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The Power of Truth Spoken by Joseph G. Jemsek, M.D. ~Part 1

by Tina J. Garcia

Cognitive dysfunction. Excruciating pain. Crushing fatigue. These are the daily aches and pains of suffering Lyme disease patients. Medical board prosecutions and costly lawsuits. These are the daily aches and pains of Lyme medical practitioners who honor the medical profession by serving those infected with Borrelia and other vector-borne disease. These are the soldiers who have been forcefully thrust into this saga called the Lyme Wars.

The Lyme disease community is an army with limited resources, limited strength and the limited ability to have our voices heard amid the roar of the mighty Giant. We are like young David from days of old-facing formidable foes which show no mercy or compassion for our plight, but only disdain and contempt for our resilient survival.

We are painfully experiencing the dominance of government agencies, the wealthy insurance industry and influen-

tial medical societies, all of which wield power capable of crushing anything and anyone who stands in the path of their objectives.

In defending our position, the Lyme community must aim carefully so as not to miss our mark. We are armed only with a slingshot and the Stone of Truth. But don't underestimate our weapon, for Truth hits hard and squarely between the eyes. It paralyzes the gut. It stings sharply and jolts the senses.

Many a Lyme soldier has run in fear from the Giant named Monopoly. But a few brave warriors have stood their ground, taken aim and slung the Stone of Truth. One of those valiant Lyme warriors is Dr. Joseph G. Jemsek.

Dr. Jemsek began treating Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) patients in early 1983, when he is believed to have diagnosed the first case in North Carolina. By 2006, Dr. Jemsek had cared for more than two thousand HIV/AIDS patients.



Dr. Joseph G. Jemsek, M.D.

In 1998, showing gratitude for service to the HIV/AIDS community, North Carolina Governor James Hunt presented Dr. Jemsek with the Governor's Award, a Certificate of Appreciation. In 2003, Dr.

Jemsek formed a non-profit that provided case management and education financial assistance to HIV/AIDS patients to help them with the cost of their treatment. Governor David "Jemsek"...cont'd pg 6

From Roadblocks To Recovery The 3rd annual conference on Lyme Disease, Autism and Chronic Infections

by Tami Duncan

This June, physicians, patients and parents from all over the world will gather in Scottsdale, Arizona to learn emerging therapies and treatments to heal their patients and families. This year marks the 3rd annual conference where the LIA Foundation (Lyme Induced Autism Foundation) will bring the top physicians together for this educational event.

Mark your calendars for June 25 - 28, 2009. The physicians' training day is on Thursday, June 25th and Friday thru Sunday will then open up to parents and patients for our general session. From Roadblocks to Recovery will be held at the Radisson Fort McDowell Resort and Casino located in the Scottsdale area of Arizona. Rooms are only \$109 per night and registration is affordably priced.

The LIA Foundation was formed in late 2006 with the mission of bringing doctors from the Lyme disease and

Autism communities together to share information on treating children. With four conferences under our belt, a think tank, support groups and online education, this goal is still strong. The conferences we now produce have evolved into providing the leading, emerging information for treating these diseases to the public. The 2008 conference was touted, "10 years ahead of its time". Doctors also expressed the need for this conference so that they can network and learn from each other what is working and what is not working for these ill patients.

For the 2009 conference LIA Foundation has teamed up with a local Arizona organization called CHOICE. CHOICE is the voice of Arizona's patients and doctors, an organization born in Arizona in 2007 to ensure that a wide array of choices is available in medical care.

From Roadblocks to Recovery includes some of the most sought-after physicians and speakers on these topics.

Look at our esteemed speaker list below...

Anju Usman, MD
Implications of Potential Biofilm Production in Autism Spectrum Disorder Patients and with Chronic Infections.

Ann Corson, MD
Pediatric Tick Borne Disease Presentation and Management - Physicians Training

David Berg, MD
Blood Flow in Lyme, Autism Spectrum Disorder and Other Conditions

Donna Jackson Nakazawa
The Autoimmune Epidemic: What You Need to Know

Elizabeth Hesse Sheehan, DC
Integrative Approaches to Autism and Lyme Utilizing Energetic Testing, LED, Quantum Neurology and Plant Stem Cells

Garry Gordon, MD, DO, MD(H)
F.I.G.H.T. Program for Your

Health : F=food sensitivities, I=Infections, G=Genetics, H=Heavy Metals and Hormones, T=toxins

George Gonzalez, DC, QN
Achieving Immediate Neurological Change With Quantum Neurology Rehabilitation

Heidi Noyer, MS, LPC, LCDC
Shares how she "Tackled Roadblocks To Recover" her Children from Autism and Lyme disease

Jamie Juarez, MS, LMFT
Healing the Family and Marital Unit - Coping with Autism

Jeff Wulfman, MD
The Parasite Paradigm: The Complex Web of Lyme Borreliosis and Chronic Infections

Jeffrey Smith
The Health Dangers of Genetically Modified Foods You're Eating
"Roadblocks" ...cont'd pg 14

Download Dr. Burrascano's Lyme Protocol FREE at:
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When a Complement is not a Compliment:

The Role of C3a and C4a Complement Proteins in Chronic Lyme Disease



by Ginger Savely, DNP

Readers of this publication are well aware of the controversies surrounding the diagnosis and treatment of Lyme disease. When the disease is missed in its early, easier-to-treat stage, it goes on to become a complex, multi-system disease that eludes diagnosis, mimics many other diseases, and requires aggressive, long-term treatment. Because the testing methods for Lyme and other tick-borne diseases are insensitive, many true cases of infection go undetected. Even when the diseases are detected, the unreliability of the testing makes it difficult to track treatment progress and test for cure.

Work by Drs Stricker and Winger identified CD57 positive natural killer cells as immune markers that tend to be low in chronic Lyme patients and increase with clinical improvement. An earlier article that I wrote for this publication explained how the measurement of CD57+NK cells in the blood has helped Lyme-literate health care providers in making the diagnosis of Lyme disease when tests are inconclusive. It has also provided a convenient marker to assist in following treatment progress and determining treatment end.

Although the CD57 marker has been a helpful tool, it has not been without its problems. We don't yet understand what confounding variables can skew the results. Some very sick patients start out with normal or above-normal CD57 levels. Other patients' levels stay low and never increase with treatment, despite the fact that they are symptom-free and otherwise seem completely cured. There may be large day to day variation in the CD57 level as I

observed in a study looking at twice daily blood draws over 3 days for both Lyme patients and well patients. The level can increase or decrease as much as 50% within the same day. So the CD57 level can be a useful marker for some patients but it is not always reliable and consistent.

Enter C3a and C4a, the new kids on the block in the world of Lyme diagnosis and treatment. The "C" in C3a and C4a stands for complement. Complement proteins work with antibodies to destroy pathogens. They activate immunity through control of inflammation, phagocytosis (ingestion of pathogens by white blood cells) and cell death by lysis (breaking of the cell membrane). There are about 30 of these complement proteins that

who contract Lyme disease do not develop the diagnostic "bull's eye rash", and Lyme tests are frequently negative shortly following a tick bite when prompt diagnosis is crucial for effective treatment. Shoemaker et al. suggested that elevated C3a and C4a levels can serve as early markers in the diagnosis of acute Lyme disease.

Because CD57+ NK cell levels are not always reliable markers for chronic Lyme, there is an ongoing search for new biomarkers to aid in the diagnosis of chronic, disseminated Lyme disease and to follow treatment progress. Dr. Stricker and I recently published a study in the *Scandinavian Journal of Immunology* comparing C3a and C4a levels of chronic Lyme patients to those of healthy con-

Lyme patients.

In our study, only the systemic lupus patients had elevated levels of C3a. Other published studies have associated elevated C3a with autoimmunity as well. Therefore, the C3a may prove to be a useful marker in differentiating ongoing symptoms due to an autoimmune process versus an ongoing infectious process.

For purposes of our C3a/C4a study, Dr. Stricker divided the chronic Lyme patients into two groups: 1) those with primarily musculoskeletal symptoms (MSK) and 2) those with neurological symptoms severe enough to warrant treatment with intravenous antibiotics.

Interestingly, C4a levels were significantly elevated in the MSK group, but only slightly (and not statistically significantly) elevated in the neurologic group. C4a levels were also elevated in the AIDS and systemic lupus groups, but not in the healthy controls. In Lyme patients with elevated C4a, the levels decreased in those who responded well to antibiotic treatment. Those patients who did not improve on antibiotics (more often than not, the severe neurological group) had no statistically significant reduction in their C4a levels.

Keep in mind that almost all chronic Lyme patients have some degree of neurological involvement. The neurological Lyme patients in the study who did not have elevated levels of C4a were those with severe cognitive dysfunction as evidenced by abnormal blood flow to areas of the brain noted on their SPECT brain scans. Examples of these patients are those who presented with symptoms mimicking Alzheimer's disease, multiple sclerosis, Parkinson's disease, or Autism Spectrum Disorder. Amyotrophic lateral sclerosis (ALS) patients do not have cognitive deficits and, in fact, Lyme patients with this type of severe neurological presentation did have elevated C4a levels.

The normal range for the C4a is zero to 2830. In my chronically ill Lyme patients I have seen C4a levels as high as about 26,000. However, most of my patients start with a pre-treatment level between 6000

C3a & C4a...cont'd pg 14

If you would like your health care provider to order your C3a and C4a levels, it is extremely important that the tests be performed only at the National Jewish Medical and Research Center Laboratory in Denver. LabCorp has a contract with National Jewish and therefore your health care provider can order LabCorp tests # 840702 (C3a) and # 857334 (C4a). LabCorp uses two different send-out labs for the test and it is important to indicate that samples should be routed to National Jewish for most accurate results.

circulate in the bloodstream making up complement "cascades", so called because activation of one protein initiates activation of the next, etc.

Dr. Ritchie Shoemaker and his colleagues published a study in 2008 reporting elevated C3a and C4a levels in acute Lyme disease. Many patients

controls, AIDS patients and patients with systemic lupus. The C3a complement protein level was normal in the AIDS patients, the healthy patients and the chronic Lyme patients. So, although C3a was shown to be elevated in a cohort of early, acute Lyme disease patients, it appears to be normal in chronic

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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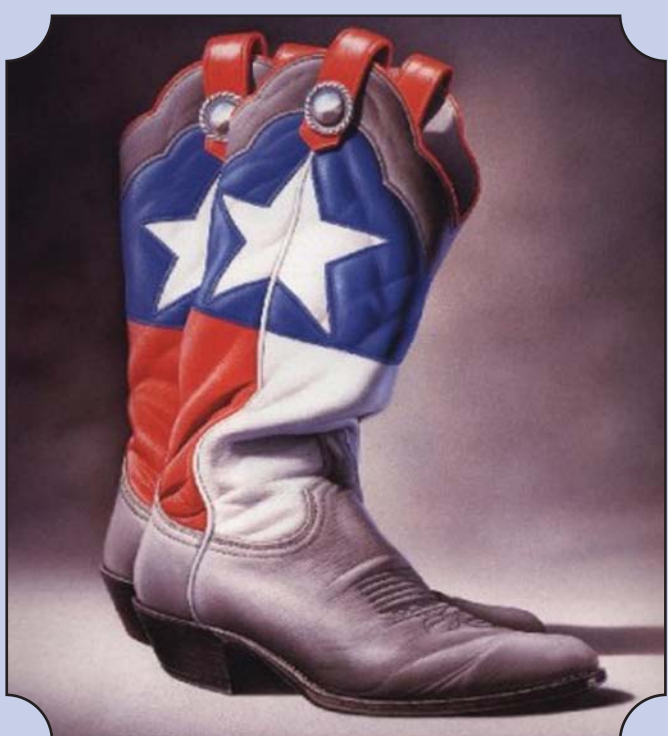
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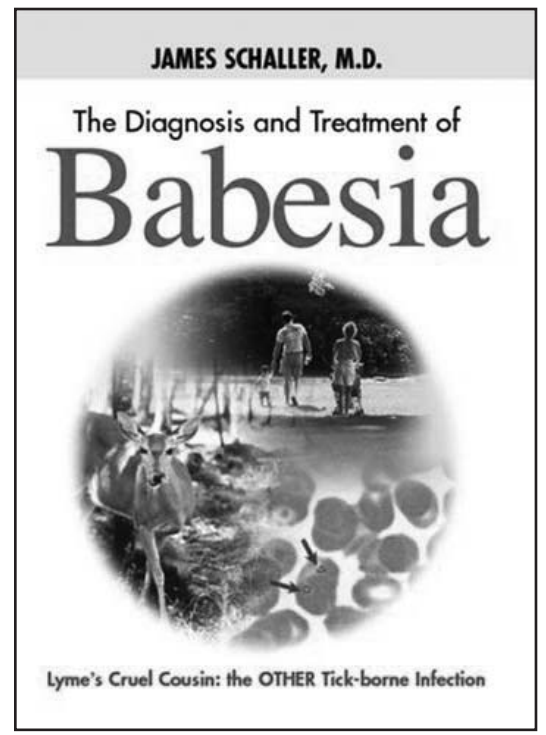
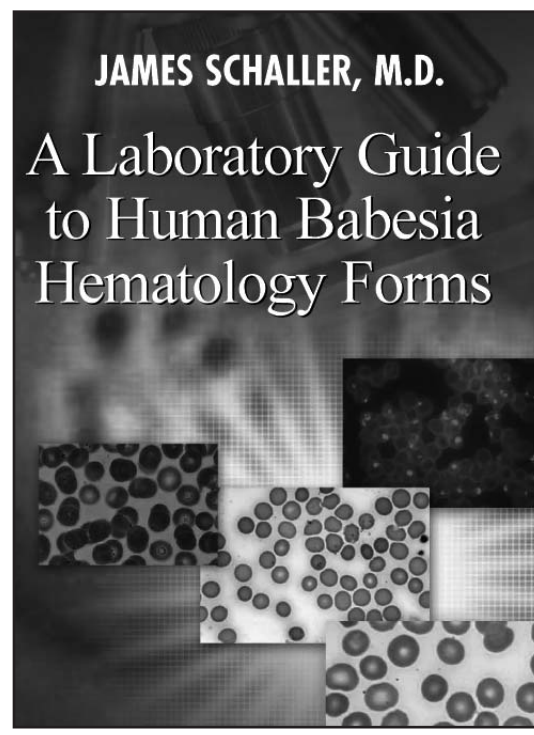
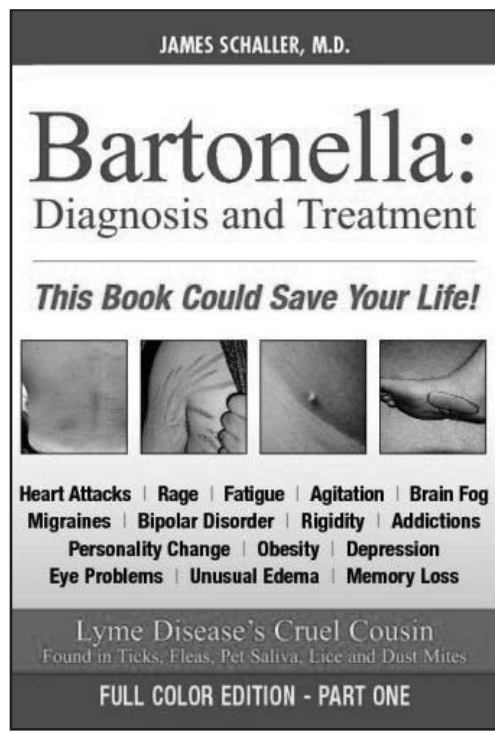
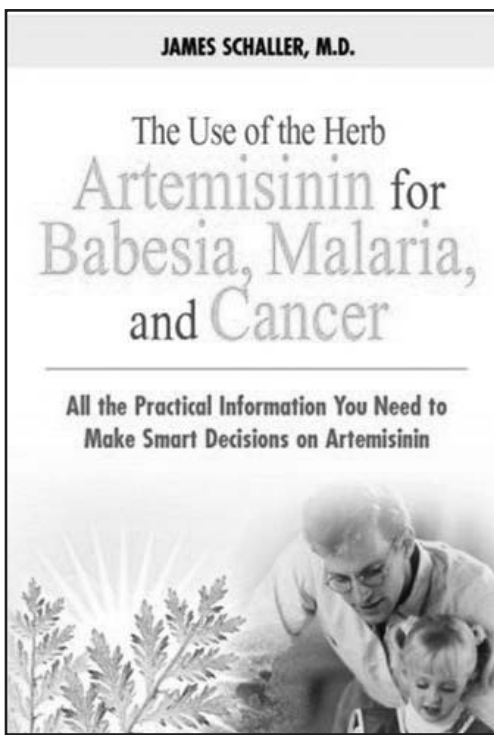


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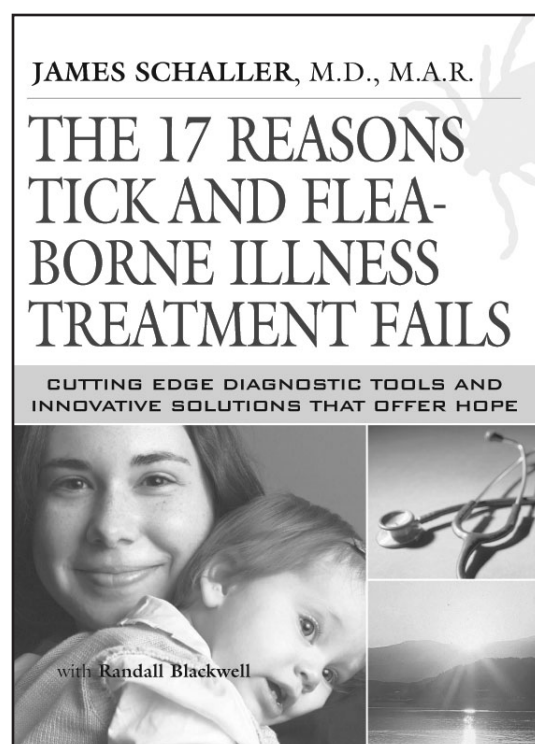
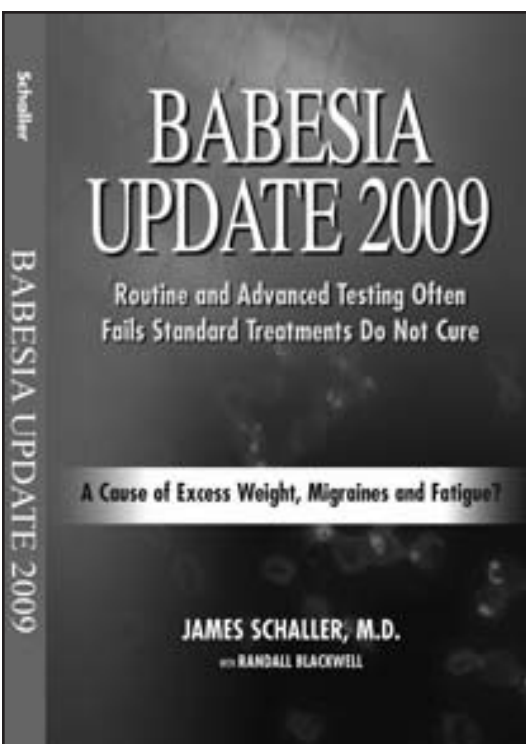
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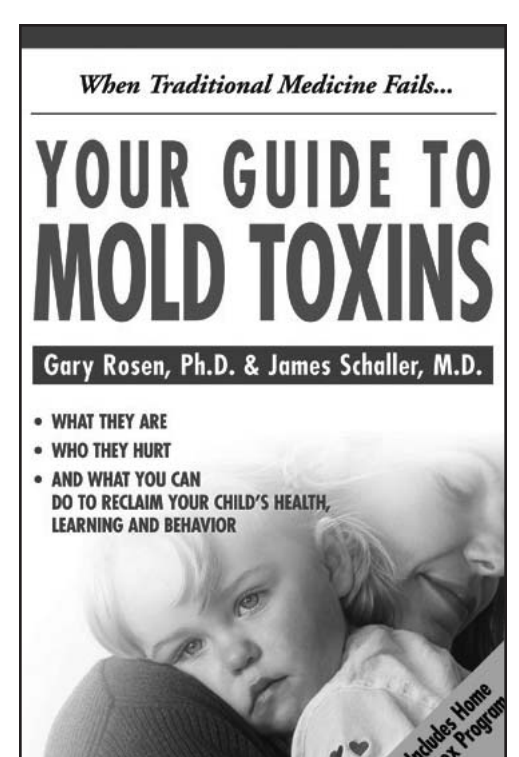
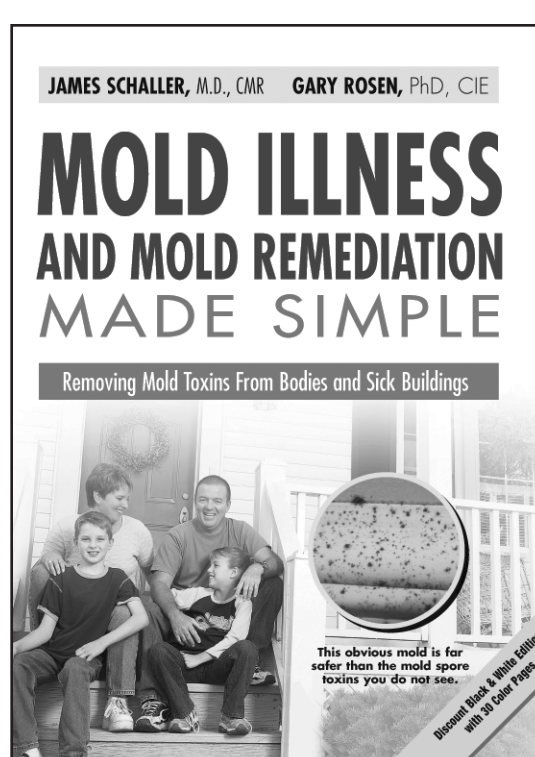
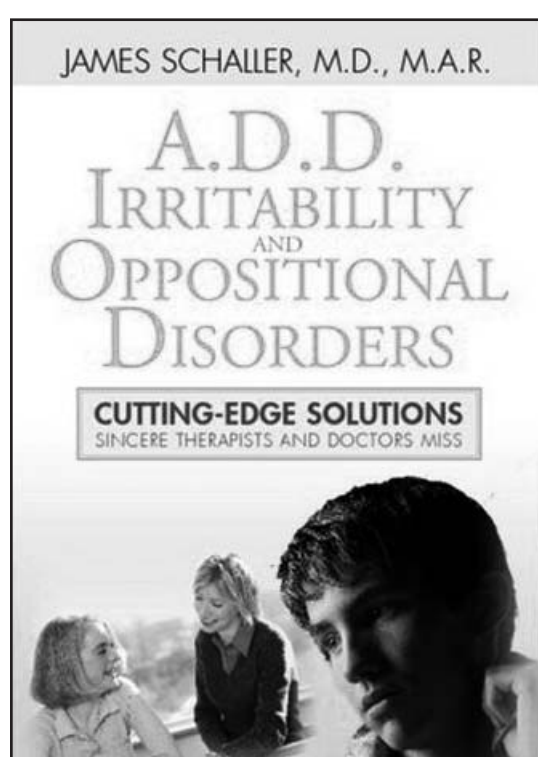
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Can I Still Bear Fruit?



by Linnette R. Mullin

If the "fruitful" Christian life is defined by acts of service, where does that leave people who are chronically sick or disabled?

Frustration coursed through me as I tightened my grip on the steering wheel. I wanted to shut the radio off. The pastor was preaching from John 15, one of my favorite passages. But today, even the words of Jesus felt like too much to bear: "He cuts off every branch in me that bears no fruit, while every branch that does bear fruit he prunes so that it will be even more fruitful. I chose you and appointed

you to go and bear fruit-fruit that will last" (vv.2, 15 NIV).

My jaws clenched as I listened to the preacher explain that the fruit Jesus was talking about is the visible outcome of our works done in His service. How am I supposed to "bear fruit" when I can hardly take care of myself?

I have Chronic Lyme disease that causes extreme pain, fatigue, and many other symptoms. I struggle to cope with the daily demands of being a wife and a mother of four children who inherited my disease. Discouragement often consumes me because of my inability to live what I've always considered the productive Christian life.

I've often heard it taught that being a faithful follower of Christ meant being active in the church and in ministry to others. But I couldn't even commit to consistent weekly church attendance-much less to teaching Sunday school, singing in the choir, or opening my home to visitors. Just taking care of myself and my family took all my energy. The idea of "Christian service" felt completely overwhelming when I was just trying to survive.

Our actions are hugely important. As James 2:17

states, faith without works is dead. But is our spirituality measured by how many "Christian service" hours we accumulate? If so, where does that leave us who are chronically sick or disabled?

Let's think about it this way. A missionary-minded believer plants the seed of the gospel at every opportunity. Does she control how many people actually come to Christ? Christian parents constantly give of themselves to instill in their children a love for God. Is there any guarantee that their sons and daughters will serve Him? What about the youth pastor who acts as a brother, friend, and counselor to every teenager in his youth group? Does he determine the life path each one will take?

Of course not. Though we influence people by what we do and how we live, the ultimate outcome is between each individual and God - salvation being the work of His Spirit.

So, what did Jesus mean when he said, "Bear much fruit and so prove to be My disciples" (John 15:8)?

As the radio minister spoke of cutting off unfruitful ministries to make room for more productive ones, I begged

God to give me insight.

Immediately, I was reminded that Jesus said many people who perform wonderful and even miraculous works in His name will actually be turned away at heaven's gate because they don't really know Him (Matthew 7:21-23).

It was then God's answer struck me: Your fruit is of the Spirit.

Of course! Why hadn't I realized this before? The fruit of the Spirit is love, joy, peace, patience, kindness, goodness, faithfulness, gentleness, and self-control (Galatians 5:22-23).

But, how are these fruits produced? I found the answer within reach of the command, "Abide in Me, and I in you. As the branch cannot bear fruit of itself, unless it abides in the vine, so neither can you unless you abide in Me. I am the vine, you are the branches; he who abides in Me and I in him, he bears much fruit; for apart from Me you can do nothing" (John 15:4-5).

The source of our fruitfulness is our union with Christ. The more we live in Him-developing an intimate relationship-the more love, joy, peace, patience, kindness, goodness, faithfulness, gentleness, and self-control become reality in

us.

While we're called to do good works, they don't in themselves produce fruit. Rather, the fruit of the Spirit initiates our service, whether that involves serving on the mission field or taking the time to offer a kind word or a prayer for your child. It's more about how we do things than what we do.

I'm reminded of the *song based on John 13:35 that says, "They will know we are Christians by our love." This is the most important and basic fruit that should mark our lives: love - both for God and for others. Everything else flows from this.

Living a vital Christian life isn't about what we can or cannot do. It's about returning to our first love and "abiding" in Him. Whether we're out tirelessly serving the sick and needy or confined to bed ourselves, Jesus Himself has made it possible for us to live fully for Him.

*Scholtes, P. "They'll Know We Are Christians By Our Love," 1966

**This article was reprinted with permission & previously published in Charles Stanley's *In Touch Magazine*. *pha*

A Checklist for Starting a Support Group



by Lisa Copen

Beginning a support group shouldn't be a task you take on that overwhelms you. But if you aren't prepared, many obstacles can come up that can threaten the environment of your group. Follow along with this simple checklist so you will save a great deal of time and heartache in the future, and instead be able to enjoy your group.

[1] Group's purpose. Spend a few minutes writing a 1-2 sentence mission statement to help you clarify your goals.

[2] Group description. What exactly is the problem people are dealing with and how do you intend to try to help fix it through your support group?

[3] Personal motives. Take some time to ask yourself "Why do I feel I am the one to lead this group?" Make sure you really want to do it, and are not just saying yes to someone because you'll feel guilty saying no, or because you are seeking personal glory.

[4] Approval. Does your group need to receive formal approval from a higher source? If you are under an organization or company, for example, have you received their approval?

[5] Group's life expectancy. What do you see as the life of your group? Do you hope it will meet indefinitely until the need fades away, growing and changing as members define it? Or would you rather ask that people commit to the group for a certain amount of time, like four months, and then recommit if they still want to attend?

[6] Frequency of meetings. How often do you want to meet? Weekly, bi-monthly, monthly? Consider the schedules of the participants. Would you rather have seventy percent show up once per month or thirty percent twice per month?

[7] Group outline. How

will the time be filled? Is it to network, go through a study, have speakers from the community? What would you prefer? What will your members desire?

[8] Location. Where will your group meet? Will it

will there be a fee for parking?

[9] Attendance. Is anyone welcome at any time or it is closed? For example, are new members welcome for a certain period of time? Is membership required in another group to attend? For example, if it's a group that a church hosts, are you expected to attend the church?

[10] Activities. Will the group be having parties, picnics, or time with family members? About how frequently?

[11] Guests. Can family members or friends come to the meetings? If the answer is yes, is this okay with other members? Is it all right on occasion only, or on a regular basis?

[12] Projects. Do people wish to be involved in outside activities for the well-being of others? For example, does your group want to deliver gift baskets to people who are homebound or provide a Christmas party for children in a low-income neighborhood?

[13] Policies. Have you written up some basic guidelines for the group? They should contain: a privacy statement, the expectation that everyone will be treated with respect, how to handle conflicts, that the group is not for

commercial use, etc. If you are an illness support group, you may want to be specific about how you will handle alternative treatment discussions and people's desire to share their most recent "cure."

[14] Handouts. What kinds of educational or brochures will be available? Can attendees bring handouts and, if so, do they need to get advance approval from you or someone else?

[15] Exchange of personal information. Do group members want their address, phone and/or emails distributed to other members as a directory or do they want it to remain private and give it out to others themselves?

[16] Promotion. What are your plans for letting people know about your group? If your group is formed under an organization, what forms of advertising are acceptable? For example, a classified in the local paper? An announcement in the calendar section of the paper? Flyers? Is there anything not allowed that you should be aware of and does the promotional piece need approval?

[17] Media exposure. Can you write a press release, or find someone who can, about your meetings and purpose? Are there people in your group
"Checklist" ...cont'd pg 13

Beginning a support group shouldn't be a task you take on that overwhelms you. But if you aren't prepared, many obstacles can come up that can threaten the environment of your group.

be a short driving distance for most people? Is it accessible for people with disabilities? Is the atmosphere comfortable or will members feel intimidated? Is the lighting good? If it's in a large building, like a hospital, will there be signs to make sure people don't get lost? Will a receptionist know when and where your group meets? Do they know where to park and



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Politics, Profits & Pandemic Fear Mongering



by Barbara Loe Fisher

Are you grabbing your face mask, stocking up on food and Tamiflu, locking your doors and keeping your TV tuned to the news to find out just how bad the "swine flu pandemic" really is going to get? While Americans are being scared to death, few are noticing how much of their tax money politicians are giving to drug companies and government health officials to grease the skids to create more experimental flu vaccines and drugs and more effective ways to quarantine or force their mass use whenever a "public health emergency" is declared in the future.

Call me cynical but not clueless. The bird's eye view I have had for the past 27 years at the National Vaccine Information Center has taught me one thing: the global alliance between Big Pharma and Big Public Health is a prescription for disaster that could extend far beyond a bout with the flu.

The international drama playing out right now before our eyes is an example of how citizens around the world can be easily manipulated by doctors and politicians engaging in fear mongering in the name of disease control to forward agendas that have more to do with ideology, power and corporate profits than health. When the U.S. Director of Homeland Security is the government official doing the talking rather than the U.S. Director of the Centers for Disease Control, put a copy of the U.S. Constitution in your pocket and take a look at federal and state legislation passed since September 11, 2001 to

understand which civil rights you don't have anymore when government health officials declare a "public health emergency."

But before we take a look at the threat to civil liberties that pandemic fear mongering poses, let's take a look at how creation of a global human market for influenza vaccines works. It is a blueprint for Successful Marketing 101 (or perhaps it is all just a coincidence).

In 2006, the World Health Organization (WHO) issued an international call for all nations to do whatever it takes to increase public appetite and demand for annual influenza shots as the main strategy to prepare for an influenza pandemic. In April 2007, the WHO used money donated by the U.S. Department of Health and Human Services (DHHS) to fund the creation of influenza vaccine manufacturing plants in Mexico and other countries one week after the FDA gave Sanofi Pasteur a license to produce an experimental bird flu (H5N1) vaccine. Sanofi Pasteur is just one of many drug companies the U.S. government has given millions of dollars to for the creation of bird flu vaccines.

On February 19, 2009, the FDA's Vaccines & Related Biological Products Advisory Committee (VRBPAC) discussed whether to give approval for the testing of experimental bird flu vaccine on American infants. VRBPAC consumer member, also NVIC's Director of Patient Safety Vicky Debold, PhD, warned that testing of an experimental pandemic bird flu vaccine on infants in the absence of a real epidemic and without assurances that unapproved novel oil based (squalene) adjuvants (AS03, MF59) are safe, could pose unacceptable risks in terms of inducing severe immune dysfunction.

On February 27, 2009 it was confirmed that an influenza

vaccine maker, Baxter International, had released a mixture of seasonal influenza viruses mixed with unlabeled live bird flu viruses to facilities in Czechoslovakia, Germany, and Slovenia. Baxter, which is waiting for a license to manufacture bird flu vaccine, explained it was an "accident" and that no harm was done.

On April 23, 2009, the world heard the first news reports about a mysterious pig (H1N1) and bird (H5N1) and human hybrid influenza virus that was making people sick near a Mexican pig farm. By April 30, the WHO had issued a Phase 5 "Alert" warning that the world was facing an immi-

Novavax, Baxter, Johnson & Johnson, Roche, BioCryst, and Vical are among the drug companies likely to benefit from the world pandemic panic.

In all the chaos that has Americans running to drug stores to buy face masks, closing schools to wipe desks down with rubbing alcohol and avoiding public transportation, there is action being taken behind the scenes by politicians and government health officials to prepare the way for implementation of future quarantine and mass vaccination of citizens with experimental vaccines and drugs that have by-passed normal FDA regulations for demonstrating purity and potency of pharmaceutical products. A "public health emergency" has become an excuse to grease the skids and rush to market experimental drugs and vaccines that are not subject to product liability in the civil courts.

The creation of this pharmaceutical company stockholder dream scenario and simultaneous erosion of civil liberties in the name of disease control began in earnest in 21st century America after the tragic events on September 11, 2001. In a time defined by shock, fear, anger and deep sadness, Congress reacted quickly and passed the Homeland Security Act while CDC officials pulled out model state legisla-

tion (Model State Emergency Health Powers Act) that gave sweeping new powers to public health officials to use the militia, if necessary, to quarantine citizens and force them to use experimental drugs and vaccines after the U.S. Secretary of Health declares a "public health emergency."

The stampede in 2001/2002 to re-write long standing public health laws in this country was fueled by reports that terrorists were in possession of weaponized smallpox and anthrax, a fear that was fostered by U.S. government officials and New York Times journalists reporting Iraq

had secret stockpiles of weaponized smallpox and anthrax. This myth played a role in public support for the U.S.-Iraq War and persuaded Congress to pass Bioshield and pandemic influenza vaccine legislation that gave billions of dollars to vaccine manufacturers, the Department of Defense (DOD) and the Department of Health and Human Services (DHHS) to create experimental bioterrorism and pandemic flu vaccines while protecting drug companies and doctors from liability for vaccine injuries and deaths that will occur.

The mandated, mass use of multiple vaccines has become big business in the last quarter century since the U.S. Congress passed a law in 1986 shielding vaccine makers and doctors from liability for vaccine injuries and deaths and the numbers of vaccines recommended by the federal health officials for American children multiplied from 23 doses of 7 vaccines to 48 doses of 14 vaccines from birth to age six. For older children and adults, there are several dozen more federally recommended or state mandated vaccinations.

All of this liability protection and government vaccine mandating has been a boon for vaccine profit-making and public health agency empire building. In 1986, four drug companies made and sold vaccines in America and, by 2007, after corporate mergers and acquisitions there were six drug company giants making and selling vaccines in the U.S. Today, there are more drug companies seeking to enter the lucrative multi-billion dollar U.S. vaccine market as financial predictions for global profits from the worldwide vaccine business by 2010 have climbed to more than \$20B.

A true global influenza pandemic that could take out projected millions of people is something all nations should prepare for using reasonable strategies to ensure the public health and safety. However, it is a matter of legitimate debate as to whether the primary strategy being urged by the WHO, pharmaceutical companies and government health agencies around

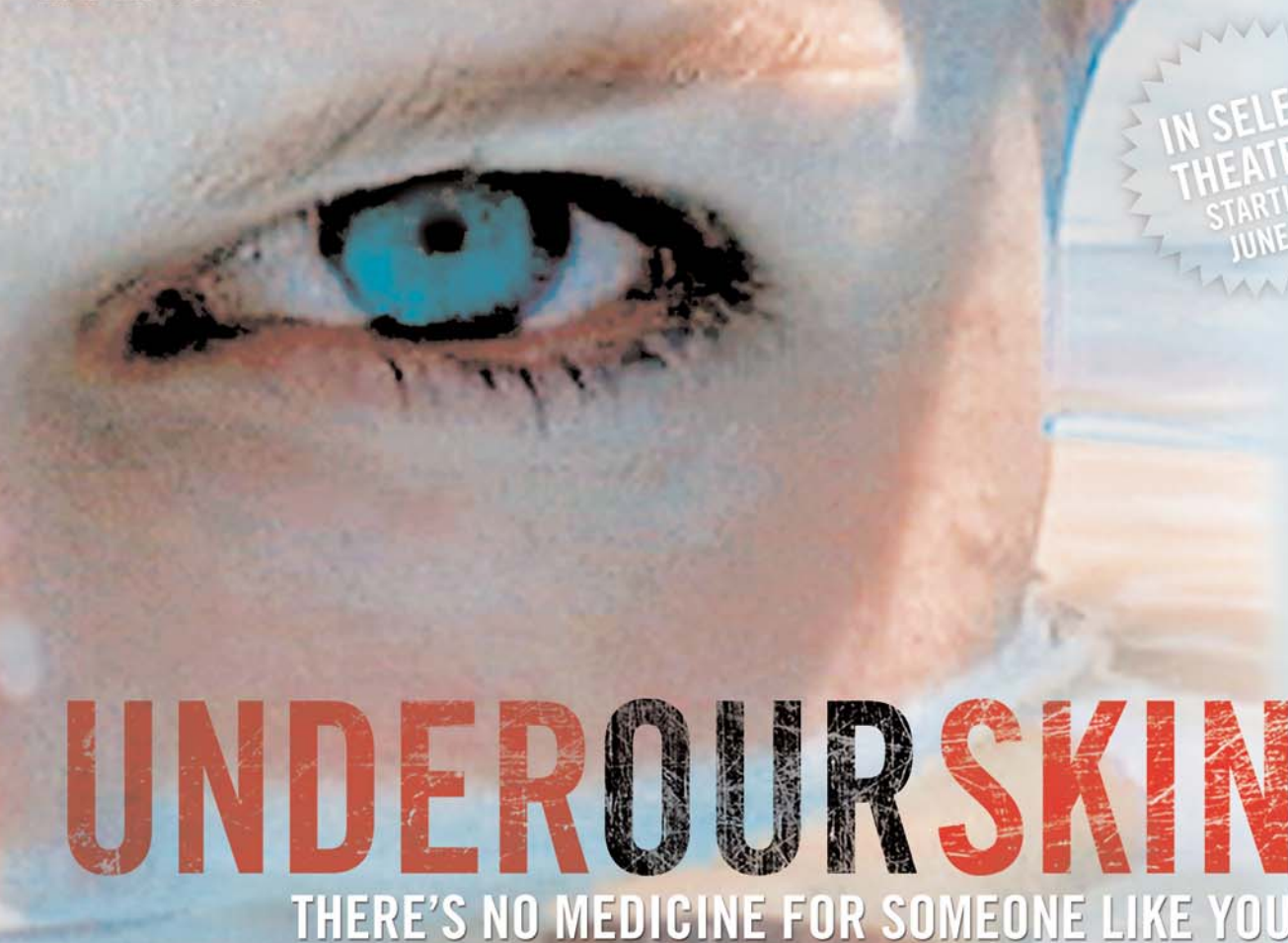
"Fear Mongering" ... pg 13

Call me cynical but not clueless. The bird's eye view I have had for the past 27 years at the National Vaccine Information Center has taught me one thing: the global alliance between Big Pharma and Big Public Health is a prescription for disaster that could extend far beyond a bout with the flu.

nent influenza epidemic on the strength of several hundred cases of "swine" flu and less than 10 confirmed deaths.

The pandemic flu panic that has an especially strong grip on people living in Mexico and the U.S., thanks to the governments of both countries declaring a "public health emergency," has been a good thing for pharmaceutical companies in the pandemic flu business. Wall Street revealed that the pandemic scare sent stock prices soaring for drug companies making anti-viral drugs, rapid flu diagnosis tests and influenza vaccines. Sanofi Pasteur, GlaxoSmithKline,

"EXPLOSIVE" – Fox News



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Jemsek...Con't from pg 1

Easley, who succeeded Governor Hunt, also awarded Dr. Jemsek with the Governor's World AIDS Day Volunteer Service Award in 2004.

Over the years, Dr. Jemsek and his staff were leaders in FDA clinical trial research for new therapies in HIV/AIDS, participating in almost one hundred FDA approved pharmaceutical trials, of which twenty-two became established treatment protocols for those suffering from HIV/AIDS.

In 2001, shortly after establishing the Jemsek Clinic as an HIV/AIDS clinic, one by one, another abandoned patient community approached Dr. Jemsek for help. Those suffering from Lyme Borreliosis Complex desperately sought what Dr. Jemsek had provided to his HIV/AIDS patients - an open mind, a listening ear and the ability to research and analyze the complex infections that were destroying their lives.

Quite sadly however, in 2006, despite his research and philanthropic efforts, Dr. Jemsek faced political and legal battles related to his involvement with treating Lyme disease. These actions resulted in the loss of his HIV/AIDS practice, which at that time consisted of more than one thousand patients. Dr. Jemsek tried to salvage his practice to continue serving the HIV/AIDS community, but ultimately, the circumstances separated him from the patient population on which he has built his entire career, and left many of these patients without suitable options for health care.

Fortunately, Dr. Jemsek's experience with the HIV/AIDS epidemic has had a long-lasting and positive impact on his current view of medicine and the way in which he now focuses his resurrected practice on those suffering the ravages of Lyme Borreliosis Complex.

Tina: Dr. Jemsek, on March 20, 2009, you hosted an event in Charlotte, North Carolina to bring awareness to Lyme disease. Would you please tell us about your awareness event and its success as such?

Dr. Jemsek: We hosted the Into the Light Gala and it was a huge success! It was a landmark evening! We came up with the idea after I attended the Unmask the Cure Gala in New York in November 2008. It was the second time I went to that event, where I had the good fortune to become acquainted with Staci Grodin, founder of the charitable foundation, Turn the Corner, which sponsored the New York Gala. To my knowledge, Turn the Corner has been the largest fundraising organization for the Lyme cause in the country for the past several years. Like so many others, the Grodins were impacted by Lyme Borreliosis Complex and decided to take assertive action for positive change. Turn the Corner is head and shoulders above everyone else, both in their success and their ability to inspire, because they conduct themselves with integrity and do it for the right reasons.

So, I was inspired by Turn the Corner and felt that we should do something similar

in Charlotte, not so much as a fundraiser since that requires much more infrastructure and time, but more as a major awareness campaign and a way to feature the film *Under Our Skin*.

When I told Staci we wanted to do a gala for Lyme awareness in North Carolina and asked if her organization would be supportive, she jumped on board right away. That's one thing I love about Staci -- she agreed to help without hesitation. Turn the Corner graciously agreed not only to sponsor our Gala, but also agreed to be the surrogate charity for the event. In this way, all donations to support the Gala went to them as a charitable organization and offerings became tax deductible. In short order, I then asked National Capital Lyme, who has 2000 members from their DC area, to become a co-sponsor. They agreed, also, and it worked out great.

With our major sponsors in place, I put a team together and started by assigning our research coordinator, Michelle Thomas, to head up the Into the Light Gala committee. Michelle, along with Mark Pellin, a journalist and editor, put in hundreds of hours and made several key contacts important to the Gala, including arranging the involvement of a skilled graphic arts professional. This group was joined by my wife, Kay, and they came up with the amazing tri-fold invitation, along with the beautiful banners displayed at the event, among many other things.

Very early on, we also worked closely with Kathy Fowler in DC, a media journalist with great experience in the Lyme issue and featured in the documentary. In addition, Staci generously allowed us to work with a chief staff member for Turn the Corner, Darren Port. In the end, rather quickly, we had a professional organization and marketing team that communicated regularly and functioned very well together.

Even in the beginning, I had a sense that we were going to have a successful event. We started in November, with the Gala held in March, so there wasn't a lot of time to pull it off, but I just had this calm sense that it was all going to come together. It did come together and I believe it was the time in our history when it was meant to happen. And more things like Into the Light need to happen and will happen.

The Into the Light Gala hosted over 450 people, some traveling from a great distance. It was a very powerful evening, as one can glean from the DVD overview of the Gala. In remembering the evening and looking at the DVD images, there is definitely a sense of energy, mass and purpose coming out of the event. The Gala gave us a chance to come together to support each other in spirit and have that physicality there, too. It gave us the opportunity to honor some wonderful people with a cate-

gory which we termed our Courage Award. Most of the award recipients have suffered from this illness and then done extraordinary things to try to help others with the illness. Among the recipients were PJ Langhoff, author of the incredible, recently published book *The Baker's Dozen* and the Lunatic Fringe and Kathy Fowler, who I mentioned earlier.

We opened the doors at 6 p.m., but by 5:30 we already had about a hundred people in the lobby. The movie began

"You're vilified around the world for your policies, so please consider this. I'm proud to be a member of this organization, but you need to open things up."

~
It would certainly appear that they came after me, because I was spoiling their party, and I think we'll learn much more about the ruthlessness of their actions over time.

around 7:15 and people hung around until midnight. We filled two theatres by using a simulcast operation. It was very exciting! I wanted to invite as many people who weren't aware of the epidemic as possible, so as to create awareness to people who can make a difference, whether it was friends or business community and political leaders. Several Charlotte city council members were there, as was a representative of the Governor of North Carolina, an individual who suffered from Lyme disease years ago. The media coverage was definitely there and was particularly good for a first time event.

We're going to have a professionally produced DVD made of the production by Andy Abrahams Wilson of Open Eye Pictures. You'll see that eventually. We want the photos and the DVD, in particular, to be our legacy to open doors down the road.

Jordan Fisher Smith, the park ranger portrayed in *Under Our Skin*, who is now working professionally as an author and lecturer, was our Master of Ceremonies. He did a wonderful job of tying the evening together. Mandy Hughes gave a moving acceptance speech on behalf of our Courage Award recipients. In another awards category, the Vision Awards, Turn the Corner Foundation, National Capital Lyme represented by their founders and leaders, Gregg and Monte Skall, and Andy Abraham Wilson, producer and director of the documentary, were all

honored for their priceless contributions to promoting positive change. And everyone was blown away by the movie.

After the film concluded, I said a few words. I called on my profession to do better for its patients, to regain its mission for putting the patient first. I also called for the outing of our corrupt health insurance industry. This was an opportunity to speak in a clear and civil manner about the debacle of our health care system and the disgrace promulgated by certain physicians in power, who have exacerbated and prolonged the suffering experienced in the Lyme epidemic. I tied together the Lyme epidemic and some of the issues we're experiencing in our economy, with regard to the excesses we observe all around us, fueled by greed and arrogance. In the end, I hope everything tied in together, and I do think it really resonated with the audience. All I really did was say out loud what everyone already knew.

Tina: I do appreciate this event from a distance, because it opens doors for every one of us. Thank you for holding the Into the Light Gala and for sharing it with the readers. On a different note, I'd like to ask you for your opinion on pulpit sermons on Lyme disease that emanate from the Infectious Diseases Society of America (IDSA).

Dr. Jemsek: I do belong to the IDSA and it's a really excellent organization, but like any large organization, it depends on leadership, truth and integrity in leadership. Their leaders have done everything they can do to be denialists, and I think their leaders have put them on the path to perdition. The IDSA body has just been bamboozled by this 'Lyme Cabal', which consists of only one or two dozen individuals.

Tina: As a member of the IDSA and acting Treasurer of the International Lyme and Associated Diseases Society (ILADS), you could, under the right circumstances, act as a facilitator. You could be someone who could bridge the gap between the two organizations. It is outrageous that your attempts to do so, in the form of letters written to the IDSA about what you were seeing with Lyme disease, fell on deaf ears. This speaks volumes about the IDSA agenda.

Dr. Jemsek: I think those attempts are what got me into "trouble". In a series of letters over several weeks that began in late 2005, I communicated to them with comprehensive and referenced reviews of the arguments at hand and pleaded for change. I made it very clear to them that, not only was I concerned about my patients but also the IDSA Society, if they insisted on staying on their path.

One day my letters will

be public and in them can be found my statements to them that said, "You're vilified around the world for your policies, so please consider this. I'm proud to be a member of this organization, but you need to open things up." It would certainly appear that they came after me, because I was spoiling their party, and I think we'll learn much more about the ruthlessness of their actions over time.

However, I had no idea that these people and others would so ruthlessly guard and advance their agenda. And there is a sickening sense of evil connected with their actions. At any rate, the bloom is definitely off for me now.

This whole experience and the actions of groups in power is now 'up close and personal' with me, and frankly still leaves me incredulous. I thought I knew a lot about human nature and it turns out I knew very little. You see, I had this wonderful medical experience in HIV/AIDS for over two decades, and I've witnessed incredible cruelty to suffering patients and I've also seen incredible kindness and giving. So, I thought that I had already seen the best and worst of human behavior before the Lyme story happened. But I never fathomed that the corporate world and their counterpart in medical politics could be as ruthless and evil as they are. They really wanted to take me out. For me, what's happened is I've learned about things that I didn't want to learn about.

Since they blew me up, I've learned about trial lawyers and lawsuits, medical boards, insurance companies, malpractice companies and academic physicians and their motivations. I didn't want to learn about any of this stuff, but now at least it's all demystified for me. Nothing rattles me too much now. Of course, there's always going to be something else to learn about, but trust me, I've learned about being in the courtroom, filing bankruptcy, foreclosure on my building and the near loss of my house. My family went through all that with me and my wife stuck with me throughout it all. But I'm just that much stronger, and I'm a big problem for them now.

Let me tell you something funny. One patient said they were watching a show late at night, *Golden Girls*. It was from 1985 and it was about Lyme disease. The patient was sick and tired of getting brushed off by all the doctors. But the upshot of the show was that the woman was finally diagnosed and got better, but then raised hell with a doctor in a public place saying, "You should listen to your patients!"

And the same patient brought me an old magazine tear out from a home health guide, probably from Jackson, New Jersey, talking about Lyme disease and how it could be passed to the fetus, how it could be chronic and how it can require long term antibiotics. And this tear out was from 1991.

Then there was a total shift by these arrogant individuals. Sometime in '93 or '94 there was an embargo on the "Jemsek" ...cont'd pg 11

2009 Morgellon's Medical Conference Held in Austin

by Harriet L. Bishop

The Second Annual Morgellon's Disease Medical Conference held Saturday, April 4 drew doctors, researchers and patients from 19 states and Mexico, ranging in age from 4 months to 80 years! The Westoaks Baptist Church at 2900 W. Slaughter Lane in Austin was the venue for this medical conference which announced results of recent research that shed some light on this mysterious illness that affects systems throughout the entire body, often but not necessarily presenting with unhealing skin lesions. Persons affected are generally those who have had contact with soil, such as farmers and gardeners, or those who have had contact with dirty water, as in hurricanes and flooding. Evidence was also presented suggesting that Morgellon's may be another of the tick-borne diseases, as over 40 different bacteria and parasites have been known to be transmissible by the bite of a

single tick. Infected deer ticks are widespread throughout North America.

The common plant bacteria *Agrobacterium tumefaciens* which causes gall disease in plants is implicated because DNA has been found in skin lesions of some patients, but the results remain inconsistent, suggesting that more research is needed. It is believed that this is the first time a plant bacterium has been known to cross from the plant kingdom to animal kingdom to infect human beings.

Featured speakers were experts in the field who had come from both US coasts as well as the heartland to present their findings. The disease appears to be more prevalent in states with seacoasts, such as California, Texas and Florida although cases are found in other states as well.

Lyme disease is believed to be a precursor to or co-infection with Morgellon's disease, as 97% of Morgellon's patients also test positive for

Lyme disease. The most effective treatment at this time for this little known illness is to treat for the underlying Lyme disease, a process that may involve taking various antibiotics in combination for a period of years. Body systems are protected from adverse effects of prolonged antibiotic treatment by careful administration of milk thistle (silymarin), several types of specific probiotics, monthly lab work and frequent examination by the medical professional.

The Charles E. Holman Foundation, based in Texas, is committed to public education and research of Morgellon's disease. Principal Investigator Randy Wymore, Ph.D. conducts research at Oklahoma State University Health Science Center. On the Charles E. Holman Foundation website www.thenmo.org more than 20,000 households currently report being affected by Morgellon's disease, which remains a medical mystery. Stay tuned!



Left to right: Cindy Casey, RN Director of The New Morgellon's Order/The Charles E. Holman Foundation; Ginger Savely, DNP one of the top experts in the US on diagnosis and treatment of tick-borne diseases and Morgellon's disease, San Francisco; Raphael Stricker, MD, Past President of ILADS, author of over 200 medical journal articles, now specializing in tick-borne diseases, San Francisco; Harriet Bishop, President of Texas Lyme Disease Association; Randy Wymore, PhD, Director of the Oklahoma State University Center for Health Sciences, Center for the Investigation of Morgellon's Disease; Amelia Wüthington, MD, Staff Psychiatrist at the Crozer-Chester Medical Center in Chester, PA

Top 10 Tips to Prevent Chronic Lyme Disease

by International Lyme & Associated Diseases Society

Chronic Lyme disease patients may face a long hard fight to wellness. People with chronic Lyme can have many debilitating symptoms, including severe fatigue, anxiety, headaches, and joint pain. Without proper treatment, chronic Lyme patients have a poorer quality of life than patients with diabetes or a heart condition.

The fact is Lyme is a complex disease that can be highly difficult to diagnose. Reliable diagnostic tests are not yet available which leaves many—patients and physicians alike—relying on the so called "telltale signs" of Lyme disease: discovery of a tick on the skin, a bull's eye rash, and possibly joint pain. However, ILADS research indicates that only 50%-60% of patients recall a tick bite; the rash is reported in only 35% to 60% of patients; and joint swelling typically occurs in only 20% to 30% of patients. Given the prevalent use of over the counter anti-inflammatory medica-

tions such as Ibuprofen, joint inflammation is often masked.

Based on these statistics, a significant number people who contract Lyme disease are misdiagnosed during the early stages, leading to a chronic form of the disease which can prove even more difficult to diagnose and treat. Lyme disease is often referred to as the "great imitator" because it mimics other conditions, often causing patients to suffer a complicated maze of doctors in search of appropriate treatment. ILADS is committed to the prevention of chronic Lyme disease. The following tips are designed to offer guidance and minimize the risk of contracting chronic Lyme disease.

1. Know that Lyme disease is a nationwide problem

Contrary to popular belief, Lyme disease is not just an "East Coast" problem. In fact, in the last ten years, ticks known to carry Lyme disease have been identified in all 50 states and worldwide. Although the black legged tick is considered the traditional source of

Lyme disease, new tick species such as the Lonestar tick and a pacific coast tick, have been found to carry *Borrelia burgdorferi*, the corkscrew-shaped bacterium that causes Lyme disease.

Avoiding a tick bite remains the first step in preventing chronic Lyme disease. One needn't have been "hiking in the woods" in order to be bitten by a tick. There can be ticks wherever there is grass or vegetation, and tick bites can happen any time of year. Spraying one's clothes with DEET-containing insecticide, wearing long sleeves and long pants, and "tucking pants into socks", continue to be the best ways to avoid ticks attaching to the skin. But don't forget the post-walk body check.

2. Check your tick facts

Ticks can vary in size from a poppy-seed size nymphal tick to a sesame-seed size adult tick. The ticks can carry other infectious agents besides the spirochete that causes Lyme disease, including Ehrlichia, Anaplasmosis,

Babesia, and Bartonella. Lyme disease can sometimes be hard to cure if these other infections are not treated at the same time.

3. Show your doctor every rash

The bull's eye rash is the most famous, but there are many other types of rashes associated with Lyme disease. In fact, Lyme disease rashes can be mistaken for spider bites or skin infections. Take photos and make sure a medical professional sees the rash before it fades.

4. Don't assume that you can't have Lyme disease if you don't have a rash

Lyme disease is difficult to diagnose without a rash, Bell's palsy, arthritis, or meningitis, but you can still have Lyme and not have any of those signs or symptoms. Many people react differently to the infection and experience fatigue, headaches, irritability, anxiety, crying, sleep disturbance, poor memory and concentration, chest pain, palpita-

tions, lightheadedness, joint pain, numbness and tingling.

5. Do not rely on test results

Currently there is no reliable test to determine if someone has contracted Lyme disease or is cured of it. False positives and false negatives often occur, though false negatives are far more common. In fact, some studies indicate up to 50% of the patients tested for Lyme disease receive false negative results. As a result, the CDC relies on physicians to make a clinical diagnosis based on a patient's symptoms, health history, and exposure risks. Doctors who are experienced in recognizing Lyme disease will treat when symptoms typical of the illness are present, even without a positive test, in an effort to prevent the development of chronic Lyme disease.

6. Be aware of similar conditions

Chronic Lyme disease is called the "great imitator" because it is often misdiagnosed as another "Prevention" ... cont'd pg 11

Columbia, South Carolina Lyme Rally Thursday May 14th between 10-11:30 a.m. State Capitol North Grounds

Please RSVP to Kathleen Liporace at greenvillelyme@bellsouth.net, so we can have a head count.

People from any state are welcome to come. Bring family, friends and of course, wear lime green. CALDA has great t-shirts!

For those of you in the Greenville Lyme Support Group, we will not have the support group meeting planned for May 16th in lieu of the rally.

Please join us for this historic event and make your presence known. Lyme Disease, as you know, is a much bigger issue than is imagined by the general populous which barely knows what it is. We need to show this by our numbers.

Your presence or those that you know of will be a huge boost to getting Lyme into the mainstream and recognized. If you have any media contacts, please inform them and ask them to come and cover this event. Thank you all so much!



Lt. Governor Andre Bauer will be speaking on behalf of patients

A Clowning Achievement



by Virginia Sherr, M.D.

The woman sitting with me one day in 1996 was outwardly a picture of youthful haute couture. In actuality, when she spoke, I could see she was an anxious, middle-aged waif of a person appearing more like a hunted/haunted zombie. She was in my psychiatric office on an emergency basis. Alicia trembled and shook as she tried to tell me about the panic attacks and total insomnia that she had been experiencing despite the fact that she had been taking massive amounts of prescription medication to counter these problems. Her symptoms had led her to admit herself to a local mental hospital in the recent past in the hope of finding relief, but it was not to be.

Actually, nothing had seemed to work for Alicia either in the hospital or out. She demonstrated no hint of the competent real estate agent that

she once had been; she actually appeared somewhat limited. She was childlike, passively accepting of the ambient idea that she somehow must have been defective to develop all these unexplained symptoms.

Alicia was married to a well-known radiologist who had high expectations of others. In an attempt to justify herself in his eyes, she tried in extreme, unasked-for ways to anticipate his needs. She began to develop compulsive checking and other new habits such as rising daily in the morning's wee hours in order to vacuum the house. She developed odd obsessions. Occasionally she would rave that she "couldn't take it" any more. She had become less able to organize tasks so was better able to function when there was less complexity in the environment which, in turn, abetted her tendency to clean the house at 4 AM. It didn't upset her to do this because she couldn't sleep anyway, not at all, night or day for weeks at a time. While some of her symptoms improved with my assistance, I kept puzzling over why the others did not.

Now in her second marriage, Alicia remembered well that she had experienced a horrific physical trauma in her teenage attempt at matrimony. She wondered if that shock long ago could have weakened her so that she ended up a shuddering mass of nerves, although she had functioned well and competently before

1992 when her symptoms began. She unsuccessfully had sought help from a caring psychologist and from numerous doctors and now, desperate and depressed, saw me as a last resort.

It was only after two years of working together that I began to suspect tick-borne diseases (TBDs) were behind all her symptoms and that Lyme disease was the reason that she had never regained the ability to sleep on her own nor overcome her sense of urgency. Although she was no longer zoned out on multiple medications, she still required fairly significant doses of the medications that were needed so that she could function. Her extreme compulsive behavior and her sense of anxiety lessened somewhat but did not go away despite therapy targeting these symptoms.

In the 6 years since the onset of her symptoms, and even in the 2 years that we had worked together, Alicia had not had one moment of joy or peace - her sense of herself had changed unshakably to "inadequate." A woman who had loved to cook creatively and to do interior decoration, she had become a frazzled phantom struggling to do its best so long as meager energy reserves held out.

It was only when Alicia began to lose her hair, have severe jaw joint (TMJ) pain, major weight loss, fatigue, muscle aches, and unexplained ear pains, that it became obvi-

ous to me (1998) that she needed to be tested for TBDs. In the meantime, Barry, her husband, was becoming high-handed. He was constantly irritable and could be demanding. He was impatient to an unreasonable degree at times. There was no sense of humor in either him or her and no hint of the change that was to occur when his own chronic TBD's were properly diagnosed and treated, along with hers. We were all surprised at that development. When one knows a person well, gradual changes in personality, as happen with chronic Lyme disease, are not so noticeable and tend to be explained away by daily stresses.

Alicia and Barry did not need any convincing that their positive tests for the tick borne diseases Lyme, babesiosis and ehrlichiosis needed urgent attention. They undertook intensive treatments, including the rigorous one, quinine, for their malaria-like babesiosis. They made truly remarkable recoveries. The unique thing was that they recovered more than they had lost!

As he continued his antimicrobial treatments, Barry began to develop a sense of playfulness. He took delight in entertaining children and to the amazement of his wife and her psychiatrist, he became a professional clown on his weekends. Today, he still thrills the sick kids at local hospitals - in a role quite different from the more usual isolated-from-patients employment of many

radiologists. He is no longer seen by others as a distant authority figure but is experiencing the joy of his own creativity and the affection it brings to and from others. His patience has grown and he is a happy man with a happy wife who is proud of him for many old and new reasons.

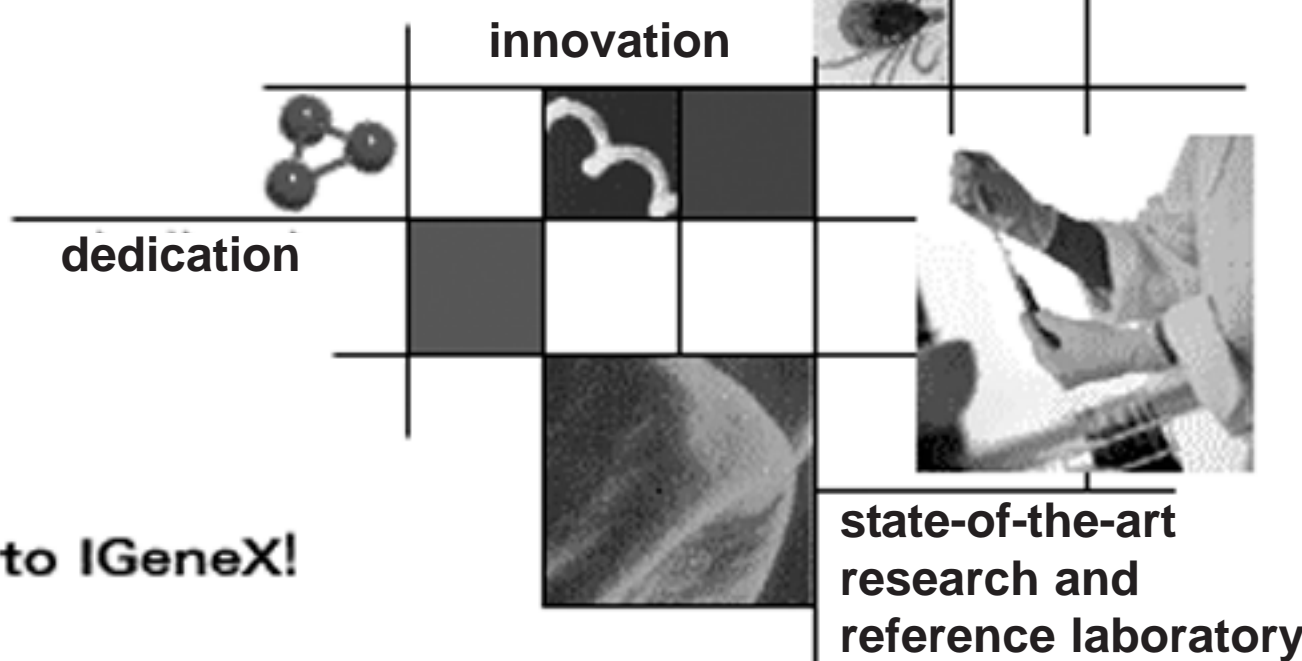
Alicia accompanies him now during his hospital events. She assists in his act. She enjoys creating outlandish costumes for his "performances" and loves the laughs they share together in the process. She has returned to her own hobby of painting, untouched during the many years that her sense of organization and her own sense of playfulness were unavailable to her. And her cooking! Her husband kids that he will open a gourmet restaurant with her as the stellar attraction.

A colleague, Dr. Rick Brand, once mentioned that his patients who were afflicted with Lyme disease experienced a spurt of creative imagination in the recovery phase. His words rang true when Alicia brought me photos of Barry in his latest colorful home-made clown regalia. This couple's emergence from the personality-distorting effects of chronic Lyme disease demonstrated joyful evidence of their sharing such a rebirth together.

[Previously re-printed in the Lyme Times.]



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Morgellons Mystery

Conference on Strange Disease Held in Oak Hill, Texas Area

by *Corinne Carson*
The Oak Hill Gazette

It sounds like science fiction. People report strange unknown fibers emerging from under their skin in hues of blue, red, white, black, even turquoise. Researchers report that the fibers are made of cellulose, which is not normally found in the human body, and some have even found fibers coated in metal. Some fibers have been observed to move. The fibers are accompanied by an intolerable feeling of something crawling, stinging or biting under the skin, a feeling that gets worse at night. This torment is accompanied by a variety of other symptoms, including skin lesions and "brain fog" and the symptoms are sometimes shared by whole families, and even their pets.

The condition, known as Morgellons Disease, is not officially recognized by the mainstream medical community and sufferers are often diagnosed with other skin illnesses or told that they are suffering from a psychological condition known as delusions of parasitosis – in other words, that it is all in their head.

Although the mainstream medical community does not recognize the illness, on one day out of the year, the often self-diagnosed Morgellons patients and sympathetic medical professionals and allies gather for their international conference. This year, that conference was held April 4th in Southwest Austin at the Westoak Woods Baptist Church.

The conference is sponsored by the Charles E. Holman Foundation, a non-profit that states its mission is to support "research, education, diagnosis and treatment of Morgellons Disease" and included lectures from sympathetic medical professionals and researchers. Charles Holman is the late husband of Cindy Casey RN, a Morgellons patient. He founded the "New Morgellons Order" to raise awareness of the disease after accompanying his wife to a number of doctors' appointments and watching as she was told she was crazy. The foundation was renamed in his honor when he died of a heart attack in 2007 and his wife Casey took over as the executive director.

Cindy Casey's story is like many others. She began experience symptoms of chronic fatigue and occasional skin lesions as far back as 1997. By 2003, the lesions had become so prevalent and excruciating, with the characteristic fibers emerging from her skin and the intense itching, pain and cognitive problems or "brain fog" that she decided to seek treatment.

Like many "Morgies" as Morgellons patients sometimes call themselves, Casey was told by several dermatologists that she suffered from delusional parasitosis, a condition in which the patient hallucinates the sensation of bugs crawling under the skin, often accompanied by skin wounds caused from excessive itching or picking at the skin.

In an intermission during the conference, Casey rolled back her sleeve and lifted her pant leg to reveal arms and legs covered with numerous lesions and discolored whiter skin where she said previous lesions had healed. "They start out as little pimple marks and then they become open wounds, so I have them in all different stages," she said.

Other patients came up, lifting their skirts and pant legs to reveal the same lesions dotting their skin. Some had lesions under white cotton gloves or hidden under handkerchiefs tied over their head.

Of the lesions, Casey said, "They are so painful it's hard to describe – the itching is worse. It's just this insatiable itch that you can't even describe. I've had poison ivy and those things itch bad but this is just, it's just so bad it makes you want to come unglued."

Casey, like many others at the conference, credits Ginger Savely, DNP, a nurse practitioner famous for treating the controversial Morgellons and Chronic Lyme diseases, for finally showing her respect and compassion, and for giving her treatment that she says has reduced the number of lesions and the severity of her pain and itching.

Savely, who has a PHD in nursing, is practically worshipped in Morgellons and Lyme circles. She gave two lectures at the conference, one in which she described case studies of various Morgellons patients she has treated, and another discussing treatment options for the disease. While acute Lyme disease has finally become recognized by the medical community, Chronic Lyme, in which the Lyme symptoms persists after the normal course of antibiotics, is still controversial. Many doctors do not believe it exists.

Not only is Chronic Lyme real, Savely maintains, but it has a strong association with Morgellons. She discovered the connection while treating Chronic Lyme patients in her practice in Austin. She found that approximately 10 percent of her chronic Lyme patients had the fibers, lesions and skin-crawling sensations characteristic of Morgellons. As news of the Morgellons phenomenon spread over the Internet, she started hearing from more patients who came to her for Morgellons treatment. She says overall, about 95 percent of Morgellons patients she has treated are co-infected with Lyme disease.

Savely postulates that Lyme may weaken the immune system, making patients more vulnerable to whatever pathogen causes Morgellons, but she admits she does not know what that pathogen is.

And this is what really upsets many in the mainstream medical community. They criticize her for prescribing heavy doses of a variety of medications for extended periods, outside the normal medical guidelines, when she doesn't even know what she is attacking or which of her treatments will work.



Left: A Morgellons fiber: 0.1 mm. Right: Morgellons sufferer Cindy Casey shows the scars left by the disease on her arms. The rest of her body bears similar marks. ~Photo by Will Atkins

"I've been told that I'm just randomly giving these different treatments to the patients without knowing what the pathogen is and that's really irresponsible. But I think what's irresponsible is ignoring suffering people and not treating them at all," Savely said, and the crowd erupted into applause.

And treat she does. She first works to heal any co-infections such as Lyme disease, and then prescribes simultaneous heavy doses of antibiotics, dewormers, anti-fungals and various topical creams, trying various medications on a patient until she finds the ones that work, sometimes treating patients with these medications for years at a time.

"Every patient is unique. The more I treat this illness the stupider I get," she said, explaining how she will often find a treatment that works well for a time and then just stops working, and that what works well for one patient, won't necessarily work for another.

Savely doesn't know why the de-wormers are effective, since there are no "worms" found in Morgellons patients but suspects that they are in some way toxic to the pathogen. When she prescribes them, she says patients experience an immediate worsening of lesions and of the crawling, biting and stinging sensations, which she attributes to a "mass-exodus" of the fibers out of the skin. "I do warn patients, you're going to get worse before you get better. That's to be expected, and the majority do get worse before they get better."

But she says most patients do get better, although not all become completely symptom free. One of Savely's success stories stood up, a woman who Savely said was at one time totally debilitated by the condition but has now been symptom-free for three years.

Despite the success stories, some in the medical community feel Savely's treatments are dangerous. She was forced to leave the state of Texas when the medical board put pressure on her sponsoring physician and she could find no other Austin physician to work with. She now practices in San Francisco, California where the

laws governing medical treatment are more liberal.

She says she carefully monitors her patients' liver function and blood count over the course of treatment and has seen only on very rare occasions, very minor adverse affects such as a small elevation in liver function, which she says she easily reverses by reducing the medication. "It sounds scary to the pharmacist and they will try to scare you, but I just haven't seen the problems, and people tolerate them (medications) very well," she said.

Although Savely is willing to treat the disease now, everyone agrees that finding the cause of the disease is necessary to find the most effective treatment. The Center for Disease Control (CDC) is currently investigating Morgellons but they have not published any findings.

But other researchers are also looking into the cause. One such researcher who spoke at the conference is Dr. Raphael Stricker, MD, a clinician who, like Savely, treats Chronic Lyme and Morgellons patients in California. Morgellons skeptics dismiss Stricker's research because he was fired from the University of California in 1990 for allegedly suppressing data in a 1985 research paper on AIDS that would have contradicted his hypothesis. But Stricker has consistently denied the charges and Lyme and Morgellons message boards abound with patients posting messages in his defense.

Stricker presented research he conducted along with Savely and Vitaly Citovsky, Ph.D of the State University of New York at Stony Brook, in which they tested lesions from seven Morgellons patients as well as biopsied skin samples from a healthy control population. They found agrobacterium in all seven Morgellons patients and none was found in the control group.

Agrobacterium is a bacteria that infects plants, causing Crown Gall disease in trees, and it is the only known organism to engage in lateral gene transfer among kingdoms, transferring genes from the plant kingdom to the animal kingdom. The bacterium pro-

duces copious amounts of cellulose fibers, and Stricker and others have found the fibers found in Morgellons patients to also be made of cellulose, a plant material.

Skeptics point out that cotton is also made of cellulose fibers. But Forensic scientist Ron Pogue of the Tulsa Police Crime Lab in Oklahoma told ABC News that he checked a sample of Morgellons against every known fiber in the FBI database and found no match. The lab's director, Mark Boese, told ABC that the fibers are "consistent with something that the body may be producing." He added, "These fibers cannot be manmade and do not come from a plant. This could be a byproduct of a biological organism."

Stricker has a theory, but acknowledges a lot of research needs to be conducted to see if his theory is correct. He speculates that agrobacterium, which is found in the soil and also in a high percentage of ticks, is the cause of Morgellons, and that the reason many are co-infected with Lyme is that they may contract Morgellons from the same tick that gave them the Lyme disease.

Furthermore, he notes a very curious finding. Telomerase is an enzyme that adds more DNA to the end of a chromosome after cell division. "Every cell and species has telomerase," said Stricker. "There have been comparative studies of telomerase in different organisms and it's been shown that the telomerase in Lyme and agrobacterium are exactly the same."

He continued, "This is a peculiar coincidence because telomerases are usually completely different among different species and types of bacteria. This suggests when there is co-infection with Borrelia, which causes Lyme disease, and with agrobacterium, the two bacteria can actually help each other by adding pieces of DNA to each other's chromosomes and this could cause variation in both bacteria, that could then lead to changes in what the bacteria are doing in the human body. It's a very interesting possibility that also needs to be examined in further

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Contact PJ Langhoff
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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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“Jemsek” ... cont'd from pg 6

truth. Overnight, things turned around and white became black and vice versa. For example, in the infamous 1994 Dearborn meeting, Allen Steere pretty much turned everything around and said there was too much Lyme disease being diagnosed, and as PJ Langhoff writes in her book, they hijacked the truth and turned Lyme into junk science in order to promote their vaccine and other interests. It was all about their own motivation. It was just incredibly wrong, and we're still living with this fifteen years later.

Tina: How are doctors able to ignore ethics and put their own agenda above the patients they promised to heal?

Dr. Jemsek: As I spoke of at the Into the Light Gala, our mission has been lost in medicine. Our doctors have lost their way. I think it came about in a lot of complicated ways, such as the increasing change in the independence of the physician and their failure to invest in their own profession by integrating with all the disciplines that deliver healthcare.

In other words, doctors have always had this tremendous ego, which I think is a huge protective bubble for them. Unfortunately, I think it is unearned and misplaced ego.

And what that does is create a situation wherein if the doctor doesn't understand something, they make the patient the problem. It's kind of dummed-down medicine to the point that, if they don't understand or listen to what a patient with complex medical issues tells them, they put it in one of three big buckets-fibromyalgia, chronic fatigue or crazy. That's really sad because life and medicine are more complicated than that.

One of the things I said in my speech is that arrogance trumps reason. So, if you are arrogant for whatever reason, it totally corrupts the doctor-patient relationship. In addition, the doctors have been brought under pressure economically because of the restructure of medicine with the HMO's, Medicare and paperwork. They have to jump through many hoops to satisfy the leaders of American health, the insurance companies.

I really am very sad about doctors having lost their profession. We're now working for insurance companies and hospitals. Instead of turning our energy outward to try to change things, we often turn it inward against each other. Often doctors are jealous of the one who is more creative, disagrees, who has new ideas, who

makes more money or who seems to be more popular. As a group, we as doctors are really small-minded people. And the chasm between patient and doctor has been magnified since we've gone full bloom in the information age, so that patients have access to information they didn't have in the past.

Tina: Unfortunately, this occurs at a time when chronic infections are rampant. You've certainly made your case for something you expressed in your speech at the Into the Light Gala, when you said, "The delay in recognizing our nation's Lyme epidemic presents a prime example of our broken health care system. The way in which a society deals with a marginalized population is the signature and indelible stamp of that society's character...give the U.S. health system an F grade for its work here."

Dr. Jemsek: Yes, we do a horrible job of dealing with chronic illness. In a strange way, the Lyme epidemic may be the tipping point for making significant change, because it is so painful and so complex that it's going to force us to finally work it out. It's not going away, no matter how long Gary Wormser holds his breath. We

need to think about the whole picture of interaction and inter-relationship of chronic infection and epidemiologic control and examine why we have so many other co-morbidities. Could chronic infections be at the root of a lot of our rheumatologic and other diseases?

Tina: Does what you refer to as Lyme Borreliosis Complex or LBC include Lyme and co infections?

Dr. Jemsek: Yes. You see, one thing I noticed with HIV early on, is that we have a different paradigm in that the virus replicates every thirty minutes or so. With LBC we have what we call pleomorphism and polymorphism. Pleomorphism has to do with different life forms and polymorphism has to do with different genomic patterns within the same species. So, as organisms evolve and multiply in a host, they're not carbon copies.

When I talk about the Lyme Complex, what I mean is that I realized early on that our patients are multiply infected. Because I came from an AIDS background, I saw the immune system melt. Although we have a different model with Lyme Borreliosis Complex, the concepts are similar. And what happens is that the immune sys-

tem melts and we get opportunistic infections that come up after a while. What we saw in the early days of HIV medicine was absolutely bizarre back in the early 80's, because we only read about these things in textbooks. Like, pneumocystis pneumonia, for example. That was something only kids with leukemia at St. Jude's Hospital in Memphis got after they had received high-dose steroids for months. Or, it was also seen in the malnourished in Auschwitz. But then we started seeing this regularly, and it became by far the most common life-threatening infection in HIV/AIDS.

We also saw the yeast infections and shingles (herpes zoster) come on in twenty year olds. We saw people go blind from cytomegalovirus (CMV) infections. We saw mycobacterium avium complex in blood cultures and as sheets of mycobacterium in stool samples. We saw bizarre stuff, but after a while, it all started to fit into a big pattern. And so, after you see a few hundred patients, you start to realize that when you see a certain CD4 count, the patient's going to get this or that. And we started to get better at that. And we realized how many other systems were affected whether they be meta

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“Prevention” ... cont'd from pg 7

condition such as Multiple Sclerosis, Fibromyalgia, chronic fatigue, or anxiety. Misdiagnosis is a common experience for patients with chronic Lyme disease. Treatments that work for these other illnesses are not appropriate for treating Lyme disease. Currently, the only effective treatment for Lyme disease is antibiotics. Ask your doctor to carefully evaluate you for Lyme disease even if your tests are negative.

7. "Wait and See" approach to treatment may be risky

Up to fifty percent of ticks in Lyme-endemic areas are infected with Lyme or other tick-borne diseases. With odds like that, if you have proof or a high suspicion that you've been bitten by a tick, taking a "wait and see" approach to deciding

whether to treat the disease has risks. The onset of Lyme disease symptoms can be easily overlooked or mistaken for other illnesses. Once symptoms are more evident the disease may have already entered the central nervous system, and could be hard to cure. This is one case in which an ounce of prevention really is worth a pound of cure.

8. Don't be afraid to get a second opinion

Recognize that opinions on how to diagnose and treat Lyme disease vary widely among physicians. It is worth getting a second or even a third opinion, especially if you are symptomatic and your doctor advises not to treat, or symptoms recur or persist after treatment. Keep in mind that your physician may focus too nar-

rowly on diagnosing and treating a single symptom. For example, a physician may diagnose a pain in your knee as "arthritis", and not see this as just one part of a larger set of symptoms that adds up to a diagnosis of Lyme disease, which requires different treatment.

9. Know your treatment options

Work with your doctor to identify the appropriate treatment option if your symptoms persist. There is more than one type of antibiotic available. Longer treatment is also an option. You should also work with your doctor to make sure you don't have another condition.

10. Expect success

You should expect to get better. You should not accept "watchful waiting" - the practice of stopping antibiotic treatment before you are well and then waiting for symptoms to clear on their own. Some doctors advocate stopping Lyme treatment while the patient is still symptomatic and then hoping that he or she will eventually recover without further treatment. Government trials have identified a number of individuals whose symptoms did not clear when treatment was cut off prematurely. There are doctors who feel your symptoms will clear with further antibiotic treatment.

Support by Turn the Corner Foundation

Turn the Corner Foundation (TTCF) is dedicated to the support of research, education,

awareness and innovative treatments for Lyme disease and other tick-borne diseases. Since its inception, TTCF has organized and supported countless programs that address Lyme disease education, diagnosis and treatment.

About ILADS

ILADS is a nonprofit, international, multidisciplinary medical society, dedicated to the diagnosis and appropriate treatment of Lyme and its associated diseases. ILADS promotes understanding of tick-borne diseases through research and education and strongly supports physicians and other health care professionals dedicated to advancing the standard of care for Lyme and its associated diseases.

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Under The Eightball:

An Interview With Film Producer Timothy Grey



by Marjorie Tietjen

Lyme disease is fast becoming the scourge of the 21st century. Thousands upon thousands are being misdiagnosed with disease labels such as Chronic Fatigue Syndrome, ALS (Lou Gehrig's Disease), Multiple Sclerosis, Parkinson's, Lupus, Fibromyalgia, BiPolar, Depression, Arthritis, ADD, Alzheimer's, and the list continues on. Most of these disease classifications have no known causes, cures or definitive tests...only symptomatic treatments. The current testing for Lyme disease, and the many other insect borne co-infections that often accompany Lyme, is very unreliable. Instead of allowing these infections to be clinically diagnosed and treated appropriately (by treating the cause), this growing plague is being cleverly swept under the rug.

Untold numbers of people are suffering and dying when all that may be needed are antimicrobial drugs, with the support of natural antibiotics and a healthier lifestyle. In November of 2008 a young writer and editor died of what was diagnosed as ALS. Her name was Lori Hall Steele. Lori became ill during September of 2007. Rather quickly she began to develop odd neurological symptoms. Within a year she began to lose muscle function and eventually had to be hooked up to a breathing machine. Nearer the end of her illness Lori was diagnosed with Lyme disease. Intravenous antibiotics were administered and she did begin to improve. However, she was then taken off of the antibiotics and reverted to her declining status. Could Lori's death have been prevented?

I would like to share with you a very touching essay written by Lori and then we will talk with her brother, who is producing a film, to try and answer some of the questions people have long been wanting answers for...such aswhy is the seriousness of Lyme disease being ignored and misrepresented? Why do patients have such a difficult time getting appropriate long term treatment, even when it is obvious that the treatment is helping, and why are doctors who treat chronic Lyme being targeted? Where did Lyme disease and the ticks that carry this disease come from?

Snow Patrol by Lori Hall Steele

Driving back from a specialist's office three hours away, my mom and I crested the big hill, the one where the bay spreads out below and you know you're home. This song (Hit Play) came on the radio as

we silently looked out the windows at melting snow and cold air and the glinty last remnants of sunset on the bay. It was that time of night where everything exhales blackness, and the blackness slowly absorbs the last light.

"The sky acutest at its vanishing", as Wallace Stevens wrote.

*The doctor ordered more IVs, and said there is a school of thought among some physicians that Lyme causes what the French call *Maladie de Charcot*. But no one knows. Our motor neuron maladies are more mysterious to modern science than AIDS and cancer and the moon, so mysterious that even accurate diagnoses elude us. So we're left to lay still, minds intact, as our voluntary muscles stop working.*

*My mother arrived three weeks ago and now helps me move from thing-- bed, chair, bath -- to thing. My boy has been a trooper but the night before our trip to the new doctor, he broke. I tried and tried to stand and pivot into bed to lay next to him and read *One Fish, Two Fish, Red Fish, Blue Fish*, but again and again my legs wouldn't lock. I told him I was so sorry, but I couldn't do it.*

He began sobbing. "Try again! Try again ONE MORE TIME!" he cried over and over. I just couldn't. As much as I wanted to. I finally grabbed him from bedside and held him and sang him into quiet. He finally talked. "Maybe the special doctor will make you better."

And maybe he will. The special doctor ordered an array of new drugs, said such regimes have been successful in halting symptoms in his patients who've been diagnosed with ALS, and one's been alive and kicking for 12 years, when most with that diagnosis are hit in the lungs and die in two to five years, starved for air. So there is hope.

*My mother and I believe this. I looked over at her as *Snow Patrol* played on the radio, and we both were crying. We both looked back at the water and snow. Then I felt her warm hand slide into mine, and we drove the rest of the way home like that, saying nothing, as night fell on the bay.*

Andalusian Dogs is the name of the film company which is producing the soon to be released movie, Under the Eightball. I had the privilege to be able to view the first half of the film before it was completed. The producers, Timothy Grey and Breanne Russell, held a screening of their "movie in progress" at the Peer Observation's Physician's Roundtable in February of 2009 in North Carolina. The first section of the movie depicted Lori's story and what the family went through while desperately

trying to find answers as to why she became sick and, at the same time, searching for solutions. Parts of this movie made you laugh, parts made you cry and at times you would just shake your head at the senselessness of it all. Some scenes in the movie were filled with burning raw emotion and one couldn't help coming away with feelings of compassion and anger.....all mixed together.

Interviewer: When did you become interested in making films?

Timothy : My background is in Music and Graphic design. I was in a band that had just released a CD and we were promoting it. A friend had a small DV camera and I got everyone together and made them do an intro, a short ten minute movie that we would run before we would perform. It was fun, and I really found it to be an enthralling medium as it encompasses elements of art

day, every day. Our production company had a different name then. When we went into production for Under the Eightball, we felt it was time to change the name. So, I suggested Andalusian Dogs, and everyone was like "there is no way that's not taken already". So we looked....and here we are with this disturbing name.

Interviewer: What are your goals or objectives for this film?

Timothy : To wake people up. This is a much larger global concern than many people, even people involved in the controversy, realize. There is a school of research that suggests that Fibromyalgia and CFS are different varieties of Lyme, and that they always have been. If this is the case we need more accurate math, and quickly. The CDC states that there is an under-reporting of Lyme by a factor of 10X. This would bring the numbers to an estimate of 200,000 cases a

I believe that Lyme played a significant role in my sister's death. I have said that she died from complications of Lyme-- not simply the physical effects but also from the social and medical climate that permeates this disease. We first had to convince the doctors that it was Lyme we were treating, that Lyme disease exists in Michigan, and then how they should treat it. The most dangerous symptom of this disease is ignorance.

year. The statistics for Fibromyalgia and CFS, combined, are in the millions.

Interviewer: Is Lyme disease prevalent in the area where your sister Lori lived?

Timothy: According to the medical community in Michigan, it's rarer than conjoined quadruplets. We were, with all honesty, told that there "has never been a case of Lyme in Michigan." Apparently these people have no access to the CDC's website, but will continue to wax profound, profoundly misinformed.

According to the CDC there has been Lyme in Michigan since the early eighties. We have a handful of LLMDs here that are helpful, but given the state of politics in the medical community concerning Lyme, this makes it very difficult to diagnose and treat effectively.

Interviewer: I understand that your production company is conducting an illness survey in the Traverse City Michigan area. Can you tell us a bit about that and have you had any responses?

Timothy: We had placed ads in the local newspapers and online. The response was somewhat modest, less than 100. The ad asked for age, sex, illness, length of diagnosis, and address. We concluded that people were uncomfortable discussing illness in this manner, even though the purpose and use of the information was clearly stated.

Interviewer: Have you encountered any obstacles or roadblocks while trying to get interviews?

Timothy: Yeah, there are a group of doctors with The Infectious Disease Society of

America, whom we've been trying to contact for interviews and they have not returned our calls or emails. I think we should try carrier pigeons-- do you think that might be too much?

Interviewer: Do you feel that Lyme played a role in Lori's ALS?

Timothy: Yes, I believe that Lyme played a significant role in my sister's death. I have said that she died from complications of Lyme-- not simply the physical effects but also from the social and medical climate that permeates this disease. We first had to convince the doctors that it was Lyme we were treating, that Lyme disease exists in Michigan, and then how they should treat it. The most dangerous symptom of this disease is ignorance. Doctors have been led to believe it is something completely different than what it really is, which is a complex multi-systemic constellation of presentations which assault every department of a human being, without reason, without purpose-- not simply a bull's eye rash with achy knees. That said, the main failure in this case, and in the entire Lyme disease world, is one of ambivalence.

Interviewer: Do you have any thoughts as to how this epidemic emerged?

Timothy: Yes, I do. Unfortunately I am unable to go into great detail about this, but I can say that if this disease has been around for centuries why has it only become a problem, possibly pandemic, in our lifetime? This will be discussed in full in the film.

Interviewer: When will your film be coming out and where will people be able to go see it?

Timothy: We are releasing the film June 22nd. The premiere will be held at the State Theater in Traverse City. The State Theater is run by Academy award winning director Michael Moore. We will also be launching an online premiere on the same date. People will be able to purchase tickets for the one-time viewing online. The film will then go into select viewing/speaking engagements with myself and Breanne Russell, my co-director and producer, at colleges and theaters throughout the US, Canada and Europe.

Interviewer: Thank you, Timothy, for taking the time to answer these questions. I am looking forward to the completed movie and I know it will help to bring more awareness to a world where Lyme disease is causing much needless confusion, suffering and death. The time has come for investigation-- not just of the Infectious Disease Society of America (IDSA) but of the powers which are allowing the IDSA and other government agencies to get away with what they are doing, which is essentially disabling the population and making them dependent on the medical industrial complex.

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“Jemsek” ...cont'd from pg 11

bolic, hormonal, malignancies and so forth.

With Lyme disease, there is absolutely no reason to believe that there are simple answers and simple solutions. When people are really sick, they are multiply infected. And I learned a lot from the animal studies, which indicate that if you're infected with Lyme, you're going to get weak and dizzy. But if you add babesia or bartonella, the animal will die. So I learned that and in my own practice, I started looking for signs to tell me why people relapse or do not get well. And in the early years, I came to the conclusion that they're multiply infected, and you have to treat it as a group or conglomeration of infections and regard it as an immune suppressive illness. In other words, we have a Lyme Borreliosis Complex syndrome and a multisystemic chronic illness.

Tina: In your experience with Lyme patients, have you seen anyone who has exhibited AIDS-type symptoms from

immunosuppression?

Dr. Jemsek: Well, I had some AIDS patients who had Lyme. And you know what? The Lyme was worse on the patient.

Tina: Do you currently treat any HIV patients?

Dr. Jemsek: No, I pretty much had to close it down because of the insurance cancellation and lawsuit against me. When that happened, when the dominant insurance company in North Carolina took away our contract, it spelled the end of my HIV practice. When the insurance company sued me, I lost any reasonable chance for a turnaround. What was clearly vicious and premeditated is that they were just trying to take me out; they didn't have to sue me nine months after the news of a medical board review. That was a kill shot, and as I said, they were just trying to take me out.

Basically, their actions assured that a thousand HIV patients were put out on the street. And we had one of the

largest HIV practices in the U.S. and the world, and we were going to double our patient population in four years. We did this with a high standard of practice and very good care in a really good setting. It was our dream to do that. As I say on my website, since there were six practitioners seeing new Lyme patients, we probably also had the largest Lyme and tick-borne illness practice in the country. In late 2005, we were seeing eighty to one hundred new patients a month for possible tick-related illness.

Our case is still ongoing and it will probably take another two to three years to resolve. History will judge us for what we've tried to do and I'm fine with that. I don't totally understand it and I don't try to understand it anymore, but there's a reason I've been put in this position. I also have a sense that people are attracted to my story because Americans like underdogs and resiliency. So, I believe that there's a reason I lost my HIV practice, but now I have a new love in medicine and an incredible challenge.

One of the real tragedies about this epidemic is to think about all the sick people who are clueless about their illness and lead wasted lives, or worse, know their illness and can't access care. And then to consider the sheer size of the epidemic is simply staggering. Even with more efficient models of treatment at our clinic, it still takes a couple of years to get people really better. So, anyone can do the math. It's horrible to consider, but this epidemic can bring our nation to its knees.

The Lyme epidemic is going to forever change how we look at chronic illness. We're going to have to get out of the patch-and-pay model that we have and get into real answers. And if we were all really pulling together and trying hard to get answers for complex patients, we would be well on our way to making significant progress. As it is, the politicization of this epidemic and the corporatization of health care have literally put us twenty years behind, and in the end, this indifference to the

human condition will have victimized millions.

Be sure to read Part Two in the July issue of Public Health Alert.

More Information:

Joseph G. Jemsek, M.D. received his Doctor of Medicine degree from the University of Illinois, Medical Center of Chicago. He served his internship and residency at the Medical University of South Carolina in Charleston. This was followed by his post-graduate fellowship at Baylor College of Medicine at the Texas Medical Center in Houston.

Dr. Jemsek's practice, Jemsek Specialty Clinic, is located in Fort Mill, South Carolina. For more information, visit www.jemsekspecialty.com.

Tina J. Garcia is a Lyme patient and Founder of Lyme Education Awareness Program, L.E.A.P. Arizona at www.leaparizona.com.

“Fear Mongering” ... cont'd from pg 5

the world - ramping up production and use of seasonal influenza vaccine and fast tracking the creation and human testing of influenza vaccines using novel but potentially risky adjuvants and cell substrates - is the way to effectively deal with public health or a future influenza pandemic.

Certainly, the loss of the human right to bodily integrity and informed consent to taking pharmaceutical drugs and vaccines that may pose serious health risks is not justified in the name of controlling pandemic influenza or any other infectious disease outbreak.

Politicians should not bow to additional pressure from vaccine manufacturers and public health officials to by-pass normal FDA standards in proving safety and efficacy of pandemic flu vaccines and their components for the purpose of rushing them to market in response to the pandemic panic that has been created. The swine flu debacle of 1976 should have taught Congress that lesson.

A rational perspective that reduces pandemic fear and includes common sense advice for staying healthy in every season is being offered by holistic health doctors, such as

Joseph Mercola, D.O. and physician Congressman Ron Paul, M.D. The next time you turn on the TV or the radio or search the internet for the latest news on the flu pandemic, take a deep breath and consider all the natural ways to stay healthy and resist influenza or any illness: washing your hands; eating nutritious food; drinking plenty of water; getting enough exercise, rest and sunshine, and lowering stress - which includes not walking around filled with fear, anxiety and dread.

For more information on vaccine safety go to

The National Vaccine Information Center

www.nvic.org

“Checklist” ...cont'd from pg 4

who would be willing to be interviewed by journalists?

[18] Videotaping or photos. It can be helpful to videotape the group meetings for people who are not able to attend so they can hear guest speakers, etc. Inform your attendees so they can choose to sit in view or out of view of the camera. Know when conversation is personal and the camera needs to be turned off. If you aren't sure how you will use the tape, have participants sign a release form. Don't post it online without permission from those who are on the tape. Are attendees comfortable having photos for the media, for exam-

ple, if a journalist wants a photo of the group for a local story?

[19] What kinds of promotional pieces do you need to help promote the group and who can design them? Things like posters, flyers, business cards and stickers can all be very useful in spreading the word about your group. Ask if anyone does design or digital scrapbooking for help and ideas.

[20] Online communication. Does your group wish to have a "hub" online to exchange information or encourage one another? Do they want something simple,

Does your group wish to have a "hub" online to exchange information or encourage one another? Do they want something simple, or a social network setting available through a source like Ning?

like just email exchanges, or a social network setting available through a source like Ning?

[21] Online web site.

It's easy to set up a simple web site using free blog software online. This can be a great place to post your groups' calendar of events, links of resources, announcements, etc.

You can also share online information with your group from other organizations and web sites as well. Use RSS feeds, links to online radio programs, and more. This can quickly give your group the support that they may need that you may not be able to provide on our own.

Don't miss out on the remaining steps 22-35 at Lisa Copen's chronic illness and pain support social network for support group leaders. Be prepared for the hurdles. Read Lisa's book, 'So You Want to Start a Chronic Illness Pain Ministry: 10 Essentials to Make it Work' at Comfort Zone Books or Amazon.com. *pha*

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“Morgellons” ... cont'd from pg 9

detail."

He added, "My speculation, and it still is speculation, is that Morgellons Disease may represent the first known human illness caused by a plant bacterium. And in fact, when people say they have these fibers attached to the skin that don't come out, that are very adherent, in a way they are kind of turning into plants."

He also noted that his research has found some fibers to have a metallic coating, which could explain why many people have witnessed these fibers moving. He said the metal could become charged with electricity, causing the fibers to move.

"The movement is real," said Casey. "Most everyone you can talk to has seen these things move. It's almost alien. It's like your worst science fiction movie. A lot of us will get together and you can put them on the end of a tweezers and see them moving around almost, like a cobra dance."

But getting together, even if it is just to commiserate about the movement in the fibers, is something that seems to help these patients. Savely said, that in addition to light exercise, nutrition, and her treatment regimen, she urges her patients to seek out human contact.

Because some are afraid

Morgellons could be contagious, (there is no evidence to show it is contagious under casual contact) and other are ashamed of their disfiguring lesions, like modern day lepers, many sufferers isolate themselves.

"I think human touch is so important," said Savely. "You can't go without it. I've had patients come up to me and I give them a hug and they start to cry and they say, 'That's the first time I've touched a human being in five years.' How can you live like that? You know you can't. You can't isolate yourself. You need to be around your family now more than ever." *pha*

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C3a & C4a ...cont'd from pg 2

and 12,000. In the two years that I have been using the C4a test to track treatment progress, reduction in C4a levels has consistently correlated with clinical improvement.

Patients often ask if there are other medical conditions that may lower or raise the C3a and/or C4a. Both of these complement products may be increased in normal pregnancy and in certain types of vasculitis (an inflammatory condition that destroys blood vessels). C4a levels are elevated in adult insulin dependent diabetes. Those who suspect that chronic fatigue syndrome (CFS) may actually be misdiagnosed Lyme disease may not be surprised to hear that C4a is also elevated in CFS patients. In fact the C4a is probably elevated in all sorts of infections,

and therefore is not specific to Lyme.

If you would like your health care provider to order your C3a and C4a levels, it is extremely important that the tests be performed only at the National Jewish Medical and Research Center Laboratory in Denver. LabCorp has a contract with National Jewish and therefore your health care provider can order LabCorp tests # 840702 (C3a) and # 857334 (C4a). LabCorp uses two different send-out labs for the test and it is important to indicate that samples should be routed to National Jewish for most accurate results. Ask your health care provider to write on the requisition slip in large letters: "ACCESSIONING: C3a & C4a MUST BE ROUTED TO NATIONAL JEWISH". To find

the LabCorp drawing station nearest you, go to www.labcorp.com and enter your city or zip code in the space provided in the lower left of the home page.

If your health care provider writes the ICD-9 (diagnostic) code of 279.3 (Immune dysregulation) on your LabCorp requisition slip, insurance will more than likely cover the C3a and C4a tests. However, if your insurance does not cover the tests, the prices are not prohibitive. Each of the tests cost \$ 75.60 (valid as of 3-25-09).

Because most lab technicians are unfamiliar with the C3a and C4a tests, it is in your best interest to go to the LabCorp drawing station knowing exactly how your blood should be handled. This way

you will be assured that your sample will arrive at the lab satisfactory for testing. The blood needs to be drawn into an EDTA tube ("lavender top") and immediately spun and separated. The plasma should be frozen right away and sent frozen to National Jewish.

The C4a is not as specific to chronic Lyme as the CD57+ level because it may be elevated in many types of infection, including other tick-borne diseases. However, in patients with known tick-borne infections, the C4a complement protein test can provide a useful way to determine initial degree of infection, to follow treatment progress and to aid in deciding upon treatment end. For more information about the C3a and C4a, please see the suggested readings below:

Shoemaker RC, Giclas PC, Crowder C, House D, Glovsky MM. Shoemaker, R. C., Giclas, P.C., Crowder, C., House, D. Glovsky, M.M. **Complement split products C3a and C4a are early markers of acute lyme disease in tick bite patients in the United States.** *International Archives of Allergy and Immunology*, 146(3), 255-261.

Stricker, R. B., Savely, V.R., Motanya, N.C. & Giclas, B.C. (2009). **Complement split products C3a and C4a in chronic Lyme disease.** *Scandinavian Journal of Immunology*, 69(1), 64-69.

pha

“Roadblocks” ...cont'd from pg 1

Joe Mercola, DO
How Sunshine and Vitamin D Can Radically Improve Your Health (Dr. Mercola will be speaking at the Friday night dinner)

Dietrich Klinghardt, MD
HemoPyrrol-Lactam-uria (HPU), in Lyme disease and Autism

Lawrence Klapow, PhD
Varestrongylus klapowi, a New Zoonotic Parasite from Grazing Animals Found in CFIDS and Lyme Patients

Lee Cowden, MD, MD(H)
Electro-Dermal Screening and Urine Dipstick to Predict Genetic SNP's in Autism and Response to Treatment (Physicians Training) and

Autism Treatment Basics (General Session)

Mary Coyle, DiHom and Lisa Rudley
Using Homotoxicology to Elevate and Support the Health of Those with Autism and Chronic Illness, Better Addressing the Microbial Load

Pramila Srinivasin, PhD
An Online Web-based Treatment Tracking System supporting Visualization and Analysis, for Parents and Physicians: ChARM

Stephen Fry, MD
Evidence of vector borne disease and Epierythrocytic bacteria in Chronic Fatigue Syndrome, Fibromyalgia, Autoimmune Disease, and

Autism

Toby Watkinson, DC
Chronic Illness to Targeted Healing: From Autism to Lyme a Focused Approach

Vicki Warren
Creating a Healthy Home - A workshop on making your home a safe sanctuary from EMR/EMF and more!

Victoria Bowmann, PhD
Start in the Gut: An Overview of Cleansing, Role of Colon for Liver Detoxification and the Value of Rectal Probiotics

"This conference is years ahead of its time, if you want to learn the cutting edge treatments, this is the conference to be at," says Linda Heming, conference

co-coordinator and founder of CHOICE. Whether it is sick children with autism or adults with Lyme disease, Chronic Fatigue or other illnesses, there is something we can all learn and benefit from at this conference. There is hope, there is healing.

Sunday will offer a complete workshop on the top 10 items that need to be addressed to provide healing to all people. This workshop will be presented by Thriiive. The Thriiive panel will include speakers such as Joe Mercola, D.O., Dietrich Klinghardt, MD, Lee Cowden, MD, MD(H), Anju Usman, MD, Robert Slovack and more. Attendees will hear detailed information on life, energy, water, food, exercise, emotions, testing,

body, supplements and detoxification. More information on our special conference workshops can be found online at: <http://lymeinducedautism.com/2009arizonaconference/workshops.html>

Location, registration and exhibitor information can be found online at: www.from-roadblockstorecovery.com *pha*



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