptoms. Currently the number of self-reported cases exceeds 14,000 and the tally is rapidly rising (www.mrf.org, accessed 9/2/09).

The Symptoms of Morgellons Disease

Dr. Savely recently completed a descriptive study of 122 patients who had a posi-tive in-office examination for microscopic, subcutaneous fibers. In this sample group, the top ten symptoms specific to the patients' skin condition and experienced by more than 70% of the sample were: crawling sensations under the skin, spon-taneously-appearing, slow-heal-ing lesions; hyper-pigmented scars when lesions heal; intense itching; seed-like objects and black specks coming out of the lesions; a sensation of some-thing trying to poke through the skin from the inside out; "fuzz balls" on intact skin; fine, thread-like fibers of varying colors in lesions and intact skin; and thick, tough, translu-cent fibers that are highly resistant to extraction.

Morgellons and Lyme Disease: Is There a Connection?

Most patients with MD also suffer from severe chronic fatigue, decreased exercise tol-erance, self-described brain fog, cognitive decline, weakness, joint pain and muscle pain. However, according to Dr. Savely's recently completed study, these systemic symptoms may be attributable to a surpris-ing infection that 97% of MD patients share in common - Lyme disease, a bacterial infec-tion acquired through the bite

of a tick. Although no one knows the reason for this perplexing association, one guess is that whatever pathogen causes MD may be present in the tick gut. Ticks are filthy creatures, known to be cesspools of infec-tion. Tick borne disease experts are becoming increasingly aware that co-infections com-plete the diagnosis and treat-ment of Lyme disease. Could it be that a tick bite simultane-ously infects a victim with numer-ous pathogens, one of which may be the etiologic agent of MD?

Lab Findings in Morgellons Disease Patients

When com-mercial laboratories examine wound biop-sies of MD patients, the fibers are usually mislabeled as textile in origin. However, research scientist Randy Wymore, PhD at the Oklahoma State University Center for Health Sciences, Center for Investigation of Morgellons disease (CIMD) in Tulsa, OK examined these fibers in conjunction with the Tulsa Police Department Crime Lab. After comparing the fibers to 10,000 known inorganic sub-stances in the FBI database and 90,000 organic compounds, the crime lab deter-mined that the fibers are not textile or any known environmental contaminant. Thus far, CIMD has determined that only individuals claiming to have MD have been observed to have these unknown fibers in their skin. Wound cultures of Morgellons patients have been unrevealing, growing only normal flora of human skin. Lichen simplex chronicus has been noted when lesions are biopsied. This find-ing is not surprising consider-ing patients' overwhelming drive to scratch and gouge at the spontaneously appearing lesions in an attempt to remove the painful fibers. But standard commercial laboratories are looking for what is already known and present in their databases. It will take more than a commercial lab running standard tests to unlock the mystery of Morgellons disease.

Research into Morgellons Disease

Oklahoma State University's CIMD is the only known private Morgellons research facility with funding limited to contributions from MD patients, their families, and dedicated grass roots organiza-tions. Their research has yet to reveal anything conclusive regarding the etiology of the disease, but they have ruled out many substances that the MD fibers are not. The Centers for Disease Control and Prevention (CDC) initiated an investigation into MD in January of 2008. Results are pending and patients are growing discour-

aged, as publicized conclusion of the analysis is way past the proposed completion date. So the cause and cure for MD remains a mystery.

What About Transmission?

Patients and health care providers often express concern about the possibility of person-to- person transmission of MD. To date, experience has shown that this is not an issue. Many patients, including Cindy, have not contaminated their partners or other family members. It appears that the agent of MD must somehow enter the body through open skin such as through a bite, cut, or splinter.

After examining over 300 patients with Morgellons disease, we have contin-ued to be impressed with the consistency of the patient complaints. Patients come from all parts of the country and from all walks of life. Many have been ranchers or farmers, without access to the Internet, thus debunking the often held notion that the increasing incidence of DOP is nothing more than mass hysteria fueled by online chat groups.

Therefore, much as is the case with HIV, casual transmission is an unlikely possibility.

The Internet's Role in a New Disease

After examining over 300 patients with Morgellons disease, we have continued to be impressed with the consis-tency of the patient complaints. Patients come from all parts of the country and from all walks of life. Many have been ranch-ers or farmers, without access to the Internet, thus debunking the often held notion that the increasing incidence of DOP is nothing more than mass hyste-ria fueled by online chat groups.

What the Internet has done for these frightened patients is help them know that they are not alone. Victims of Morgellons disease from all over the world have been able to communicate with one another and realize that they share identical symptoms. When Cindy and Charles heard of the disease and saw Mary Leitao's website, they had their first glimmer of hope. At least Cindy was not alone and if there were others afflicted with her condition, surely help would follow. But finding a name for Cindy's condition and knowing that there were others in her situation were only the first steps in what was to become a frustrating and wear-i-some journey. Extremely few health care providers are will-

ing to even admit the disease is real, much less try to help the patients who are suffering from it.

The Charles E. Holman Foundation

Cindy worked her last shift as a nurse in November 2005. She misses her job and the people she worked with for 16 years. Cindy still struggles with Morgellons symptoms daily and her disfigured body bears little resemblance to the vibrant, healthy nurse that she once was. She now lives on Social Security Disability Insurance and has become a passionate advocate for Morgellons patients all over the world. In 2007 Cindy started a foundation named The Charles E. Holman Foundation in honor of the husband she had just lost to an untimely death. Charles had seen Cindy through her most difficult times and she still feels fortunate that she had his support as well as that of her family and friends who took her symptoms seri-ously from the beginning.

Duties of the Diagnostician

The responsibility for a psychiatric diagnosis should not rest in the hands of a der-matologist. The proper pro-cedure is to refer to a psychi-atrist but only after every effort has been made to examine the patient carefully and thoroughly to rule out physiologic abnormalities. The distinguishing character-istic of Morgellons disease is the presence of microscopic subcutaneous fibers, which can be visualized by the examiner with lighted magnifi-cation using diligence and patience. The dermatologist must at least make an effort to find these fibers before initiat-ing a psychiatric referral.

The diagnosis of a delu-sional disorder is not one that should be made lightly. Once patients are diagnosed delusion-al, the label prejudices other health care providers against them in a never-ending struggle to be taken seriously. A delu-sional diagnosis can lead to alienation of family and friends and loss of employment. Furthermore, in some cases, children have been removed from the parent with purported DOP. The despair caused by being disregarded leads to iso-lation and hopelessness and in some cases, suicide.

Eleanor Roosevelt said, "There is no more liberating, no more exhilarating experience than to determine one's posi-tion, state it bravely and then act boldly. Action creates its own courage; and courage is as contagious as fear." Whether or not Morgellons disease proves to be a distinct entity, its vic-tims deserve to be taken seri-ously and treated with respect. Until valid research teaches us more about this insidious dis-ease, anyone who comes in contact with these marginalized patients has the opportunity to "act boldly" by listening with an open mind, acting with an open heart and validating the reality of this living nightmare.

pha

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http://www.thenmo.org/

“Attention Deficit Disorder” ...cont’d from pg 2

increasing number of children exhibit autism and other forms of toxicity-related illness such as asthma, diabetes, ADD, and depression.

Getting to the Root Cause

Root causes of the ADHD syndrome may be multiple, including brain processing abnormalities, problems with the entire listening/hearing system, food or environmental allergies, metabolic insufficiencies, or heavy metal toxicity, among other things.

We know many cases of ADHD behavior have been cleared up by making a few extremely important changes in diet. Removing sugar has stopped some children from "bouncing off the walls." Removing specific foods to which they are sensitive has been the answer for others. Sometimes fish oils correct a fatty acid deficiency and restore normalcy. A new Oxford study of 117 underachieving children found 40% of them made dramatic improvements in reading and spelling when given fish oil supplements high in omega-3 fatty acids.¹³ Harvard and Columbia researchers recently recommended that artificial food colorings are one reason for the surge in children's hyperactivity and attention problems. They asked, "Do children's foods really need to be colored with petroleum-based dyes like Red 40 and Yellow 5 when there are plenty of natural dyes available? Are food manufacturer's profits worth the tradeoff in our children's health?"¹⁷

In 2008, the American Academy of Pediatrics said the Southampton/McCann Study of September 2007, finally convinced them to reverse their long-standing position on food additives:¹⁸ "Thus, the overall findings of the study are clear and require that even we skeptics, who have long doubted parental claims of the effects of various foods on the behavior of their children, admit we might have been wrong.

"In real life, practitioners faced with hyperactive preschoolers have a reasonable option to offer parents. For the child without a medical, emotional, or environmental etiology of AD/HD behaviors, a trial of a preservative-free, food coloring-free diet is a reasonable intervention."

It's not always clear which came first - the processing problem or the metabolic

insufficiency. For example: Children raised on commercial baby formulas (some are 50 percent corn syrup), likely have been metabolically challenged since their very beginning. They may have lost brain function because they took in more manganese than what is in breast milk. Manganese occurs at very low levels in breast milk, but it is added to infant formula made from cow's milk and occurs naturally at even higher levels in soy formula. It is dangerous for infants to consume more manganese than they would get from breast milk because infants have no capacity to excrete excess amounts until they are older. The effects of too much manganese include inattention, impulsivity, and hyperaggression.¹⁹ Soy baby formulas do not contain nearly as much protein as breast milk, depriving the developing brain of what it needs. Researchers at Brown Medical School compared premature infants fed with breast milk to those fed formula and found breast fed babies clearly did better on tests of mental development by age 18 months. The more breast milk they consumed, the better they did on the tests. Ingredients in breast milk, particularly fatty acids, seem to help the brain develop properly.²⁰ Additionally, breast milk builds a strong immune system.

Some children are impacted by the high body burden of heavy metals which interfere with the normal developmental processes. Take lead for example: Children with higher exposures to lead are more easily distracted, less organized, and apt to be hyperactive, impulsive, aggressive, and easily frustrated. Sound familiar?

Governmental research reports the average American baby, at birth, has more than 200 chemicals in its body.²¹ Even after 9 months of growth in the womb, the infant's nervous, respiratory, reproductive, and immune systems are not yet fully developed. They are in a dynamic state of growth with cells multiplying and organ systems developing at a rapid rate. Pound for pound, children take in more air, food, and liquids than do adults. For example, carpets are typically made with toxic materials; children tend to make direct contact with carpet with their faces and hands as they play.

Neurotoxin experts Phillippe Grandjean and Philip Ladrigan reported in 2006 that

the widespread use of pesticides, cleaning products, glues and other chemicals that contaminate our air, water, and homes are causing a "silent pandemic" of brain diseases in children. When children reach their "toxic overload" point, out-of-control behaviors can be the result. Medical schools do not train physicians in detoxification procedures, nor does medical school curriculum yet embrace the mounting evidence that environmental toxins cause breakdowns in body systems that cannot be corrected simply by adding a prescription drug - yet another toxic substance.

The Cincinnati Children's Hospital Medical Center study is the first to examine how genes, toxins and gender interact to shape ADHD. "Our analysis confirms a suspected link between prenatal tobacco exposure and ADHD, and it demonstrates that the greater the level of blood lead, the greater the risk of ADHD, says Bruce Lanphear, MD, director of the Children's Environmental Health Center at Cincinnati Children's and corresponding author of the study. "These findings underscore the profound behavioral health impact of these prevalent exposures and highlight the need to strengthen public health efforts to reduce prenatal tobacco smoke exposure and childhood lead exposure." Investigators found approximately 270,000 cases of AD/HD attributable to mothers smoking during pregnancy. Children exposed to tobacco before birth had a 2.5-fold higher risk of ADHD compared to children not so exposed to tobacco. The study is based on data gathered between 1999 and 2002 from a parent or guardian of 4,704 children.²²

Food sensitivities and heavy metals create inflammation in the GI tract. If we have an inflamed "gut," we are not able to efficiently process and absorb the nutrients in the food we eat. As some wise person once said: we are not what we eat, we are what we absorb. It is important to have a strong body biochemistry and metabolism²³, so that the brain processing can be corrected, and will hold fast even under stress.

Lyme Disease & ADHD

There is growing evidence that some children with ADHD symptoms actually have Lyme disease. Lyme's effect on the brain can appear as increasing anxiety, irritability, chronic

depression, cognitive decline and memory loss, and much stronger ADHD tendencies.

Lyme Disease is called "The Great Imitator" since it can affect the entire body in a myriad of ways. It is often misdiagnosed as ADD, ADHD, rheumatoid arthritis, autism, depression, chronic fatigue, multiple sclerosis, and more. The co-infection bartonella has been associated with neuropsychiatric disease.

Most experts agree that the incidence of pediatric neurological dysfunctions, including autism and ADHD, has increased at least four to five times in the last decade. The vast majority of promising evidence connects many of these dysfunctions to the emerging inter-relationship of the neurological and immune systems.

Non-Drug Approach

Comprehensive treatment for ADD and ADHD includes brain processing, food sensitivities, environmental allergies, heavy metal and other toxicities, metabolism, and function of the intestinal (GI) tract, so we can determine the origin of the problems.

It is well known that people with ADHD, depression, head injury, and other forms of brain dysfunction often have a slowing of the activity in the frontal lobes - that area of the brain in charge of executive function: planning ahead, decision-making, remembering, language, and other important cognitive functions. Sometimes an ADHD individual has been robbed of the ability to hear and process specific frequencies because of chronic ear infections, severe allergies or lots of very loud concerts. The ear becomes unresponsive and must be stimulated in order to be able to tune into the desired sound. Attention, focus, learning, and language abilities can all be improved by retraining the brain to listen using different frequency sounds, so that whatever is available is working at maximum capacity. This kind of brain dysfunction can be treated without drugs.

Hemoencephalography (HEG) uses light to measure activity in the frontal lobes by measuring the oxygenation in the blood. Oxygenation of blood flowing to the frontal lobe can be increased through a computer-assisted biofeedback mechanism. This can improve all the functions dependent upon frontal lobe activity. This can bring order from chaos in

the brain of a child - or adult - with ADHD.

As oxygenation increases, neurons are able to make new connections. HEG is combined with exercises for auditory processing and vestibular function, cognitive development, and brainwave entrainment in a successful program called BrainAdvantage™. It is unique program that encourages neural connections all over the brain and brainstem.

The pieces of the puzzle necessitate a holistic approach with emphasis on nutrition. In some people, ADHD symptoms can be reversed by eliminating sugar, wheat, corn, chemical additives from their diets. Parasitic infections are common with ADHD and good homeopathic remedies can correct that. Sleep deprivation is another piece of the puzzle that can be addressed through both behavioral and nutritional means, sometimes with specific supplements.

Some children have turned around just by removing specific foods to which they are sensitive and adding omega-3 fish oils to correct a fatty acid deficiency. Others get a big boost with chelation to remove metals which are silently warehoused in brain and bones and gum up the works.

By treating the origins of the dysfunction, and determining if Lyme disease is a factor, we can avoid the need for dangerous stimulant medication. But most importantly, we give parents a way to restore their child's health naturally and bring forth the person who got lost when the body's functions got confused.

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“Marriage” ...cont’d from pg 4

For You alone are worthy, O Lord, forever to be praised and adored.

Help me love You and adore You and bring glory to Your name.

When I cannot see Your will or hear Your voice say, "Peace, be still."

Oh dear Jesus, come and guide me; keep me safely by Your side.

I cannot always understand all the things that life demands.

Help me trust in You and serve You no matter what comes my way.

Chorus:

Oh, how You love me, Lord, so much more than I deserve.

You died for me on a cruel tree; from sin You've set me free.

Oh, how You love me, Lord, so much more than I deserve.

Give me faith to see that You rescue me, that You always meet my needs.

Though verses one and three are similar, nuances expose the journey of mind and heart as I wrote. It also demon-

strates my next point.

3. Balance correct Biblical principles with a God-seeking heart.

Correct Bible teaching is vital. However, there must also be a heart for God - even a desperate and distraught heart - that follows through; otherwise, doctrine becomes empty religion. In the song, you see a troubled, confused heart clinging to what it knows to be true even in the midst of struggling to do so. While struggle of the heart and mind is not a pleasant thing, it is not a bad thing.

Without it, we grow too comfortable to seek to know our Savior more.

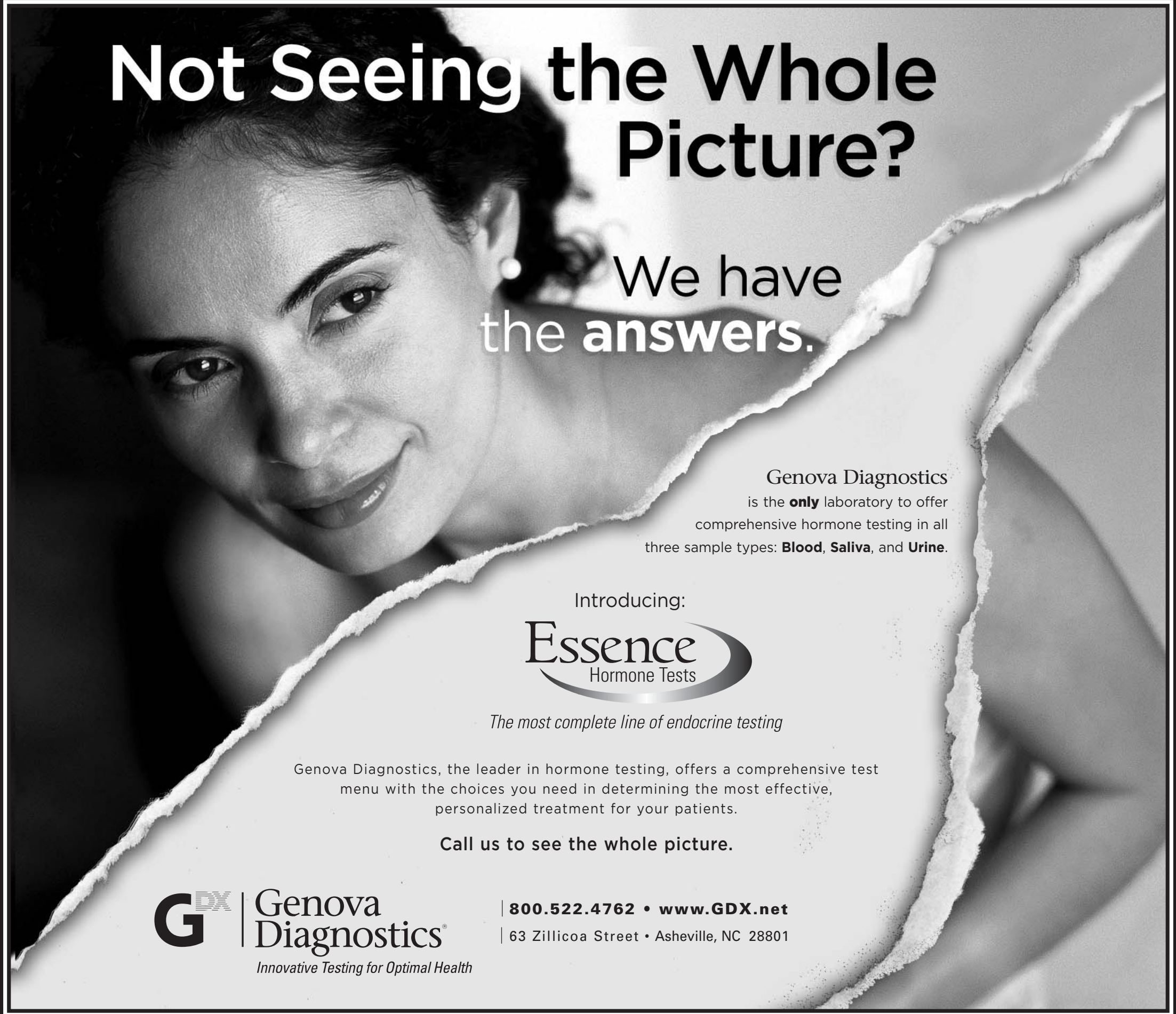
Three key tools to developing an intimate relationship with Christ are prayer, mind renewal, and honest self-talk. I hope to cover these in my next article on "Maintaining Marriage in the Midst of Chronic Illness." Until then, think about the things you've read and wrestle with them. Just don't grow discouraged. All personal spiritual growth takes time, patience, work, and even mistake-making, but it is so worth it all!

Special note:

May God bless you and yours this Christmas with the fullness of His love, the vast sea of His amazing grace, and the wisdom and strength to live fully in Him both now and in the coming year! Lovingly in Christ, Linnette & Family

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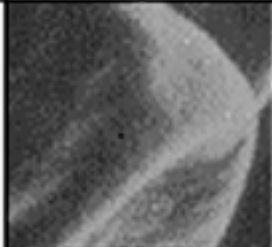
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“Insights”... continued from page 5

better treatment outcomes may be achieved. For example, in the book a couple of practitioners stated that combining antibiotics with herbs is a more effective treatment approach for ridding the body of infections than just using antibiotics alone.

Did you notice any common ground in your research that the practitioners all agreed upon?

Yes. There is no one-size-fits-all treatment approach that works for everyone. Killing the bugs isn't enough for recovery. You must support the body, too. Be wary of treatments that don't have any track record to support their long-term effectiveness.

I also noticed that the consensus seems to be that all Lyme disease testing is very poor. Would you agree with that?

Yes. Many people test negative to antibody, as well as antigen tests. This happens for a multitude of reasons. Diagnosis must be foremost clinical; that is, based on symptoms, and based on tests only secondarily. Tests can help to support a diagnosis, however, and for some people, is an effective indicator of infection. Sadly, though, the CDC requires positive results on these tests in order for doctors to positively diagnose their patients with Lyme disease, which means that up to 60% of people with Lyme disease may go undiagnosed, unless they are in the hands of a competent LLMD who understands that people with Lyme don't always test positive to the infection.

Some of the practitioners seem to have conflicting opinions about how to best treat tick- borne illnesses. Was there any common ground or startling difference you would like to discuss?

The common ground is that they all advocate a holistic approach to healing, which

involves supporting the body, eliminating toxins and cleaning up the diet, as well as other factors. The startling difference might be that some are strong proponents of antibiotics, while a few are actually against them because of the damaging effects that they have upon the body.

As you were interviewing these doctors, did you get the impression that co-infections such as babesia, bartonella, mycoplasma, HHV-6 etc, were much more common that previously thought?

Personally, I have always thought that co-infections are found in just about everybody with Lyme disease. So to me, it was not a surprise to learn of the other infections. What was interesting to me was learning about how sometimes, certain "random" infections such as parvovirus can be primary in the overall symptom picture.

Some of the medical professionals’ opinions about treatment approaches seem to contradict what another medical professional has said or believes. How would you advise a patient to comprehend this?

I think that most of the perspectives shared are valid, and the best treatment approach probably depends somewhat upon the individual and his or her particular case. When deciding upon which treatment to undergo, I would say to the Lyme sufferer, Pray, and go with your gut. I think there's a lot to be said about what our gut, god or intuition tells us. Research and talk to as many people as you can who have tried different approaches, compare that to your own experience with different treatments, and then just pick the next thing to try. Sometimes, it boils down to just picking a strategy and running with it to see what happens. We can't always know beforehand what will work for us.

If you could take the advice of all the medical professionals featured in your book and wrap it all up into one "Lyme Pope", would you think a cure could be found? Or do you believe that all the varying opinions on how best to treat Lyme are actually favorable?

I think any practitioner who has had success in treating this disease has something valuable to offer. Not all opinions (of all the Lyme doctors in the world) are probably valid. I would be wary of receiving treatment from any practitioner who doesn't have experience and knowledge in treating this disease. It's just too darned complicated. I don't think that a single cure could be formulated based on the plethora of information found in this book, because being cured depends as much upon an individual's biochemistry as the perfect protocol. And our biochemistry is far too complex, and the dysfunctions found in Lyme far too complicated and varied for us to be able to come up with one "Lyme Pope" or one protocol that will work for all. We haven't found that yet. But most people can achieve great strides in healing if they are armed with the kind of knowledge that is found in this book, because I believe that the best of the best of what's out there is represented here.

How close to you think we are as a community to finding a cure for Lyme and associated diseases?

I wish I knew! I know that remission is possible, but finding a cure implies more than being able to eradicate these tenacious, wily organisms. It implies being able to fix multiple systems in the body that have gone awry or been damaged due to chronic illness, and that is something I think we have yet to learn much more about. The more I learn, the more I realize that I don't really know anything about chronic illness involving

Lyme! But if Lyme disease could actually be recognized for the epidemic that it is, and if more research and funding were dedicated to finding a cure, then yes, I believe that we could find a cure, eventually. I think creating awareness about the disease is a good first step, though.

What are the top 5 things you learned in your research writing this book?

- 1) That in order to heal, patients must be able to focus on the disease, but not make it the focus of their lives. (Dr. Harris made this brilliant statement in the first chapter of the book)
- 2) There is no one-size-fits-all healing protocol that works for everyone
- 3) Lyme disease isn't always the primary cause of illness. Sometimes immune or endocrine dysfunction, or another infection are what caused the Lyme infections to become active and healing these things is important in order to get over the Lyme
- 4) No doctor has the monopoly on treating Lyme disease
- 5) Emotional and financial support is crucial for healing

Something that stood out in your book was the question you asked each professional. You asked them what they thought was the deciding factor in a patient's healing; Who are the patients who got well, and who are the patients that do not. Can you summarize your findings on this subject?

Yes. Those who heal have access to financial resources. They have emotional support. They have dealt with their emotional trauma. They are able to detoxify. They don't have a million co-infections, and if they do, they have an adequate protocol for dealing with those. They maintain a good diet. They exercise. They do what is required of them to get better, which means taking

their supplements, faithfully detoxing, exercising, going to bed on time, etc. They don't give up. They give their protocol a chance to work. They maintain a positive outlook. They focus on Lyme but focus on other things, too. Then again, there are sometimes no identifiable trends in healing!

Personally, I agree with all of the above. Intuitively, I feel that emotional support and attitude are foremost in healing. The people that I don't see improving are the ones who don't have financial or emotional support from loved ones. Also those who are bitter and angry, who are constantly negative and suspicious of every protocol and doctor out there, seem to have a harder time of it, from what I have witnessed. Yes, this disease makes people angry, but it's important to try to find some measure of hope and joy throughout the healing process, no matter how difficult it is.

As I researched this book, I kept thinking, "I wish I had had this information five years ago when I started out on my healing journey." If you purchase this book, please know that you have been given a jewel. The information contained therein is the cumulative result of many years of experience and research from thirteen professionals who have been in the trenches with this disease and know what it is about and how to effectively treat it. It represents a vast amount of knowledge that only the best of the best could provide. I am grateful to all those who participated, and believe it will be a valuable resource for those who choose to use it as a guide for their healing. May you all be blessed in your journey towards wellness!

For more information about Connie Strasheim, and to purchase her books please visit, <http://www.lymeinsights.com> and <http://www.lymebytes.blogspot.com> .

pha

“Communicating” ... cont’d from pg 4

disease right now, and I don't really want to sit around and discuss them, but I also want you to be aware of them. This brochure explains them in case you are interested."

Look for other ways to vent besides your spouse's shoulder

"I realized that I held in all of my frustrations of pain throughout the day and then when my husband walked through the door I verbally 'threw' them at him," shares Cheryl, who lives with chronic fatigue syndrome. "My actions set the tone for the rest of the evening. I may have felt better because I got it off of my chest, but he felt worse and it lasted the whole evening. I could tell he was starting to dread walking through the door."

Cheryl began to put aside the last two hours of her day to spend time writing in her journal, praying and doing something she enjoyed that

calmed her. "Writing in my journal gave me the chance to express my frustrations, and then prayer really began to minimize the negativity too. My husband quickly noticed a difference and it's made our relationship so much stronger."

Get involved in some new hobbies

How do you spend your time? A lot of time we may be talking about our illness because we don't have much more going on in our lives other than trips to the doctors or to the lab. Get involved in something else, even if it's just a couple hours a week. For example, volunteer to be on a prayer chain, start reading through the classic books you've always wanted to read, put together photo albums for your grandchildren. You will soon discover that even you aren't that interested in talking about your illness when you have much more exciting things

to share about.

Conclusion

So, the real question is how much is too much! There is no perfect answer, because it's different for each person and each marriage. Practice being objective. How often are you bringing up your illness? How do you benefit from talking about it more often than necessary? Do you need validation? Understanding? Actual physical help with tasks? It's not wrong to admit that maybe there are days we really do just want the attention from our spouse and this seems to be the only way to get it! How can we get some of these needs filled by God instead of our spouse? How is it negatively impacting your life, or those around you, by discussing it all the time?


Next, ask yourself "What is a more creative way that I can create intimacy with my spouse, other than just sharing my aches and pains? How

can we share some activities and time that can help us grow closer together?"

When you want to share about your illness, say a little prayer first: "Lord, I bring to you my pain and my emotional needs because of it. You know that I don't want to burden anyone else with something they can't fix, but I also want a friendship where I can just be myself and really share what I am experiencing. I really need a hug from you right now. I know how much my spouse cares about me; please give me the wisdom to know when to ask for help and comfort from him/her and when to come only to You and ask you to fulfill all of my emotional needs."

Don't miss other articles and overall support while living with chronic illness visit Rest Ministries and subscribe to fresh content at restministries.com and be entered for our monthly giveaway. Lisa Copen is the director of Rest Ministries, author

"Beyond Casseroles: 505 Ways to Encourage a Chronically Ill Friend" and founder behind National Invisible Chronic Illness Awareness Week.



Support while living with illness...

Read Lisa Copen’s words of encouragement at www.restministries.org/

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toll free: (866) 348-3257
fax: (301) 978-9854

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Ambler, PA 19002
Phone: 215-643-5434
Toll Free: 1-877-GEHRIG-1 (1-877-434-7441)
Fax: 215-643-9307
alsassoc@alsphiladelphia.org

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http://www.alsa-south-tx.org/
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toll free at (877) 257-4673

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s.melson@alsanorthtexas.org
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877-714-0088

The ALS Association Upstate New York Chapter
323 Route 5 West
P.O. Box 127
Elbridge, NY 13060
315-689-3380
Toll Free for PALS: 1-866-499-PALS
info@alsaupstateny.org

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www.timeforlyme.org
914-738-2358
Meetings: first Thursday of every month from 7-8:30 p.m. at the Greenwich Town Hall

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www.LDSG.org

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WI / IL / MNRegional areas
Contact PJ Langhoff
(920) 349-3855
www.Sewill.org
www.LymeLeague.com (Intl)

Western Wisconsin Lyme Action Group
Marina Andrews
715-857-5953

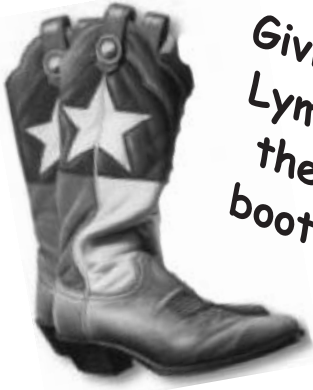


Military Lyme Disease Support

Military Lyme Support is an online source of information and emotional support. This site is for Military Members, Veterans, and their family members who suffer from Lyme and other vector-borne diseases. Members are stationed in the United States and abroad.

<http://health.groups.yahoo.com/group/MilitaryLyme/>

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Dallas - Fort Worth Lyme Support Group

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We meet in the left wing when facing the front of the building.

Contact our group leaders for more information:

Rick Houle, email: Pedler3710@aol.com
Home: 972.263.6158 or Cell: 214.957.7107

John Quinn
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Meeting the Challenges of Chronic Illnesses

The Landford Foundation, LifeLyme, Inc. & P.A.N.D.O.R.A., Inc

LIFELYME originally began as a Lyme support group in Tallahassee, Florida. Our original mission was to act as a educational resource for Lyme disease and related illnesses. By acting as an educational resource for both patients and advocates, LIFELYME hoped to effectively educate the public, physicians and other health care professionals about Lyme disease and its relationship to other illnesses bringing about better diagnosing and treatment of Lyme disease, co-infections and the many illnesses that shared similar symptoms.

The formation of THE LANFORD FOUNDATION - Lifelyme, Inc. a non-profit 501 (c)3 Charity was established in 2006. A partnership between LIFELYME, Inc. and PANDORA, Inc. followed soon after attending the IACFS Conference in early 2006 hosted by PANDORA, Inc. held in Fort Lauderdale, FL. The conference was hosted by PANDORA, Inc. a Chronic Fatigue/Myalgia Encephalopathy, Encephalitis, (CFS/ME) Fibromyalgia, Gulf War Syndrome (GWS), Multiple Chemical Sensitivity (MCS) non-profit located in Miami, FL. PANDORA's founder and president, Marla Silverman invited LIFELYME, Inc. to sponsor a speaker for the International Alliance for Chronic Fatigue Syndrome (IACFS) Conference. We chose Garth Nicolson, PhD. a well known Gulf War Syndrome researcher and author. Shortly after this conference PANDORA, Inc. recognized Sandi Lanford, Founder/President of THE LANFORD FOUNDATION - Lifelyme, Inc. by naming Sandi 'Advocate Extraordinaire'. The recognition was for her advocacy work and dedication to create awareness for Lyme Disease in Florida and beyond.

On January 19th, 2008 a conference entitled "Similarities and Paradoxes in Chronic Illnesses" was held in St. Petersburg, Florida. The event was sponsored by THE LANFORD FOUNDATION - Lifelyme, Inc., the University of South Florida, and Morton Mease Hospital. The conference was notable as it brought together for the first time speakers from the Lyme com-

munity and the Chronic Fatigue/Fibromyalgia community. The sharing and resulting merging of information on the connection between Lyme disease to Chronic Fatigue/Fibromyalgia etc. at the conference was a eye opener for many of the physicians and health care professionals attending the conference. The conference also resulted in bringing attention to the obvious fact that similarities and paradoxes exist in chronic illnesses and more and more research is connecting these illnesses to infections, both bacterial and viral. Shortly after the conference, PANDORA, Inc. added Lyme disease to the list of illnesses their organization included under the umbrella of NEIDS. More recently, the Fibromyalgia Clinics across this country have now also added Lyme disease to the diseases they diagnose and treat.

It was Marla Silverman who came up with the name - Neuroendocrine Immune Disorders (NEIDs). Under the umbrella of Neuroendocrine Immune Disorders are listed the following diseases: Chronic Fatigue Syndrome, Fibromyalgia,, Gulf War Syndrome, Multiple Chemical Sensitivities, and Persistent Lyme Disease. All of these illnesses share overlapping symptoms with Persistent Lyme Disease. The latest research is even connecting Autism and Alzheimer's to the infectious agent Borrelia burgdorferi (Bb). In addition to Bb the bacteria that causes Lyme disease, there are other pathogens called co-infections that often accompany Lyme disease. They are Babesia, Anaplasmosis, Mycoplasma, Rocky Mountain Spotted Fever, Bartonella, and Rickettsia.

Lyme disease is the fastest growing infectious disease known to be spread by ticks, mosquitoes, fleas and mites. The CDC (Centers for Disease Control and Prevention) records an average of 20,000 newly reported cases of infection each year. However, the CDC also says that only one in ten cases which meet its strict surveillance criteria are reported. Therefore, the annual number is at least 200,000 new infections occur each year in the US. Recent studies at the University of

New Haven, New Haven Connecticut by Eva Sapi , and at the University of North Florida, Jacksonville, Florida by Dr. Kerry Clark, PhD. Epidemiologist, show that ticks are infected with not only the Lyme bacteria Borrelia but are carrying Mycoplasma, Bartonella, Babesia, Anaplasmosis, Rocky Mountain Spotted Fever, and Rickettsia. Dr. Clark has even discovered a new strain of Bb in the state of Florida.

Recently the collaboration of THE LANFORD FOUNDATION - LIFELYME, Inc. and PANDORA, Inc. has resulted in a grass roots initiative to establish a Neuroendocrineimmune Disorder Research Center. The establishment of this center will be based on the philosophy that the similarities in symptoms of NEIDs are the human bodies response to similarities in the underlying pathophysiologies that cause these illnesses. Neurological and psychiatric problems and auto immune diseases are implicated in patients diagnosed with NEIDs. Research is connecting Autism, Alzheimer's, MS, Parkinson's Lupus and other auto immune diseases to bacteria/viral infections, and immune dysfunction. Immune deficiency in cancer patients is well documented, and tumor cells have developed a variety of cellular and molecular mechanisms to avoid anti-tumor immune responses. Accordingly, the cornerstone of the NEIDs research mission is that discoveries and advances made in any one of the NEIDs will be beneficial to other NEIDs and chronic illnesses in general. Lyme Borreliosis causes, mimics, is manifested as, is misdiagnosed as or is a contributing factor to over 300 medical conditions.

The Mission for the Neuroendocrine Immune Center

The NEI disorders (Neuroendocrine Immune) Center of America is the first Institute of its kind in the Northeast. It is based on the philosophy that the similarities in symptoms of NEI disorders are the human body's response to similarities in the underlying pathophysiologies that causes these disorders. Accordingly,



and the cornerstone of the NEI Center of America's mission is that discoveries and advances made in any one of the NEI disorders will be applicable and beneficial to other NEIDs. At its inception, the NEIDs Institute of America will include (in alphabetical order) the following disorders/illnesses: Chronic Fatigue Syndrome (CFS), Fibromyalgia (FM), Gulf War Syndrome or Illness (GWI), Lyme Disease including Relapsing and Persistent Lyme Disease (LD), and Multiple Chemical Sensitivity Syndrome (MCSS). Other illnesses may, and probably will, will be added as circumstances permit.

The goals of the NEI Center of America are:

1. To promote research of NEI disorders
2. To conduct research on NEI disorders
3. To provide patient care and treatment for NEI disorders
4. Serve as a repository of NEI disorder research data and publications
5. Serve as a site of exchange of NEI disorder research data and publications.
6. Serve as a repository of NEI disorder patient care data and publications

7. Serve as a site of exchange of NEI disorders patient care treatment protocols
8. Serve as a resource for NEI disorders researchers by providing information, publishing information and sponsoring scientific meetings.
9. Serve as an information resource for treating physicians by disseminating the latest advances in NEI disorders diagnostic and treatment protocols.
10. Provide educational and support programs to patients and caregivers using social networks available technology implemented through local and nationwide outreach programs.
11. Serve as a referral office and liaison to any of the available social services for the disabled and chronically ill in the areas of: medical access, prescription drugs, MEDICARE, MEDICAID, Social Security Disability and other disability systems, special transportation services, Food Stamps, physical and occupational therapy, public housing, hospice, food delivery, psychological assistance and home aid services and any other local, state and federal assistance programs in existence, which will enhance the quality of life of these individuals and will assist their families in their care.

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The Landford Foundation



LIFELYME, INC.

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Patient Alliance for
Neuroendocrine Immune Disorders
Organization for Research Advocacy

www.pandoranel.net/info/

“Choices” ...cont’d from pg 3

that's being built in Gilbert, Arizona. I'm very much an advocate for that project with Bill and Sherry Lund. I have been blessed by the people who have come into my world. It seems that there is a whole movement that's demanding this healthcare of the future. I notice that a lot of the doctors whom I have met, who have come into Envita, just can't readily change out their equipment. You see, it costs two to three million dollars for standard equipment, and they still have to make payments on it. Then there's the cost of training doctors, too.

I also think the younger generation is much wiser and open to the move toward natural healthcare, because they see that the other way just isn't working. Now, I'm not against traditional medicine. I just think that if you're sick, you want to make sure you have all the answers and options.

Tina: Which is why informed consent guidelines from the American Medical Association are so important. Every physician is supposed to inform their patients of all treatment options available to them, along with the risks and benefits, whether or not such treatments are covered by insurance.

Sandy: The problem is that most doctors are not educated in both worlds of medicine. So, if you can build a center that has MD's, DO's and ND's , now we're talking medicine. That's when we will have our bases covered. Why can't you have the top cardiologist with the top naturopathic doctor working together for the good of the patient? Every country and every continent has them. Why are we shunning one field of medicine? One of the reasons is that traditional doctors don't know enough about that field. It might take them another six years to get a degree to find out about that side of it. It's silly, but that's the reality.

Our Fullness of Life Foundation is educating the public. One of our greatest events that transpired was when the Foundation premiered the Under Our Skin video here at our office in Scottsdale, Arizona. We had about 350 people attend that are now aware of Lyme disease. If the public only knew about how it affects us. Even though Lyme

disease is not a good thing to have, you can still have a great life, and knowing what you have is ninety percent of the battle in living with it. Knowing that there's a center right here in our own backyard that has become one of the top treatment centers for Lyme disease is unbelievable. And it happens to be Envita, the place that saved my life from cancer.

Tina: What about the spiritual side of your experience and how it relates to your starting the Foundation?

Sandy: You know, I have surrounded myself with positive people and positive attitude, especially with my husband, because he was my guardian angel throughout this whole ordeal. I never would have looked at the integrative side had he not done the research. I was trusting what the traditional docs were saying. We had so many of our friends and family members that were saying, "Just do what the doctors at the Mayo are telling you! Are you crazy? You have advanced cancer!"

That was the hardest decision we ever had to make, because we were in that zone where we had to make a decision. Then we were in that zone again four months later in deciding whether to continue the chemo or just go with the treatments that were offered at Envita. What do you do in that situation? I didn't know what the outcomes would be. All I knew was that my outcome at that time wasn't good. Where was my guarantee that I was going to make it? There wasn't any.

So, what it really depended on was faith. I knew how bad the chemo was for my body. I knew how it made me feel, and I didn't like it. I hated it. I hated the smell and I hated the taste. And I'm telling you, prayer came into the mix of that equation as to what to do. Yet, there was a calming sense in thinking, "What do I have to lose?" I had nothing to lose by going to Envita. I thought that if that ends up not being the right choice or the best choice, at least I'll have lived a quality of life till the end versus a life of misery.

The power of prayer and knowing that I had faith and belief in God made me believe that this was the direction that I was supposed to take. I just had that sense of

knowing, and there was something about the founder of Envita, Dino Prato, that gave me a calming sense. I believe that he has been anointed to be the one that breaks out and goes against the norm. He is very passionate, because he believes in healing and curing all disease. It's his life's mission. How could I not follow that? How could I not, through the grace of God, listen?

So, prayer is ninety percent of the mental. It helps you think in the right direction, so you don't worry about the consequences, because you have that faith and knowing that you have nothing to lose. It's something that comes from within, and you just have a calming sense to just see it through to the end, however long it takes.

Tina: That's really beautiful, Sandy. Really beautiful.

Sandy: Well, thank you. Tina: And I'm so glad you were able to listen to that, because not everyone has the strength to follow the prompting to move in a certain direction.

Sandy: That's the hardest thing. I say this, because my husband and I have been very successful with our business. One of the most rewarding parts of our business is seeing families win with their finances. We can take someone who is in debt, get them out of debt, see that their kids go to college and see that they are able to retire comfortably. We can put a family in business for themselves and watch their business grow until they're making a six-figure income. This changes their lives in a positive way. They're just ordinary people like me. I was a waitress before, but now I'm achieving much greater success in life. It's really about how you feel about you that determines your life. If you feel good about you and what you do with your life, life is great, and I think people are always searching for that.

But you know, to meet Dino Prato when he needed me at the most important time in his life and his career, when he was starting Envita, was really special. You see, I was his first patient during the first week he was open, and I also needed him at the most important moment in my life. So, we have this very special bond. I'm also connected to a 125,000

person sales force that knows who Mark and I are, because we are motivational speakers. We speak around the country on how to become successful, how to win in business and how to win in life.

As soon as I started telling my story and speaking about Envita, people wanted to know more about it. I can't tell you how many of our company's leaders have been through Envita to be treated and how many friends and family members they know who have also been to Envita. By spreading the word like that, Envita has grown tremendously.

As I mentioned, I'm from Canada, and we didn't know anyone in this country when we moved here twelve years ago, but God found these two strangers in this city. Who would have thought that I would be an advocate for Envita by starting the Fullness of Life Foundation for the kids, so they can be treated at Envita? I'm also working with wonderful people who are building hospitals to put all of this in the forefront. It's really great!

Tina: Thank you for all that you're doing, Sandy.

Sandy: Well, you, too. We need more advocates. Our Fullness of Life Foundation is holding a big benefit concert in LA on October 17th of this year. Mark and I also sing and play in a band, along with some other people in our company. I sing and Mark plays guitar. We played for our company's corporate event in front of 60,000 people at the Georgia Dome.

We do benefit concerts and a Celebration of Life concert for the Fullness Of Life Foundation. Our band is called One Night Stand, because we were only supposed to play one night at a charity event in Las Vegas ten years ago. Even though we had never played before, we played so well together that now we're doing the Foundation's big event. There should be up to 10,000 people at the Convention Center in LA. So, we're spreading the word. We're doing a Primerica fundraiser that day, and I've got all the top leadership and motivational speakers scheduled. The topics are health and winning in life in all areas, with God first, family second and business third.

We hosted the Believe Concert last year with Chevy

Chase, and it was fantastic! To have Chevy Chase and wonderful musicians grace the stage was just amazing. Chevy Chase believes in what we're doing. We were also blessed to have Dennis D'Amico, a great producer who produces all of the benefit concerts for Paul McCartney and the Linda McCartney Foundation, help us with that event.

I had never met the man before, but one of our board members who is a musician, suggested we meet Dennis. So, Mark and I flew to New York and had lunch with him, and he serves as an advisor on our board. He produced the concert and brought in all of these artists for next to nothing, donating their time. And Chevy Chase donated his \$50,000 to the Foundation. And he's going to be back next year when we do it again in 2010.

So, we're serious about being around for a long time, and I believe in a grassroots effort. We are a voice for the people. I really believe that we have a cause that's like no one else's. There is no other foundation that I know of that wants to change the world in such a way on how people think about their healthcare options. We need to pave the way for these doctors who want to heal and cure the sick, so they can do it with every means possible. I've dedicated my life to this mission!

Sandy Yozipovic is a Co-Founder and serves as President of the Fullness of Life Foundation at www.fullness-foundation.org.

Tina J. Garcia is Founder and President of Lyme Education Awareness Program (L.E.A.P. Arizona) at www.lea-parizona.com.



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FEATURE

Clarifying the Goals of the NeuroEndocrineImmune (NEI) Center™ and the Inclusion of Lyme Disease

The NeuroEndocrine Immune (NEI) Center™ (of New Jersey) is dedicated to research, patient care, education, and community social services for patients with a group of illnesses that affect the nervous, endocrine, and immune systems. The body of current scientific research confirms that these illnesses share commonality and overlap of symptoms, which suggest shared pathophysiological mechanisms that produce chronic illness in these patients. For example, in recent and in-press publications, researchers have reported that approximately 30% of previously diagnosed chronic fatigue syndrome (CFS) patients test positive for Lyme disease (LD). The Centers for Disease Control and Prevention (CDC- William Reeves) at the May 27-28, 2009, CFS Advisory Committee meeting stated that Lyme disease is known to be a potential trigger for CFS. Therefore, if some patients with CFS are treated for LD, their quality of life and health will improve considerably.

The NEI Center™ is dedicated to increasing knowledge, improving patient care, developing new therapies, and serving as a repository and dispenser of scientific information regarding these illnesses. It is not the intent or role of center personnel to classify or reclassify or to name or rename any of these illnesses.

The NEI Center™ is committed to the development of a robust, healthcare community within the State of New Jersey. We believe that any interested party who wishes to mount a research, patient care, educational, or social services program within the state, and who is willing to abide by the laws and safeguards provided

by the state and the federal governments, has the right to engage in such activity without the infringement or opposition of another organization.

Representatives of the NEI Center™ believe it is unfortunate and misguided for an alleged patient advocacy group to oppose efforts to enhance research, patient care, education, and community social services for an illness that the patient advocate group claims to represent. The motivation of such a group is suspect.

With regard to recently written materials already being circulated on the Internet and the comments made by a patient advocate group that has gone on record as opposing the inclusion of Lyme disease in the disorders to be studied at the NeuroEndocrineImmune (NEI) Center™, we respond:

* The NEI Center™ (also referred here as the Center) will serve as a repository for all data generated by its investigators and by those researchers who wish to submit their data to the Center.

* The NEI Center™ has not, and will not, address the issue of the classification of any of the illnesses being studied within the center or elsewhere. It is the position of the NEI Center™ that the classification of illnesses (be they diseases or syndromes) is the responsibility of the World Health Organization, which catalogues and classifies the recognized illnesses of the world. (ICD10/ICD9). It would obviously be presumptive of the NEI Center™ to usurp or attempt to alter the work of the World Health Organization.

* The NEI Center™, as does

Western medicine, recognizes the distinction between symptomatic treatment and curative treatment of illness. Although curative treatment is the ideal goal of health care, curative treatment is not available for all illnesses. When such treatment is not available, or even if it is available, symptomatic treatment is standard medical procedure. Thus, for a patient with pneumonia, antibiotic treatment may be curative, but such treatment does not preclude the physician from dispensing medication that will ease the patient's cough or reduce his or her fever.

* The NEI Center™ believes that many neuroendocrineimmune disorders have complex etiologies. Many researchers and physicians feel that long-term, chronic infection will deplete and invoke changes in the immune system. Multiple co-infections are now being found in many chronically infected patients. To preclude the investigation of co-infections in patients with Lyme disease based on the fear that such findings would suggest immune system abnormalities as stated by this patient advocate group in Lyme disease patients (see attachment), does a significant disservice to Lyme disease patients and prevents the freedom of scientific inquiry that is the basis of success in biomedical research and the development of new therapeutic agents and procedures.

* The NEI Center™ maintains that Lyme disease, as well as the other neuroendocrineimmune disorders (NEIDs) that the center embraces, is not currently classified as autoimmune disorders. Unless future scientific research demonstrates otherwise, Lyme disease will

always remain in its current class of illnesses and thus not be included or classified as an autoimmune disorder. However, the current and/or future classifications of Lyme disease do not preclude an autoimmune component from being present in this disease. The NEI Center™ and the biomedical research community should be permitted the right to investigate the possible presence of an autoimmune component in chronic or persistent Lyme disease (PLD) or the induction of autoimmune defects in persons exhibiting chronic or PLD.

* The NEI Center™ believes that the inclusion of Lyme disease in the center's mission will accelerate research and the development of therapeutics for patients with LD as well as speed up research and development of therapeutics for illnesses with shared and overlapping symptoms.

* The concept and mission of the NEI Center™ is a scientific, medical, pharmaceutical, and patient-driven grassroots initiative that aim for quality of life solutions for a large population of Americans that for far too long have been forgotten and underserved within our current medical system. The overall concept of the NEI Center's mission is already fully supported by administrators within the CDC, the National Institutes of Health (NIH), and the Vermont Department of Health.

* The NEI Center™, as proposed, complies with the new biomedical research model being promoted by the NIH and will stand as an example of the implementation of its Roadmap Initiative.

* The enhanced and accelerat-

ed study of neuroendocrineimmune illnesses, including Lyme disease, at the NEI Center™ can only improve the knowledge of and therapeutics for all these illnesses. There are no negative aspects to the inclusion of any related illness in the mission of the NEI Center.

We appreciate the opportunity to respond to you on this important issue and we are at your disposal for any questions you may have on this crucial piece of proposed legislation. It is with great gratitude that we say that passage of this historical piece of legislation by the New Jersey Senate, complementing the legislation already passed in the Assembly, will not only be a moral and significant victory for the citizens of the great State of New Jersey, but it will be one that will impact millions of Americans. Passage of this resolution will happen because of your vision, compassion, and caring for the citizens you so proudly represent. You will be a champion for not only our community of suffering, but for every American affected with these significant healthcare challenges. You will be making a difference in the lives of the many individuals whose voices are being silenced by the devastating consequences of these illnesses.

[This letter was addressed to New Jersey Senator “Kip” Bateman and the NJ Senate on behalf of NEI when a National Lyme Advocacy group opposed the inclusion of Lyme in the NEI spectrum. The PHA whole-heartedly supports the inclusion of Lyme disease in the NEI Spectrum.]

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(1) Journal of the American Nutraceutical Association 2003; 6(1): 23-26.

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