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Chronic Fatigue and Fibromyalgia Expert Creates Comprehensive Recovery Program That Truly SHINEs

by Scott Forsgren

When my quest for better health began shortly after I fell seriously ill in 1997, one of the most significant resources that I found at the time was a book titled "From Fatigued to Fantastic" by Jacob Teitelbaum, M.D. At the early stages of my illness, I was years away from a Lyme diagnosis, but I knew that something was seriously wrong and that if I did not find answers soon, I truly felt as though my experience on this planet could be short-lived.

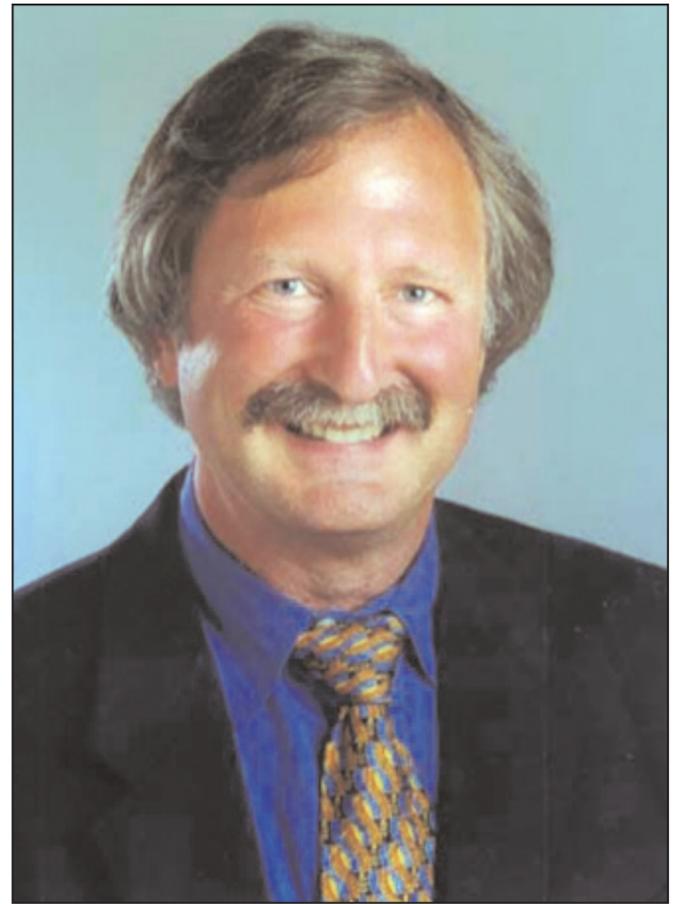
To this day, it is my opinion that "From Fatigued to Fantastic" is by far the best book available on the topic of chronic illness. With the third edition having been released in 2007, I once again became interested in Teitelbaum's work. It has always been my position that those of us with chronic Lyme disease have numerous issues which must be addressed in order to regain our health. A sole focus on antibiotic treatment to eradicate chronic *Borrelia burgdorferi* infection almost always results in sub-optimal treatment outcomes. The beauty of Teitelbaum's work is that he has created a comprehensive program that addresses the many issues that one must consider in order to recover from many chronic illnesses.

Whether we call it "Chronic Fatigue" or "Fibromyalgia" or "Lyme disease", the bottom line is that each of these illnesses has significant commonalities. There

is a trigger which causes the body to become overloaded. The result is that a fuse is blown much like having too many space heaters plugged in may result in tripping a circuit breaker in your home. The body makes the decision that it is time to go "offline" as a protective measure as it is no longer able to manage additional insults. Each of these illnesses is an endpoint for a number of overwhelming stressors. The body does not care what "diagnosis" is put on it. Nearly every aspect of Teitelbaum's protocol applies to chronic Lyme disease just as well as it does to a number of other conditions.

With Lyme disease, one of the "space heaters" that leads to a fuse being blown is without a doubt the *Borrelia burgdorferi* infection itself. However, there are numerous other stressors which add to the total body burden of infection and toxicity. These must be considered and addressed in order to pave the way to a recovered state of health. Teitelbaum believes that "we have to unplug the space heaters that blew out the fuse before we attempt to turn back on the circuit breaker."

The fuse could have been blown 30 years ago and yet if one unplugs the space heaters and turns back on the breaker, the lights will come on. For those patients following Teitelbaum's "SHINE" protocol, symptoms improve or, in many cases, the illness resolves entirely regardless of how long the patient has been ill. That



Jacob Teitelbaum, M.D., creator of "SHINE" protocol

said, Teitelbaum cautions that the patient must learn from the illness and adjust their lifestyle appropriately as to not overload the body in the future. Dr. Teitelbaum has observed that it is often the "Type A personality" or those people that "push through fatigue" that are often impacted the most by these illnesses. The illness is not the enemy. Symptoms are the presentation of a defense mechanism on the part of the body where the body is forced to shutdown in order to preserve energy for critical functions required to support life.

"SHINE" is Dr. Teitelbaum's comprehensive protocol which has been found to successfully treat patients in about 91% of cases. In the majority, patients improve by the fourth month of treatment. They continue to improve over the course of about two years and can then wean off their treatment programs and continue to maintain good health. With the SHINE protocol, Dr. Teitelbaum has seen very promising results in people with chronic Lyme disease.

"SHINE" ... cont'd pg 6

A Day of Remembrance: Vaccine Injured March on Capitol Hill

by Barbara Loe Fisher

They came by the thousands from all over the America. On June 4, 2008, mothers and fathers with vaccine injured autistic children marched down the middle of Independence Avenue and rallied at the foot of the nation's Capitol. Some parents walked with, held or pushed their children in strollers while others, whose children were too severely brain injured to attend, carried signs and photos. They had come to witness, in one way or another, what had happened to their children after vaccination.

The day broke hot and humid with a threat of torrential rains that would have drenched the marchers. But then, the skies cleared and the

sun came out in time for the determined parents and their children to gather on the grounds of the Washington Monument and line up behind Hollywood celebrities Jim Carrey and Jenny McCarthy leading the march and the "Green Our Vaccines" rally that would follow.

Although the primary message of the march was to call on government health agencies to "remove toxins" from vaccines and "adjust the vaccine schedule" by reducing the numbers of vaccines given to infants simultaneously, NVIC supporters carried signs declaring "No forced vaccination. Not in America." As NVIC co-founder Kathi Williams and I walked past the long line of families waiting to begin the march, we and our

now-grown children held up the signs featuring the American flag and statue of liberty. All the way down the line, the families of vaccine injured children clapped and cheered the message of freedom we carried to honor and empower them as we passed.

And while many at the front of the line marching down Independence Avenue chanted "Too many, too soon," those of us bringing up the back of the line chanted "Hey, hey, Ho, ho - forced vaccines have got to go!" with an African American father urging us to shout louder and louder as we approached the Department of Health and Human Services. "Let them hear you," he yelled. "Tell them what you want."

I looked at my 30-year old son, who became learning disabled after a neurological reaction to his fourth DPT shot in 1980 when he was two and a half, as he walked beside me resolutely holding up our sign and shouting in a deep voice "Forced vaccines have got to go." When he was eight years old, I remembered marching in Atlanta in front of the Centers for Disease Control in 1986 with Kathi and the young mothers of babies who had been brain injured or died after DPT vaccination in the 1980's. We were the first generation to march in protest against toxic vaccines and one-size-fits-all government vaccine policies justified by the utilitarian premise that it is ethical to throw a minority of

"Vaccine Injured"... pg 2

“Vaccine Injured” ...cont'd from pg 1



Actor Jim Carey addresses the media about the national problem of vaccine injured children.

children under the bus in service to others.

The second generation, whose children were born in the 1990's and developed autism after vaccination, held a series of rallies on Capitol Hill sponsored by Unlocking Autism beginning in 2000

when Congressman Dan Burton initiated congressional hearings on the link between autism and vaccines. In the summer of 2005, parents protesting mercury in vaccines marched and rallied on Capitol Hill. Today, the third generation knows that vaccine damage is about more

than mercury. It is also about too much vaccination: 48 doses of 14 vaccines given by age six and 69 doses of 16 vaccines federal health officials now say children must get by the time they graduate from high school.

At the rally podium, Jim Carey delivered a remarkable

address that was also a sweet love letter to his partner, Jenny McCarthy. He said "Autism is everywhere. It is on every street and in every town" and he asked the CDC "How stupid do you think we are?"

Robert F. Kennedy, Jr. and physicians such as Jay Gordon, M.D. and professor of chemistry Boyd Haley, Ph.D. called for removal of toxins from vaccines. Jenny McCarthy, who is the celebrity spokesperson for Talk About Curing Autism Now (TACA), held up the government's childhood vaccine schedule and said "Parents need to know it is called a recommended schedule, not a mandatory schedule."

Unfortunately, that may not be true in many states in the future. Lobbyists for drug companies making vaccines, medical organizations representing doctors who give vaccines and government health officials are pressing state legislators in every state to pass legislation that would automatically turn CDC new vaccine "recommendations" into state mandatory vaccination laws.

This kind of proposed legislation was beaten back in the California legislature by the education efforts of autism activist Rick Rollens last year. But right now, the New York State legislature is about to capitulate to the Forced Vaccination Lobby and force children in New York to use every vaccine the CDC "recom-

mends" or face punishment, including loss of the right to get an education.

A rally of families protesting the proposed legislation was held in Albany, NY at the Capitol Building at 11:30 a.m. on Tuesday, June 10. For more information, go to www.mykidsmychoice.com

I will never forget marching with parents and their vaccine injured children in Washington, D.C. on June 4, 2008. Just as I will never forget all the marches that have gone before during the past quarter century that parents have been asking those who operate and profit from the mass vaccination system to make vaccines and vaccine policies safer.

Three decades of begging is long enough. Now it is time for all Americans - both those with vaccine injured children and those with healthy children - to Stand Up and Be Counted for the human right to make informed, voluntary decisions about vaccination. Our freedom and the biological integrity of this and future generations is on the line. Without the legal right to say "no" to vaccination, the people have no economic or political leverage to protect themselves and their children from toxic vaccines and dangerous vaccine policies.

The next march on Capitol Hill talking about vaccines should be all about freedom.

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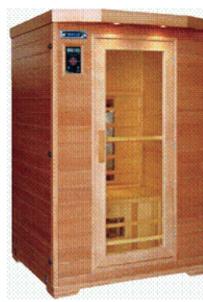
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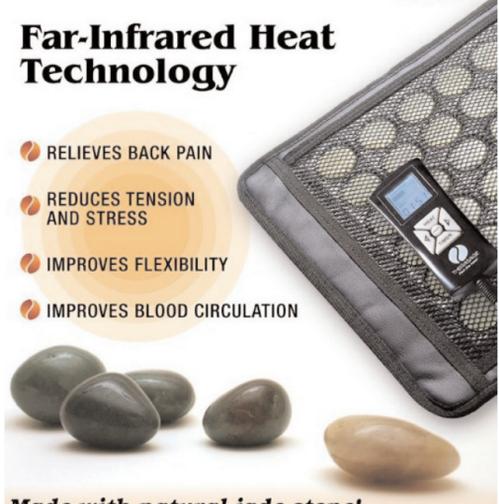
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PHA seeks to bring information and awareness about these illnesses to the public's attention. We seek to make sure that anyone struggling with these diseases has proper support emotionally, physically, spiritually and medically.

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IDSA: Did They Change the Blade in Occam's Razor?



by Dawn Irons

In the 14th century there was a principle that was established by an English logician and Franciscan friar William of Ockham. This principle purported that, "All things being equal, the simplest solution is the best." This principle became known as Occam's Razor.

The medical establishment has used this principle in training generations of physicians. The principle has also been expressed with many analogies. Who hasn't heard a doctor tell their patient, "In medical school we were taught that when you hear hoof beats we should assume it is a horse and not a zebra." [Be sure to read Dr. Virginia Sherr's article entitled In Defense of the Zebra

in this issue of PHA.]

The principle has been shared throughout the ages. The most elementary form of defining Occam's Razor is probably the old adage, "If it looks like a duck, waddles like a duck, and quacks like a duck...it is probably a duck!"

In short, Occam's Razor is the logical conclusion that simplest solution is the best answer.

Logical Simplicity vs. Complex Contortions

The Infectious Disease Society of America (IDSA), one of the largest medical societies in the United States that boasts of 8,000 members, has recently been under investigation for anti-trust violations by the Attorney General of Connecticut, Richard Blumenthal.

What are "anti-trust violations" you ask? I am so glad you asked! If we are to apply Occam's Razor to this issue, it boils down to "follow the money". Remember the Parker Brothers board game Monopoly? He who has the most property and money at the end of the game wins. The Attorney General's investigation proved major conflicts of interests (financial interests) of the writers of the IDSA's 2006

Lyme treatment guidelines. Not only did the guidelines tell physicians nation wide what the IDSA believed was the best way to treat Lyme disease, they went so far as to say that other modes of treatment (traditional or alternative) were not to be recommended. They did not suggest the use of any supplements...not even vitamin C. They did everything in their power to steer treatment options to only one possible choice. Their choice.

With the publication of these Lyme guidelines by the 8,000 strong IDSA, other previously published guidelines for the diagnosis and treatment of Lyme disease by the International Lyme and Associated Diseases Society (ILADS), whose membership ranges about 300-400 members (who are actually treating--hands-on-- Lyme disease patients on a daily basis) was completely overshadowed by this Goliath organization.

These two organizations have polar opposite opinions of how Lyme disease should be diagnosed and treated:

IDSA (the Goliath in this showdown) published guidelines that stated that Lyme disease was easily diagnosed and easily cured with 28 days of antibiotics. They stated that if symptoms persisted then

there was likely some other problem going on-but the Lyme disease would have been "cured".

ILADS (the underdog in this showdown) had a simple solution that the Occam's Razor principle exemplified beautifully. They believed that if after 28 days of antibiotics the patient still had symptoms of Lyme disease, then they would treat until the symptoms subsided because clearly they were still dealing with Lyme.

Now I am not a brain surgeon or a rocket scientist, but in my layman's opinion the simplest solution would be that the 28 days of treatment was inadequate to cure the disease and that more treatment would be warranted. I think it takes some fancy gymnastics (or a limber contortionist) to jump to the conclusion that after 28 days of antibiotics, with persisting symptoms, that the disease has morphed into some other disease entirely, but the person is now "cured" of Lyme disease. Where is the LOGIC in that?

Investigating Modes of Lyme Disease Transmission

The IDSA vs. ILADS debate will continue for years. Unfortunately the patients are the ones that suffer as collateral "*Occam's Razor*"...cont'd pg 4

It's All About Balance

Perks from the Pistol Packin' Texas Grandma

by Harriet Bishop

What do you think of when you hear the word "balance?" A graceful ballerina dancing on her toes? An agile gymnast on the balance beam? A new pair of athletic shoes? Your checking account? Your healthful diet?

All these different meanings have significance for people who are managing a challenging lifestyle by juggling the demands of chronic illness in the family while balancing the everyday chores with other activities that bring fulfilling joy.

Physical activities as tolerated such as dancing and gentle sports or games can enhance our feelings of well being unless overdone.

Solid underpinnings such as well-fitting athletic shoes, perhaps with prescribed orthotics, can help to keep our body in alignment.

Balancing our finances by using good judgment to regulate expenditures according to income can lead to a healthy bank balance.

And yes, let's not underestimate the importance of balancing our daily work with activities that bring us joy. Some of us revert several times a day to a 'hobby break,' like the busy executive wielding a putter in his office between multimillion dollar deals, or the housewife who makes beaded jewelry between laundry loads.

Others who are more serious minded may have to jot notes to remind themselves to

schedule relaxing activities that lessen tension.

And what better way to release tension than to enjoy a good laugh over a funny joke! A sense of humor goes a long way in keeping us balanced. There is humor to be found in almost any human situation no matter how dire, if we are open to seeing it. Sometimes we might have to remind ourselves that this is going to be funny later on, after we manage to get through it.

Almost everyone could use more greens and other fresh vegetables in their diets. Have you ever thought of growing your own? Even if you live in an apartment, you can fill flower boxes or planters with potting soil and plant seeds of parsley, spinach, carrots or beets on your balcony. Avoid pesticides and you'll have fresh organic foods in season, locally grown, the best foods for our bodies.

That brings to mind the greatest balancing act of all-the Balance of Nature. Stepping out onto the porch in the early spring twilight, I gasped and leaped backward, as an other-worldly creature writhed just inches from my open toe sandal. Have you ever seen a dark brown bug, fully eight inches long and two inches wide with seemingly a million legs? My heart pounded as I tried to make sense of this thing that scared me as much as if it had been a rattlesnake.

I did what any rural Texas housewife would do-no, not the pistol. I'm not that vio-

lent! I grabbed a shovel, and briefly thought that I hated to end a precious life, but quickly justified my action based on the fact that my hands were still shaking from the fright. I swiftly beheaded the ugly monster. A neighbor wanted to take him fishing-as bait! So the scary creature met his final demise in Canyon Lake.

Later that week I noted that my pansy blossoms which had overwintered in good shape were looking lacy as if something were making a meal of them. I have tried the blossoms in my salads and I admit they are tasty...but they are for my family, not for unwelcome visitors to my garden! The dampness of the early evening revealed the culprits. By the dozens, they were oozing their slime in shiny trails across the walk.

Did you know that a little dash of salt on a slug will melt him into a shapeless glob almost instantly? There were so many of all sizes from half an inch to two and a half inches long that I used a whole box of salt during the next three evenings, and had to buy more.

And then I caught them red-handed in their nasty action, curling onto a pansy petal, chomping away at the pretty purples and yellows. What to do now...you can't sprinkle salt on the plant without expecting the death of the innocent victim. And they are wa-ay too slimy to pick off by hand.

It's time to consult the experts, Malcolm Beck and his "Texas Bug Book." Because I

avoid pesticides, I was delighted to learn that jar lids filled with beer will do them in as they guzzle the brew and apparently fall in to drown. It wasn't unusual to find 15, then 20 slugs in the morning floating in the murky liquid beneath the pansy blossoms. The news spread fast among the little creatures of the garden, and I placed jar lids every few feet, only to find them full every morning. The slugs numbered in the hundreds, increasing daily.

Soon I needed larger containers, and discovered that the bottom two inches of a plastic water bottle works better than a shallow jar lid.

Returning to Malcolm Beck's book for more tips, I was startled as I turned a page to reveal a photo of the ugly monster I had beheaded! Describing it as a Giant Centipede, the text explained that its favorite food is...you guessed it...slugs!

So in my haste to destroy him through my own baseless fear of an unknown, I had interrupted his feast that night, put an end to his innocent life, and upset the delicate Balance of Nature in my garden, bringing the plague of slugs upon myself.

Ah-h-h...too late smart.

Moderation in all things, as well as balance in all areas of our lives would bode us well as we juggle the demands of chronic illness and the chores of daily life.

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“Occam’s Razor” ...cont’d from pg 3

damage when the doctors cannot agree.

There is much medical controversy over the possible modes of transmitting Lyme disease. IDSA pretty well sticks with the theory that is only transmitted by the bite of a deer tick. ILADS considers various modes of transmissions and wishes to study this issue further.

Lyme disease is a spirochetal bacterium, much like another spirochete, *Treponema pallidum* which causes Syphilis. Syphilis, we know, is a sexually transmitted disease. So it stands to reason that research into this possibility might be a benefit to the public health.

Sexual Transmission

The medical community is once again at complete odds over the issue of sexual transmission of Lyme disease. IDSA doctors stick to their guns and say that Lyme is only transmitted by the bite of a deer tick. ILADS believes they have seen enough trends and anecdotal cases that would warrant a closer look with some serious researchers (those without conflicts of interest.)

The two schools of thought rarely find common ground in their approach to the illness. Edward McSweegan, Ph.D., the former program officer for Lyme disease at the National Institute of Health's (NIH) National Institute of Allergy and Infectious Diseases was released from his duties after he spoke out on the internet about what he felt was the NIH putting forth unscientific and incorrect information about Lyme disease. McSweegan further criticized the Lyme Disease Foundation (LDF) as putting forth "wacko" theories about the disease.

McSweegan went on to publish a website called "Quackwatch". This site was dedicated to his ideas that the NIH, LDF, and much of the information on the internet concerning Lyme disease was pure quackery.

Quoting from his website, www.quackwatch.org, McSweegan adamantly says, "At least a few LLMDs (Lyme Literate Medical Doctors) appear to be telling patients that Lyme is sexually transmitted

and therefore their family members should be tested. One person reported to Quackwatch that a family member had been tested and told that the test was positive and that a 4-5 month course of antibiotics was necessary."

"There is no basis for such advice or beliefs. Lyme infections are acquired from the bite of an infected tick. People are "dead end" hosts and do not spread Lyme infections to others." This is a fact of which he is absolutely certain.

Unfortunately for McSweegan, the scientific evidence does not seem to support his theory. In fact, the research that has been done regarding sexual transmission of Lyme disease has had significant findings and suggests that further research be done.

In April of 2001, Dr. Gregory Bach presented his research which was titled *Recovery of Lyme Spirochetes by PCR in Semen Samples of Previously Diagnosed Lyme Disease Patients* to the International Scientific Conference on Lyme Disease. His study showed that initially there was a 40% infection rate among male partners of females who were diagnosed with Lyme and of male Lyme patients by the Western Blot and PCR blood testing methods. As the study progressed there were 100% positive results of semen and vaginal samples of Lyme titers and PCR blood testing in the sexual partners of Lyme infected patients.

Dr. Ron Kennedy of Santa Rosa, California says, "Sexual transmission of Lyme disease has been anecdotally reported and the Lyme spirochetes have been found in semen and breast milk. Transmission by these routes, although seemingly likely, has not been proven." He further suggested that more research needed to be done.

With all the controversy surrounding the sexual transmission of Lyme disease, and the public health implications that encompasses, one has to ask why there is not more vig-

orous research being done on this bacterium which is the fastest growing infectious disease in the country.

Congenital Transmission

McSweegan denies that congenital transmission of Lyme disease exists. His website boldly states, "The topic of pregnancy and Lyme is also rife with rumor and unnecessary fear. A recent review of case reports and other research found no specific patterns of fetal malformation or adverse events in pregnancy. In addition, the authors noted that 'larger epidemiological and

date miscarriages, still birth, neonatal death and congenital Lyme disease have all been described in the medical literature.

There have been several studies that have shown that gestational Lyme disease parallels the diversity of prenatal syphilis. (Gestational Lyme Borreliosis: Implications for the Fetus, A.B. Mac Donald, Southampton Hospital, NY.)

Autopsies and clinical studies have associated gestational Lyme disease with various medical problems including fetal death, hydrocephalus, cardiovascular anomalies, neonatal respiratory distress, hyperbiliru-

binemia, intrauterine growth retardation, cortical blindness, SIDS and maternal toxemia of pregnancy. (Gestational Lyme Borreliosis: Implications for the Fetus, A.B. Mac Donald, Southampton Hospital, NY.)

Another study out of the departments of Obstetrics and Gynecology at the University of Trieste School of Medicine showed Lyme Borreliosis positive blood tests were associated with spontaneous miscarriages.

Blood Transmission

The Centers for Disease Control and Prevention (CDC) have reported at least 21 cases of Babesia microti and WA-1 Babesia parasites having been transmitted by transfusion from asymptomatic infected donors. Babesia is one of the many co-infections that are often accompanied with a Lyme diagnosis. This raises the question of how safe the national blood supply is and what safe-guards are in place to prevent infected blood getting into the supply.

A review of the top blood banks showed some concerning trends where blood and organ donation are concerned in terms of Lyme disease and Babesia. Some banks had standards that prevented blood to be donated. Other banks had a policy of waiting 6 months. And still other banks had a policy that as long as you were symptom free they would take your blood...regardless of whether you had ever received

treatment for the disease.

The Red Cross will accept blood from a Lyme disease patient so long as they are symptom free and have completed a course of antibiotics. (This raises the issue of the controversy: does 28 days of antibiotics "cure" Lyme? If symptoms persist the IDSA says it is a new disease entirely. Then what disease has it become? Is it safe to donate with this new "yet unnamed" disease?)

The UCSF Blood Center has a permanent deferral for anyone who has ever been diagnosed with Lyme disease or Babesia. They will never again accept blood from these people. The New York Blood Center will accept Lyme patients blood if they are symptom free and are through with treatment. If you have symptoms they will defer you for 6 months. At that time they will accept your blood again even if you have not received treatment for the disease.

There are studies that show that both Lyme borrelia and Babesia microti and WA-1 parasites remain viable under blood bank conditions. To see the lack of consensus on what protocols are in place concerning blood and organ donation... this should be sounding sirens on the highest hill, the legislative Capitol Hill! This is an issue of public safety.

Back to Occam's Razor

If it is really a medical principle that the simplest solution is the best answer, it is time we start demanding answers. There is enough evidence that at least warrants some serious research into these issues.

While the medical controversy rages on, pride and ego set aside, who is going to connect the dots of the information that has significant findings but needs further research?

This we know:

Borrelia burgdorferi (Bb) spirochetes have been shown to be in the bodily fluids of breast milk, semen and vaginal fluids.

“Occam’s Razor”... cont. pg 12

As the study progressed there were 100% positive results of semen and vaginal samples of Lyme titers and PCR blood testing in the sexual partners of Lyme infected patients.

serological series have consistently failed to demonstrate an increased risk to pregnant women who develop Lyme disease if they receive appropriate antimicrobial therapy.⁷ Attempts to demonstrate venereal, transplacental and contact transmission of Lyme spirochetes in hamsters also have failed."

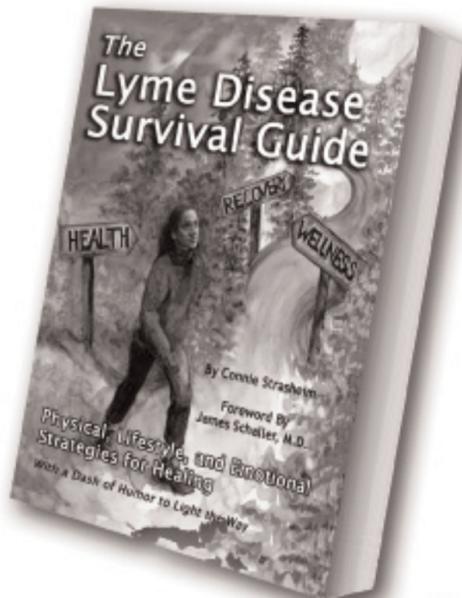
I suppose that is good news for the hamsters, but not so much for the humans. In 1985, researchers published the first proof of maternal-fetal transmission of Borrelia burgdorferi (Bb): A baby died shortly after birth and Bb spirochetes were found in the infant's spleen, kidney, and bone marrow. (Schlesinger P, Duray P, Burke B, Steere A, Stillman A. Maternal-fetal transmission of the Lyme disease spirochete Borrelia burgdorferi. Annals of Internal Med. 1985;(Vol 103) 67-68.) To

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Hope: An Anchor to My Soul



by Joan Vetter

During a recent Aglow retreat the most common "ailment" ministered to was hopelessness. The evidence that God had made heart changes showed on the faces of the women as they left after that weekend. There were smiles, hugs, lightheartedness in large quantities as women said their goodbyes.

In Proverbs 13:12 we are told that hope deferred makes the heart sick. At times we are up against a genuine setback where we find ourselves sick at heart; however the Holy Spirit will make a path through that wilderness as we learn to trust God. Regardless of the situation, the enemy loves to

whisper that it will never change. If we agree with him, we empower him. If we agree with the promises of God, we empower the Holy Spirit to hover over the chaos of our lives and bring beauty out of despair.

Our church life group is studying the book, *The Supernatural Power of a Transformed Mind*. Last Wednesday evening we discussed the author's opinion that the gates of hell are set up in people's minds - that our minds are the gatekeepers of the Kingdom of God. I've been thinking of examples of this since that study. Suddenly the scripture in Matthew 16:15-17 came alive to me, where Jesus asked His disciples who they say that He is. When Simon Peter answered, "You are the Christ, the Son of the living God", Jesus said to him, "Blessed are you, for flesh and blood has not revealed this to you, but My Father who is in heaven." He then told him that upon this rock (of revelation from Heaven) He will build His church, and the gates of hell will not prevail against it. Therefore there was a living connection between revelation (which comes through our

minds by the Spirit) and the gates of hell.

In 2 Corinthians 10:5 we are told to bring every thought into captivity to the obedience of Christ. When a thought comes that our marriage relationship will never change, our kids will never get off drugs, or our illness will get progressively worse, do we come into agreement with that thought? (Wherever two agree as touching anything it will be done for them). Or do we move to the offensive and believe that our God is a supernatural God and nothing is impossible with Him?

Today I took my granddaughter to the library. As she was busy on their children's computer, I picked up a book - *Finding Hope: Cultivating God's gift of a Hopeful Spirit*, by Marcia Ford. I love what she said: "Hope signifies God's Covenant with us, the rainbow of promise that appears at just the right moment, when we look around and see nothing but devastation. Hope pushes back the waters that threaten to engulf us, as God's hands held back the waters of the Red Sea to give the children of Israel safe passage. Hope is God's healing

touch, life-giving strength, resurrecting power. Hope revitalizes, refreshes, and rejuvenates us in body, mind, and spirit."

Graham Cooke, who will speak at Aglow's next National Conference in Washington D.C., spent some time in the International Aglow office in Edmonds, Washington. He shared that God is shaking us out of where we have been into where He wants us to be. He said it this way: "Most people don't need to be talked out of something, but talked into something. When God presents something beautiful, we let go of whatever we must in order to grab the beautiful. Your job in Aglow is to give beauty for ashes. People will climb out of the ash pit to acquire beauty in their lives. Most women are gripped by a poverty spirit, which means they live with meager possibilities. That is so NOT who you are! You must learn to think as God thinks and live a resurrected, ascended life style. The measure of God is about abundance and fullness. What do we have to un-learn in order to live brilliantly and with passion?"

I heard of a minister who effectively preached with power by a simple question.

The Holy Spirit revealed to him that many people there were heavily burdened with grief for a prodigal in their family. So he simply asked this question: "How many of you sitting here were prodigals at one time?" Almost everyone stood up. Mission accomplished - he needed to say no more! Hope sprang forth in people's hearts.

Let's envision the scripture in Hebrews 6: 19. We're encouraged to lay hold of the hope set before us, and then told that it is an anchor of the soul. I like that as I picture a boat in the middle of a tumultuous sea. The anchor keeps it steady. That's how our souls stay - steady - regardless of the turmoil around us! The Message Bible states it this way: "We who have run for our very lives to God have every reason to grab the promised hope with both hands and never let go. It's an unbreakable spiritual lifeline, reaching past all appearances right to the very presence of God where Jesus, running on ahead of us, has taken up His permanent post as high priest for us."

So...grab hold...never let go. Let hope be that eternal flame in your heart that never goes out. *pha*

Eight Reasons to Take a Break From Illness Support Groups



by Lisa Copen

Upon the diagnosis of an illness everyone, including your doctor, likely tells you to go to a support group. Research has shown that support groups can be extremely helpful in how one copes with disease. And yet, not everyone finds a group to be the answer to the kind of support for which they are searching. Like any kind of group, there are some support groups you will "click" with and others you will not. So don't rule out all support groups just because one doesn't seem like a good fit.

But is a support group really necessary right now? Whether you are looking for a amyloidosis support group in New York City or an Asperger's support group in Dallas, the real question may be, is this a season in your life when you need the support that a small group offers? Just as changes occur while we living with illness for decades there are seasons in our life when an illness support group may be where we find our very best friends; Other times it may feel like we have no desire, or even need, to attend.

Below are eight tips to help you decide if a support group is something you may not even need right now:

1. You are coping well with the day-to-day aspects of living with illness. You don't think about your illness non-stop because you're simply too busy living life.
2. You have a solid group of people who are a good influence. Friends or family members are supportive in your efforts to live your best life possible despite having an illness.
3. You don't experience feelings of anger, bitterness or resentment towards healthy people -- at least on a regular basis. You can have relationships with people with comparison of your abilities (or lack of) ever entering your thoughts.
4. You easily carry on conversations with people without ever bringing up the topic of your illness. You don't believe that your illness is such a fundamental part of who you are that it's necessary to describe your medical challenges to total strangers.
5. You don't watch others with envy. You feel you have overcome any annoyances you may have previously felt toward people who have their health, but who do not seem to be appreciating it.
6. You have found that when you sit around at support group meetings talking about the highs and lows of living with illness, you rarely leave the meeting feel better. The support group you are in is more depressing than refreshing and talking about your illness doesn't seem to be helpful.
7. You are able to be a good advocate for your well-being. When you need information on symptoms or tips about living with your illness, you are equipped to find the information.
8. You have found at

least one dear friend who lives with illness. Being able to talk openly with a good friend who has a realistic idea of what you are coping with can be extremely helpful in your daily living skills. You have the chance to vent or contribute ideas with another person who understands the details and "language" of illness.

If some of the examples above sounded like a description of where you are at with support groups, it's likely you don't really need a support group right now in order to live emotionally healthy with a chronic illness. However, you may be surprised to find that you could be an excellent leader of an illness support group. All of the statements above can be an easy way to create a proposal for starting up a support group.

The best support groups are often led by people who have overcome the daily frustrations and bitterness that accompany illness during the first years of diagnosis. The fact that you are past the initial rollercoaster of emotions would greatly benefit a group of people still struggling with them.

If you feel leading a support group is not your calling then go enjoy other things you are passionate about. Remember, there are friends in wonderful support groups who will be there when you need them. *pha*

Lisa Copen was diagnosed with rheumatoid arthritis at the age of 24. She is the founder of Rest Ministries, an online support group for chronically ill people.

www.restministries.org

LIVING IN BED

by Tracy A. Will

Living in bed is eerily surreal
You exist in a world that doesn't make sense
Where escape remains forever elusive.
You memorize every crack on your ceiling
Every cobweb taunts you, yet stubbornly remains

You want to reach up and swoop them away
Yet pathetically, lack the energy to do so.
The marks on the walls become a tapestry
Every inch indelibly committed to memory
The dust on the furniture, a permanent fixture
And close cousin to the bunnies under the bed.

Your bedside table is littered with pill bottles
Half drunk glasses of water, maybe a dish or two
Books lay open but never finished
Words blur together before anything makes sense.

Over 400 channels and nothing to watch
Nothing really matters, it is all so trivial
Attention is fleeting and hard to sustain
Back to the maze of ceiling cracks.

Though at first it feels like a sanctuary
Sinking down into the softness and calm
Aching muscles sighing with relief
Before long it becomes like quicksand
Sucking you down into its angry abyss.
I am falling, I am being swallowed whole

Into this blackness, this eternal trap
This hollow place of sickness and endless fatigue
The same sheets that soothe and envelop me
Placate me with comfort and warmth
Soon become soaked with salty sweat,
Twisted by the endless, restless writhing
Of a body seeking ever elusive peace
Evidence of invisible monsters wrestled
Yet again, to no avail.
Night becomes day,
Day becomes night

Dreams vividly haunt my sleep
Lingering relentlessly into my wakefulness
Creating a semi conscious cloud of confusion
Where I eventually succumb to the exhaustion
My brain, filled with microscopic evil corkscrews
Can no longer negotiate time and space
My body, lifeless and drab
Is left behind,
agonizing wreckage on the bed.

This bed.
I live in this bed.
My prison, my dungeon, my solitary confinement.
My solitude, my comfort, my saving grace.
My bed.

“SHINE” ... cont'd from pg 1

The components of "SHINE" are:

S = SLEEP.

Recommend 8-9 hours sleep per night. Sleep is critical in replenishing the body's energy system and promoting healing. A lack of sleep leads to exhaustion and pain and only further impedes recovery.

H = HORMONES.

Assess and treat hormone deficiencies, which are often present even if lab tests are "normal". Hormone imbalances can contribute to many of the symptoms of chronic illness.

I = INFECTIONS.

Evaluate presence of infections and treat when present. Underlying viral, bacterial, parasitic, and fungal issues must be addressed as they contribute to or trigger the illness.

N = NUTRITIONAL SUPPLEMENTS.

Nutritional supplements are essential. Many patients with chronic illnesses are nutritionally depleted. Often, specific nutrients must be provided at high doses in order to provide the body with necessary building blocks for healing.

E = EXERCISE.

"E" was an evolution of Teitelbaum's previous "SHIN" protocol. Dr. Teitelbaum observed that those patients that did the best with their recovery were those that incorporated an "exercise as able" component into their protocol.

Each component of the "SHINE" protocol is a key to improving a patient's state of well-being. None of these components can be overlooked. The following are some important points of each of the components of the "SHINE" protocol.

S - The "fuse that is blown" in these chronic illnesses is the hypothalamus. The body is spending more energy than it can generate. The hypothalamus is not damaged but is forced into functioning at a lower level. This lower-than-optimal hypothalamic function results in hormonal problems as well as an inability to attain the restful sleep required for recovery.

Dr. Teitelbaum prefers the natural options such as Valerian, Passion Flower, Wild Lettuce, Hops, Jamaican Dogwood, and Theanine. He has created a formula called "Revitalizing Sleep Formula" which is designed to promote sleep using these natural options. He also finds that a Calcium/Magnesium supplement at bedtime or ½ mg of Melatonin can be quite helpful. Even a Lavender eye pillow can support improving one's quality of sleep.

Looking at prescription options, Dr. Teitelbaum prefers Ambien. At 10mg per night, this is the single best sleep aid available. Other prescription options which may help

improve sleep include Trazadone, Klonopin, Neurontin, or Lyrica.

H - It is common for Dr. Teitelbaum to see low thyroid function and adrenal exhaustion in many patients with chronic illness. These must be evaluated and treated in order to support the body's recovery. Unfortunately, many conventional tests have such wide ranges of "normal" that the average doctor may consider these to be non-issues and yet, the patient is not functioning in the "optimal" range for health.

Dr. Teitelbaum believes that doctors rely too much on blood tests and finds that these tests are often inaccurate. In most cases, conventional lab testing does not look at the optimal range for functioning, but rather looks at only the rare extremes as out of the normal range. For example, of 100 people, only the bottom 2.5% may be considered low and the top 2.5 percent considered high. This leaves 95% in the "acceptable" or "normal" range when in fact they are not in the "ideal" range to support optimal functioning and recovery.

If a patient is tired, achy, intolerant to cold, or has had unexplained weight gain, a trial of natural Armour thyroid may be warranted regardless of what the tests show. Dr. Teitelbaum suggests against using TSH as a test for thyroid function as he finds it to be unreliable. Instead, he suggests looking at Free T4 as a more accurate indicator of the need for thyroid supplementation.

Adrenal testing is similarly misleading. Dr. Teitelbaum states that "normal" is a cortisol level of 6.0 or above. 6.0 is considered "normal" where 5.9 is considered critical and warrants a trip to the hospital. Most people have a blood level of around 20. The ranges used were not developed to look at "optimal" function. When a patient is irritable when they are hungry, this is one sign that adrenal support may be needed. Dr. Teitelbaum often uses Cortef in a very safe dose of 20 mg or less per day. Higher doses can be problematic; however at lower doses, adrenal support and immune function are both optimized. Adrenal Stress End is a product that Dr. Teitelbaum formulated to support adrenal function. It contains Vitamin C, Vitamin B6, Pantothenic Acid, Licorice, Adrenal Polypeptide Fractions, Betaine, L-Tyrosine, and Adrenal Cortex Extract which all support optimal adrenal functioning.

Another critical area to evaluate when looking at the hormonal portion of the SHINE protocol is the level of sex hor-

mones. Estrogen, Progesterone, and Testosterone should be evaluated and supported as necessary. In many cases, women require testosterone supplementation as well. If fatigue, pain, or brain fog is worse around the menstrual cycle, bio-identical hormone replacement may be appropriate. Research, however, clearly shows that synthetic hormones are dangerous and should be avoided.

I - The vast majority of patients with these fatiguing illnesses are infected with HHV-6, EBV, CMV and other viral infections, yeast and fungal overgrowth, and/or antibiotic-sensitive infections such as *Borrelia burgdorferi*, the causative agent in Lyme disease.

Blood tests for Lyme are not much better than flipping a coin. Only about half of the people with a "negative" test result are actually negative. Many people with a "positive" test results may not actually have the disease.

People with Lyme disease often have a host of other infections that must be dealt with. For viral issues, Valcyte

treatment. Dr. Teitelbaum prefers the use of vitamin powders such as that available in his "Energy Revitalization System". Dr. Teitelbaum has recently been involved in some very positive studies on the use of a product called Corvalen, a sugar known as D-Ribose, which has been found to reduce fatigue by 45% and is now a key component of every patient's recovery program.



With the "Energy Revitalization System", one drink replaces over 35 tablets of supplements. In addition to the drink, D-Ribose at five grams three times daily for three weeks and then twice daily can significantly improve fatigue.

E - A well-rounded treatment protocol should incorporate exercise. "Exercise as able" is the recommendation of Dr. Teitelbaum. He suggests walking can be a very powerful option. Do only what you can do. 5 minutes of walking daily is a great place to start. When your energy production ramps up as one continues on the SHINE protocol, exercise can be increased. It is important to remember that early on in treatment, the body has limited energy and over-exercising can be counter-productive and cause the patient to crash.

Chronic illness such as Chronic Fatigue, Fibromyalgia, Lyme disease and others are the body's way of protecting itself and taking one out of the game in order to limit further damage in the face of overwhelming stress. Dr. Teitelbaum himself suffered from Chronic Fatigue Syndrome in the mid-70's and went from medical school to sleeping on park benches as a result of his illness. He has worked tirelessly for decades to create a recovery program that truly "SHINE"s, and fortunately for us, he has done it! These are exciting times... *pha*



About the Author

Scott Forsgren is the founder and editor of BetterHealthGuy.com, a web site dedicated to sharing information regarding his personal, eleven-year journey through chronic Lyme disease. Scott is a frequent contributor to the Public Health Alert.

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Resources

Dr. Teitelbaum's web site is full of useful information and offers a free newsletter. His site can be located at <http://www.Vitality101.com>. The SHINE protocol can be downloaded at http://www.endfatigue.com/treatment_options/Shine_treatment_protocol.html.

With the success of Dr. Teitelbaum's SHINE protocol, there has been an increasing demand for doctors that approach illness in a similar manner. Dr. Teitelbaum is now the Medical Director of the Fibromyalgia and Fatigue Centers (<http://www.fibroandfatigue.com>). FFC currently has 13 centers across the nation that specialize in providing a holistic, integrated, and comprehensive approach to chronically ill patients.

To make it easy to start getting well now, Dr. Teitelbaum has created a computerized "CFS & Fibromyalgia Specialist" computer program on his web site. This free, patented program will analyze your symptoms to determine what is causing your CFS/FMS and tailor a treatment protocol to your case, so you can start to get well now! You can do the free short form online program at www.Vitality101.com (click on "Diagnosis and Treatment").

About Dr. Teitelbaum

Dr. Teitelbaum is a board certified internist and medical director of a national chain of Fibromyalgia and Fatigue Centers (<http://www.fibroandfatigue.com>). Having suffered with and overcome these illnesses in 1975, he spent the next 30 years creating, researching, and teaching about effective therapies for fatigue and pain. He is the senior author of the landmark studies "Effective Treatment of Chronic Fatigue Syndrome and Fibromyalgia - a Placebo-controlled Study" & "Effective Treatment of CFS & Fibromyalgia with D-Ribose".

Dr. Teitelbaum lectures internationally. He is also the author of the best-selling book "From Fatigued to Fantastic!", "Three Steps to Happiness! Healing through Joy", and "Pain Free 1-2-3- A Proven Program to Get YOU Pain Free!" As a patient advocate, he has a policy of not taking money from any pharmaceutical or natural product companies, and 100% of the royalties for his products go to charity.

Follow the Side bar Q&A Special Segment with Dr. Teitelbaum on page 7.

In Defense of Zebras



by Dr. Virginia Sherr, M.D.

Sometimes, when physicians hear that there may be a tick-borne cause for the mental symptoms of one of their patients, it prompts a lecture - perhaps an attempt to be helpful. A favorite strategy is the recounting of amusing old medical proverbs: "You know, when you hear hoof beats, you should look first for horses, not zebras," or, "Remember, if you hear barking it usually turns out to be dogs and not foxes."

What really is implied by the lecturer is that, while the evidence is clear to this psychiatrist that someone's brain and nervous system are on fire from chronic tick-borne infections, it ought to be kept in mind that people have had "nerves" since the beginning of time. The use of the maxims suggest that there is no sense in speculating that some new, rare, or exotic cause (hear Lyme disease, ehrlichiosis, and babesiosis, amongst others) is needed to explain a patient's symptoms. Nor is it worth considering the possibility of tick-borne cerebral vasculitis or encephalitis that is suspected by the psychiatrist.

One of the problems with being amused at the zebra-deficiency of many doctors nowadays is that what used to be thought unusual and exotic - late stage tick-borne diseases - is now commonplace. It seems that many doctors are so used to seeing "horses" and "dogs" that they have zebra blind spots and CAN'T see "zebras" at all, despite being surrounded by them and by some "foxes" as well. Perhaps scheduling pressures from managed care/HMOs have led to the substitution of rigid dogma for the medically investigative mindsets of yesteryear. This change sacrifices physicians' abilities to attend to their patients with open-minded medical curiosity. "I will always follow Dr. X's lead in the diagnosis and treatment of Lyme disease because he will always be right." These words were actually spoken by a noted infectious disease lecturer to the staff and medical students of a local teaching hospital.

Taking the time to listen to their patients with real curiosity intact would enable doctors to see that we now are

infiltrated by entire herds of "zebras" and "foxes." They could witness that in the immense geographic areas infested with infected ticks, it is much less common than it used to be to find a "horse" or a "dog" in the diagnostic pasture.

Actually, the fact is that widespread, chronic tick-borne diseases (TBDs) can cause or stir up and precisely imitate almost every problem in the medical encyclopedia in the very people who, having no ideas of them-selves as being infected, are waiting, undiagnosed, in these doctors' offices. The enormity of this concept is overwhelming for physicians, generally.

The most difficult thing for doctors to understand may be the fact that any emotional, behavioral, or mental symptom may be a "zebra" related to, for example, Lyme disease. Should they become open to the concept, there are some tip-offs that are so easy and obvious that every doctor, (psychiatrists especially), social worker, nurse, cleric and psychologist should paste them under a photo of a zebra on the wall over their telephone.

In the original call for help, one can hear the special sense of urgency of a patient with chronic TBD. Whether they are calling about themselves or a loved one, they often are desperate. What one also needs to listen for in the adult is a history of a PERSONALITY CHANGE. When a spouse says that his/her usually reasonable mate has broken down the bathroom or the screen door in a rage and that they have never acted that way before, it's time to think of "zebras."

When the caller mentions that his mate was always a good housekeeper but now is spending three hours a day scrubbing a perfectly clean floor, "zebras" should come to mind.

When one asks patients to say a few words about their physical health, and if they first say they are physically well but then go on to mention their many unusual physical problems, one needs to listen for hoof beats.

Patients may volunteer that they had no intention of talking about their physical symptoms because these prob-

lems have made no medical sense. The bizarre, fluctuating, shifting symptoms are interpreted as embarrassing examples of "hypochondriasis" and anxiety. It seems then that the doctor might hear a distant neighing.

When someone in an endemic area says on the phone that he or she has been diagnosed for the first time as having panic attacks and they fear they are going to go out of their minds, one must not think of "horses" so quickly these days. The most likely cause of Panic Disorder in the area of this Pennsylvania psychiatric office, an area that is loaded with nearly invisible nymphal deer ticks of which up to 94% may be infected, is Lyme disease and its co-infections, primarily babesiosis and ehrlichiosis. In the old days, a panic attack was serious enough, but it did not have the same quality of desperation and immediacy that is manifest today. And the panic attacks from chronic, neurologic TBDs are prolonged-often outlasting the duration usually associated with the historic Panic Disorder. Another clue to the origin of spirochetal panic is the presence of symptoms (an example would be joint pains) that do not usually accompany the classical panic attack.

In the past, people were willing to agree that their ER doctor was probably right - that this was "just" an emotional problem. Generally, this is not what is heard from the sufferers of panic attacks from chronic TBDs. They come to the office because they have been told that they should see a psychiatrist, but they keep saying, quite correctly, "I know that there is something physically wrong with me." These hoof beats may carry something striped, one could think to oneself.

When depressed persons call in, it is always important to ask up front if they are aware of any outstanding physical symptoms. Usually, now one will hear about insomnia - not rare in depression - but such a TOTAL insomnia! And then, for example, it comes out about the night sweats and the strange episode in which the face, throat, eyelid, tongue, or limb wouldn't wait right. The troublesome symptom may have gone away, but the worry

"Zebras" ...cont'd pg 14

Q&A with Dr. Jacob Teitelbaum, M.D.

What portion of your patients do you test for Lyme disease?

At what point in history will we have a good test for Lyme disease? 50% of people that have *Borrelia* infection will test negative (false-negative) and some that test positive don't actually have it (false-positive). It is reasonable to do Lyme testing if there is a suspicion of Lyme disease or the patient presents with vertigo, a tick bite, or an EM rash. Otherwise, if the patient has not improved after four months in the SHINE protocol, we then begin to look deeper for chronic infections that are contributing to the illness. At that point, it is also reasonable to consider simply giving a trial of the antibiotic, regardless of the test results.

One of the more recent research findings in testing for Lyme disease has been through the work of Dr. Ritchie Shoemaker, M.D. He has found that C3a and C4a markers can be a very useful indicator of active Lyme disease. Though this is an area that is still being actively investigated, I think this could be a very exciting breakthrough. If both C3a and C4a are high, Lyme disease is likely an issue.

How beneficial are laboratory tests in determining a treatment path?

In general, I am skeptical as to the effectiveness and accuracy of many laboratory tests. We have sent samples from the same blood draw to labs to have cholesterol tests performed and the results varied by over 160 points between the two samples. Similar issues are common with cortisol testing. In other words, we have to be careful how much weight we put on tests where the results can often not be replicated. Although thorough testing should be done, it is critical to treat the patient, and not the blood tests.

How does SHINE approach Lyme disease?

Every aspect of the SHINE protocol is a key to recovery from Lyme disease. The patient must get adequate sleep (8-9 hours a night) or they will not recover. They must have hormones evaluated and corrected where functionally low. Infections must be addressed. Nutritional deficiencies must be supplemented and an exercise program must be incorporated.

When antibiotic-sensitive infections such as Lyme are suspected, we might begin with a trial of doxycycline or minocycline. This, unfortunately, becomes more of a shotgun approach however, and our ultimate goal is to support the immune system so that it can resolve these infections without the need for long-term antibiotics. If the patient feels better on antibiotics, we may use them on an ongoing basis.

Do you support the use of long-term antibiotics?

Antibiotics have been used long-term for other conditions, even acne. Though our program focuses on supporting immune function against these infections, when long-term antibiotics are necessary, they are considered.

Where do you fall on the IDSA vs. ILADS debate in approach to treating Lyme disease?

It is a shame that we get caught up on "sides". ILADS holds views which are largely consistent with my position on chronic Lyme disease. The whole argument is a political one. People with chronic illnesses are often desperate for an answer. It is important for us as doctors to step back and recognize that there is not always one answer. Often there is a hyper-focusing on Lyme that occurs in the treatment of the disease and we need to broaden our focus in order to truly affect the patient in a significantly positive way. If treating the Lyme disease with antibiotics doesn't seem to be resulting in improvement for the patient, don't keep pounding at it. Step back and ask "What are we missing?" I do believe that there is a persistence of infection in patients with chronic Lyme disease. It is not an easy infection to resolve.

When a patient tests positive for Lyme disease, do you refer them to an LLMD?

Fibromyalgia and Fatigue Centers are trained to evaluate and treat Lyme disease as well as the common co-infections such as Babesia, Ehrlichia, and Bartonella. It is important though to go beyond just the Tick-Borne Diseases and look for other possible contributors to the illness, infectious and otherwise. I have referred some of my more difficult Lyme patients to Dr. Joseph Burrascano, M.D.

Where do you stand on the Vitamin D debate?

Vitamin D deficiency is a significant concern. For many people, Vitamin D must be supplemented in order to support immune function, avoid osteoporosis, and control pain. I often find that Vitamin D restriction can lead to horrific outcomes.

It can be helpful to perform a D 25 and D 1,25 level and if the ratio of D 1,25 to D 25 is greater than 2, there may be an infectious origin and appropriate treatment may be necessary. I generally recommend 2000-4000 units a day if a patient has decreased bone density or 1000-2000 units a day otherwise.

"Q&A" ...cont'd on pg 9

Lyme Disease Rarely Travels Alone...

Undiagnosed Co-Infections are the Primary Reason Lyme Treatments Fail

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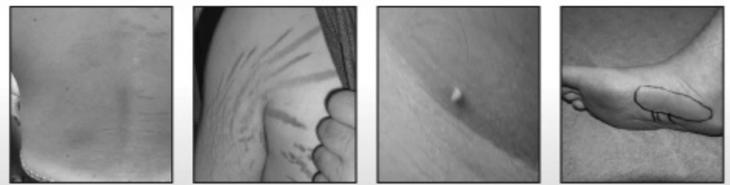
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Dr. Schaller is the author of 25 books, is published in five languages, and has published 27 peer-reviewed journal articles in JAMA, Medscape (academic arm of WebMD,) and some of the largest pediatric, psychiatric, medical, and neurological journals and newspapers in the world. He is the inventor of a natural, bio-identical anti-depressant, and has also published the first case of a functional blood cancer "cure" which has become an international standard. To contact Dr. Schaller, visit www.personalconsult.com. To locate his other current books, go to Amazon.com and enter "James Schaller."

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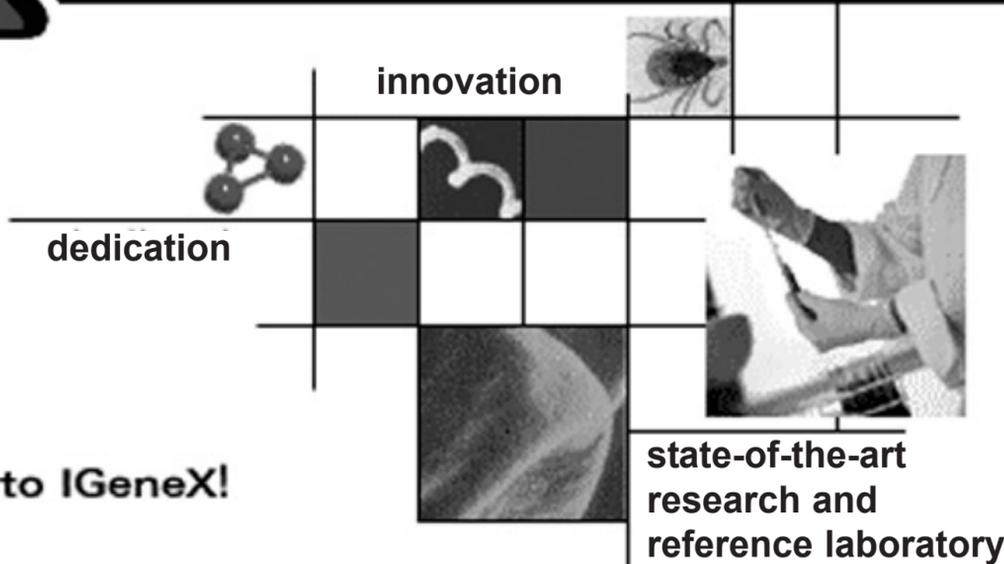


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Lyme Disease and Cognitive Impairments



by Robert Bransfield, M.D.

Introduction:

The patient is a college graduate with Lyme encephalopathy (LE). While stopped at a traffic light, she described her thought processes as having a "fog-like" sluggishness. When the light changes, she knows the change from red to green has significance, but at that moment cannot recall that green means go and red means stop.

This is one of many examples of cognitive impairments associated with Lyme disease. Although some cognitive symptoms are indirectly a result of other neurological or emotional impairments, others are a direct result of dysfunction of the cerebral cortex where cognitive processing occurs. Laboratory tests such as SPECT scans, MRI's, PET scans, and psychological testing have demonstrated physiological and anatomical findings associated with dysfunction of the cerebral cortex in patients with Lyme and tick-borne diseases. The examination of human and animal brains have further supported these findings.

The cognitive impairments from Lyme disease are very different than we see in Alzheimer's disease. Lyme disease is predominately a disease of the white matter, while Alzheimer's is predominately a disease of the gray matter. Memory association occurs in the white matter, while memory is stored in the gray matter. White matter dysfunction is a difficulty with slowness of recall, and incorrect associations. In contrast, gray matter dysfunction is a loss of the information which has previously been stored. For example, an Alzheimer's patient may not recall the word "pen", while an LE patient may have a slowness of recall or retrieval of a closely related word. Some of the symptoms I will describe are also found in encephalopathies associated with other illnesses, such as chronic fatigue syndrome, lupus, stroke, AIDS, or other diseases which affect the brain. Although no single sign or symptom may be diagnostic of Lyme disease in a mental status exam, we instead look for a cluster and a pattern of signs and symptoms that are commonly associated with Lyme disease.

Everyone with LE has their own unique profile of symptoms. The assessment of these signs and symptoms is one facet of the total clinical assessment of Lyme disease.

There are many ways of

categorizing cognitive functioning. Let's begin with a simple model of perception, encoding these perceptions into memory, processing what we perceive, imagery, and finally organizing and planning a response.

Simple mental functions such as flexing the index finger of the right hand, correlates with a relatively simple brain circuitry. More complex functions such as flying an airplane require the action of a more integrated neural circuitry. The difference between these two actions is like the difference between playing middle C on a piano vs. a symphony playing an entire concert.

Attention Span:

Many Lyme disease patients have acquired attention impairments which were not present before the onset of the disease. There may be difficulty sustaining attention, increased distractibility when frustrated, and a greater difficulty prioritizing which perceptions are deserving of a higher allocation of attention.

If we compare attention span to the lens of a camera, we need the flexibility to constantly shift the allocation of attention dependency upon the current life situation. For example, we shift back and forth between a wide angle and a zoom lens focus to increase or decrease acuity of attention depending on the needs of the current situation. A loss of this flexibility results in some combination of a loss of acuity (hypoacusis), and/or excessive acuity to the wrong environmental perceptions (hyperacusis). Hyperacusis can be auditory (hearing), visual, tactile (touch), and olfactory (smell).

Auditory hyperacusis is the most common. Sounds seem louder and more annoying. Sometimes there is selective auditory hyperacusis to specific types of sounds. Visual hyperacusis may be in response to bright lights or certain types of artificial lighting. Tactile hyperacusis may be in response to tight fitting or scratchy clothing, vibrations, temperature and merely being touched may be painful. Some patients prefer to wear loose fitting sweat suits and are frustrated that being touched can be painful. Olfactory hyperacusis may result in an excessive reactivity to certain smells, such as perfumes, soaps, petroleum products, etc.

Memory

Memory is the storage and retrieval of information for later use. There are several different memory deficits associated with LE. Memory is broken down into several functions - working memory, memory encoding, memory storage and memory retrieval.

Working memory is a component of executive functioning. An example of working memory is the ability to spell the word "world" backwards. Sometimes there are impairments of working memory as it pertains to a working spatial memory, i.e. forgetting where doors are located or where a car

is parked.

Encoding is the placement of a memory into storage. We cannot retrieve a memory that was not encoded correctly into memory in the first place. One patient described being upset that someone had eaten yogurt in her kitchen during the night. Her activity during the night was not encoded into memory.

Short term (recent) memory is the ability to remember information for relatively brief periods of time. In contrast, long term memory is information from years in the past (or remote).

In LE, there is first a loss of short term memory followed by a loss of long term memory very late in the illness. Patients may have slowness of recall with different types of explicit (or factual) information, such as words, numbers, names, faces or geographical/spatial cues. Not as common, there may also be slowness of recall of implicit information, such as tying shoes, or doing other procedural memory tasks.

Errors in memory retrieval include errors with letter and/or number sequences. This can include letter reversals, reversing the sequence of letters in words, spelling errors, number reversals, or word substitution errors (inserting the opposite, closely related or wrong words in a sentence.

Processing

Processing is the creation of associations which allow us to interpret complex information and to respond in an adaptive manner. Some LE patients say they feel like they acquired dyslexia or other learning disabilities, which were not present previously. Examples of processing functions that may be impaired in the presence of LE include the following:

Reading comprehension: The ability to understand what is being read.

Auditory comprehension: The ability to understand spoken language.

Sound localization: The ability to localize the source of a sound.

Visual spatial perception: Impairments result in spatial perceptual distortions. One example is microscopia, in which things seem smaller than they really are. One patient lost depth perception, and had several accidents when the car in front of her stopped. A problem associated with visual spatial processing is optic ataxia, in which there is difficulty targeting movements through space. For example, there may be a tendency to bump into doorways, difficulty driving and parking a car in tight spaces, and targeting errors when placing and reaching for objects. One patient with optic ataxia, was stopped by a policeman while driving two miles to my office because he kept swerving across the center line. Before *"Impairments" ... cont'd pg 14*

Q&A: Teitelbaum

...cont'd from pg 7

Going for walks and exposing yourself to sunlight are important activities to support the body's ability to generate Vitamin D. Avoid sunburn, not sunshine.

Can you tell us a bit about the importance of Th1/Th2 balance in people with chronic illness?

We can show people that their Natural Killer (NK) cell function is low. As it is almost always low in CFS and chronic Lyme disease, performing this type of testing is sometimes a waste of money.

Can elevated ANA titers be brought back to a normal range with treatment?

It is really irrelevant. The question has to be "how does the patient feel?" I've seen the same tube of blood result in both a negative and positive ANA result. An elevated ANA suggests that there is an autoimmune component of the illness. Adding DHEA or hydrocortisone and optimizing estriol can be important tactics. Willow bark, Boswellia, and fish oils are often helpful. My focus is on treating the immune imbalances, not the ANA titer. If you focus too much on the blood tests, you forget the art of medicine. If you just listen to the patient, in the first five minutes they will tell you what is wrong. In the next five minutes, they will tell you how to fix it. Ask the patient if they are feeling better. Don't chase the tests.

How do you determine when to treat a viral infection with elevated IgG but normal IgM results?

With HHV-6, if the IgG is 1:320 or above, I generally consider treating. Similarly, if IgG results for Cytomegalovirus (CMV) are above 4, this is an indication that treatment may be appropriate. IgM positivity is generally observed with acute or recent infection but not with chronic viral infection. Following the work done by Jose Montoya, M.D., we have been using Valcyte with very good results in patients with chronic HHV-6, CMV, and EBV (Epstein-Barr virus).

About 70% of patients have dramatic responses at about the fourth month with Valcyte. It has been very well tolerated and we don't observe a serious die-off effect when we add it to the entire "SHINE protocol". Valtrex has only been found to be helpful for cold sores or genital herpes and ineffective for EBV in my experience. It has been of limited to no benefit in patients with chronic fatigue.

I have also observed that when HHV-6 is treated effectively, the immune system recovers and is far more effective in mounting an attack against the Lyme-related infections.

Beyond Valcyte, what are other effective treatments for HHV-6 and EBV?

ProBoost® is a very effective option. It is an immune modulator and anti-viral agent made of thymic protein. The thymus is a key component of cell-mediated immunity which controls how various pathogens are responded to by the immune system. One packet three times a day for three months is often what I recommend. I have seen it drop EBV titers by 70% and it is likely similar in effect for HHV-6. Maitake mushroom formulas can be used. IV Vitamin C is anti-viral. IM Gamma Globulin is also very effective.

We've really been very pleased with Valcyte, however. After six months of Valcyte therapy, we usually don't see a reactivation of the viruses.

Do you support the use of FIR sauna for detoxification?

Yes, in fact, I have one in my home. I recommend High Tech Health saunas. These can be very useful and they are a good way to detoxify. I generally suggest 30 minutes 3-7 times per week. You can find information on my web site (<http://www.Vitality101.com>) that discusses using detox baths to support detoxification as well.

Much of the overall toxic burden of the body is the result of chronic infections and leaky gut syndrome. Once those are addressed, there are far fewer toxins being created.

Is there an increase in rates of cancer observed in patients with CFS/FMS?

No, quite the opposite actually. Remember that patients with these illnesses are operating with the circuit breakers turned off and thus they are operating at a reduced level of functioning. The total wear and tear on the body is often less.

What are the best treatment options for those suffering with MCS (multiple-chemical sensitivity)?

MCS can be quite difficult. NAET (<http://www.NAET.com>) is an allergy elimination technique that has produced amazing results. In fact in one study of 30 autistic children treated with NAET, 23 of them were back in normal schools within one year.

Treating yeast is a significant factor in resolving MCS. Evaluating and addressing leaky gut and exhausted adrenals are also key components of treating chemically-sensitive patients.

Do you consider biotoxins as an issue and, if so, how do you address them?

Biotoxins are toxic substances produced by living organisms. These toxins do have negative impacts on our health and how we feel. Cholestyramine is the most widely-accepted treatment for supporting the removal of biotoxins, but it really only helps in about 9% of cases.

I approach the biotoxin issue differently. Rather than looking for

"Q&A" ...cont'd pg 12

NATIONAL SUPPORT GROUPS

National Multiple Sclerosis Association:

www.nmss.org

Alabama

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

Northern California

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

Colorado

700 Broadway, Suite 808
Denver, CO 80203-3442
Phone: 303.831.0700
1.800.FIGHT.MS

Georgia

455 Abernathy Rd. NE, Suite 210
Atlanta, GA 30328
Phone: 404-256-9700
Phone: 1-800-FIGHT-MS
mailbox@nmssga.org

Florida

2701 Maitland Center Pkwy, Suite 100
Maitland, FL 32751
Phone: (407) 478-8880
Email: info@flc.nmss.org
www.nationalmssociety.org/flc

Texas

8111 N. Stadium Drive, Suite 100
Houston, TX 77054
Phone: 713-526-8967

ALS Association DC / MD / VA

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

Great Philadelphia ALS Chapter

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

South Texas Chapter

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

North Texas

<http://walk.alsanorthtexas.org/site/PageServer>
1231 Greenway Dr., Ste.385
Irving, TX 75038

s.melson@alsanorthtexas.org
972-714-0088
877-714-0088

The ALS Association Upstate New York Chapter

323 Route 5 West
P.O. Box 127
Elbridge, NY 13060

315-689-3380
Toll Free for PALS:
1-866-499-PALS

info@alsaupstateny.org

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L.E.A.P. Arizona
Tina J. Garcia
Lyme Education Awareness
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www.timeforlyme.org
914-738-2358
Meetings: first Thursday of every month from 7-8:30 p.m. at the Greenwich Town Hall

National Support:

truthaboutlymedisease.com/
Dana Floyd, director

LDA of Iowa

PO Box 86, Story City, IA 515-432-3628
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913-438-LYME
Lymefight@aol.com

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North Carolina

Stephanie Tyndall
sdtyndall@yahoo.com

South Carolina

Greenville Lyme Support
contact Kathleen at greenvillelyme@bellsouth.net

Lyme Disease Support

New Mexico

Veronica Medina
(505)459-9858
vrmolina@comcast.net

Oklahoma

Janet Segraves 405-359-9401
Janet@LDSG.org
www.LDSG.org

Portland, Oregon

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

TEXAS :

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Jquinn@dart.org
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lucher@sbcglobal.net

League City/ ClearLake & NASA Area

Sandra Mannelli
smannelli@comcast.net

San Antonio

<http://lymedisease.meetup.com/75/>
Contact: Franklin Moormann,
256-417-7466 or
210-595-1014

Washington State

Alexis Benkowski
WA-Lyme-owner@
yahoogroups.com

WI / IL / MN Regional areas

Contact PJ Langhoff
(920) 349-3855
www.Sewill.org
www.LymeLeague.com (Intl)

Western Wisconsin Lyme Action Group

Marina Andrews
715-857-5953

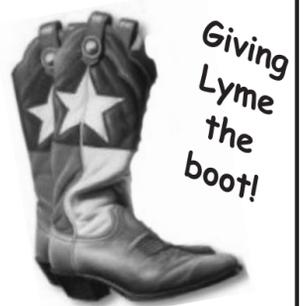


Military Lyme Disease Support

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

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

Texas Lyme Disease Association



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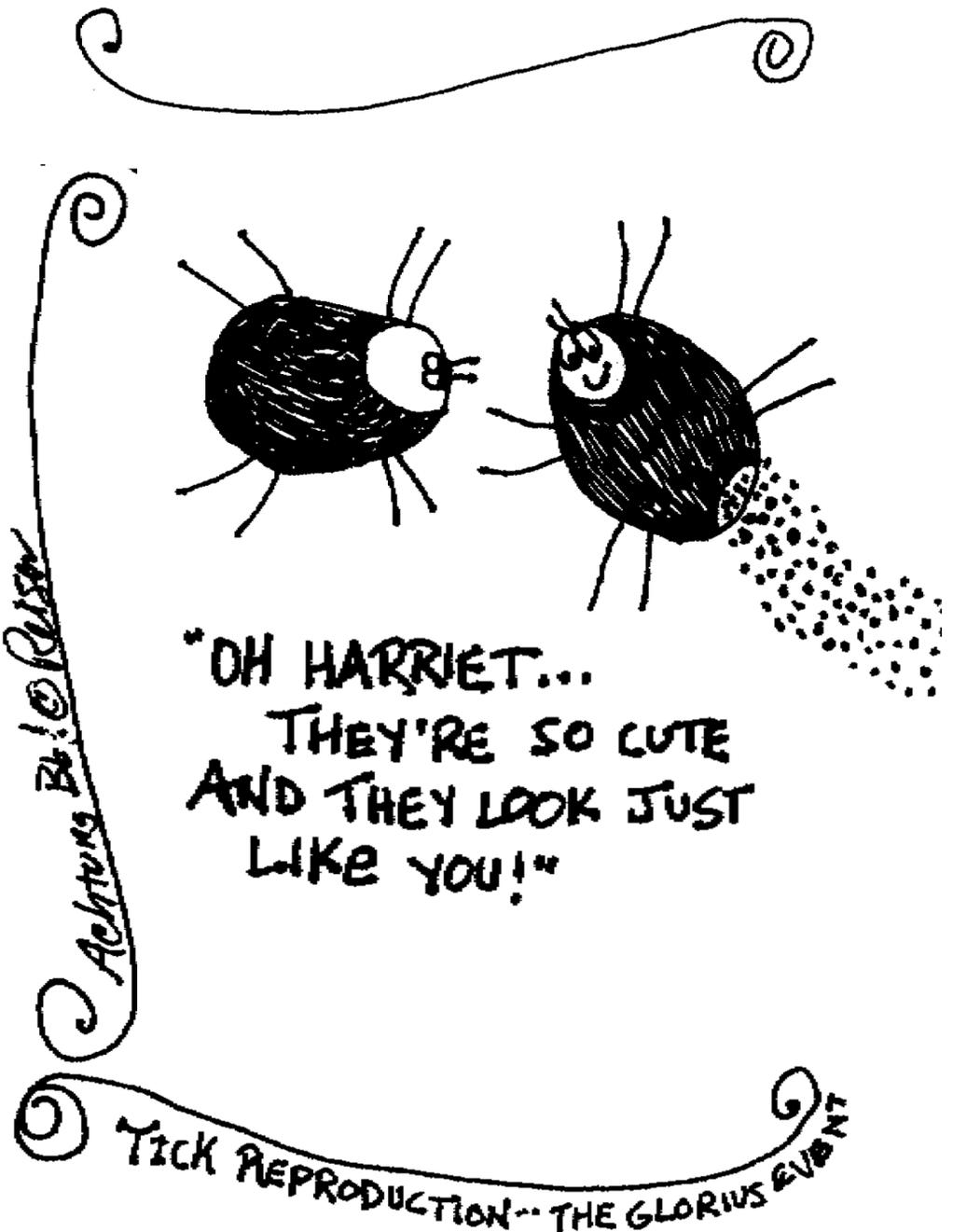
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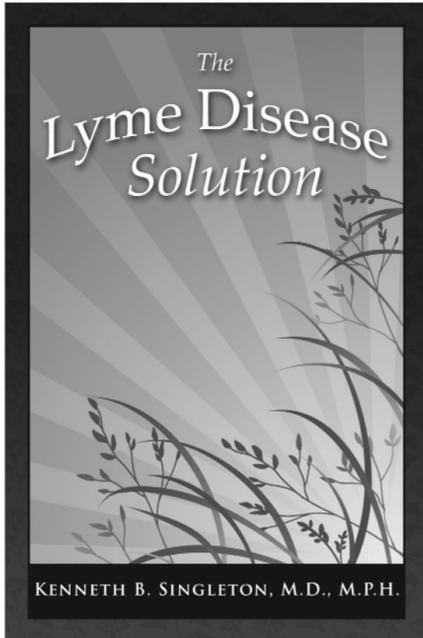
Ticktoons



by Terri Reiser

The Lyme Disease Solution

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“Occam’s Razor”... cont’d from pg 4



Bb spirochetes have been proven to survive blood bank conditions along with Babesia microti and WA-1 parasites.

Bb spirochetes have been found in the autopsies of congenitally infected Lyme infants throughout multi systemic organs.

Bb spirochetes have been found in the autopsies of fully treated Lyme patients who had the maximum recommend-

ed course of antibiotics (clearly it was not "cured.")

So if Occam's Razor is applied to the Lyme disease controversy, the only logical conclusion would be that there is a desperate need for more research. These issues are not settled issues, and for them to be treated as such should be considered criminally negligent. This disease is a close relative to another spirochete that is sexually transmitted. Can you

imagine if no one had ever demanded that blood testing for AIDS be mandated? These diseases are not dissimilar.

For the IDSA to hold doggedly to their beliefs concerning Lyme disease, even though they chose to settle out of court to avoid malpractice claims, makes one wonder that, if Occam's Razor is still a medical principle, has IDSA changed the blades/rules?

pha

Obituaries

Pamela Truscott Byrne

KNOXVILLE, Md. -- Pamela Truscott Byrne, 57, died Saturday, June 7th, 2008, at her home in Knoxville, Md., from complications of Lyme disease.

She was born March 19, 1951, in Newport News, Va. She grew up in Birmingham; lived in Maryland for 24 years and wintered in Cape Coral, Fla. At an early age, she was fascinated by plants and animals and was also a talented artist. She graduated from Ohio State University.

She worked as an agriculturalist for the United States Department of Agriculture for 33 years and retired in 2006. She was one of the first women hired by the USDA in 1973 and worked in Florida, North Carolina, Hawaii, Africa, Holland, and for the USDA training center in Frederick, Maryland as an instructor for many years. She enjoyed gardening and had seven flower gardens and a large vegetable garden.

Survivors include her husband of 22 years, Tom Byrne, her mother, Estelle Truscott; sisters Gail Truscott, Page Wichman, Helen Miller; one niece and three nephews;

step daughters, Jennifer Keim of North Hampton, PA, Elizabeth Smith of Odell, IL, Emily Johnson of Clifton Park, NY; and 8 grandchildren. She was preceded in death by her father, Starr Truscott in 2007.

Friends may call Wednesday June 18th from 12:00 until the time of a memorial service at 1 p.m. at the Riddle Funeral Home, 5345 South Street, Vermilion. Reverend Carol Rettew, pastor of the Bay Presbyterian Church, will officiate. Interment will be in Birmingham Cemetery, Ohio.

Online condolences may be made at www.riddlefuneralhome.com

THE POISON PLUM
By Les Roberts

The Poison Plum is a gripping, chilling novel exposing the rampaging epidemic of Lyme disease now sweeping across America and the disease's connection, if any, to the government's top-secret biological research laboratory at Plum Island, New York.

www.poisonplum.com

You can order the book online at the website!

Q&A: Teitelbaum

...cont'd from pg 9

ways to remove biotoxins, we attempt to identify the sources of the biotoxins and eliminate the source.

Visual Contrast Sensitivity (VCS) testing can be helpful in assessing the presence of biotoxins. Checking for nasal staph infection is important in looking at the potential sources. Lyme Western Blot testing would be appropriate as Borrelia is a known biotoxin producer. Exposure to indoor molds is another area that has to be investigated in order to eliminate as many of the biotoxin sources as possible. My book discusses a six step program to treat neurotoxins (based on the work of Ritchie Shoemaker, M.D.)

How important is the role of genetics in terms of how people respond to these illnesses?

Genetics plays a big role. Amy Yasko has some very beneficial work looking at genetics in the treatment of autistic children. Looking at these genetics is interesting in terms of research, but my preference is to move directly to treatment. I recommend Dr. Rich Van Konynenburg's "Modified Methylation Protocol" which is intended to help bypass a number of these genetic issues around detoxification.

Elevated ammonia levels can be an issue and can contribute to symptoms. Lactulose binds ammonia and pulls it out of the body.

What role do food allergies play in chronic illness?

It is not uncommon to see food allergies and sensitivities resolve once we treat yeast overgrowth, parasites, and exhausted adrenals. Most blood-based food allergy tests are unreliable in my experience. In fact, sending a patient's blood from the same sample to multiple labs performing food allergy testing resulted in anywhere from 22% to 76% of foods being allergenic. We cannot make sound medical decisions using tests that are this inaccurate.

Nambudripad Allergy Elimination Technique (NAET) can both test for and eliminate allergies in a very powerful and effective way. Another option is to try an elimination diet. Some patients have had success with sublingual neutralization drops for allergies as well, though I don't use this technique in my practice. Again, I find that if you address the root cause which is leading to the food allergy, the food allergy itself generally resolves.

How common are parasitic infections?

We see significant parasitic issues in about 1 out of 6 patients. Testing for parasites is again another problem. Diagnos-Techs (<http://www.diagnotechs.com/>), Genova Diagnostics (<http://www.genovadiagnostics.com/>), Doctor's Data (<http://www.doctorsdata.com/>), and the Parasitology Center in Arizona (<http://www.parasitetesting.com/>) are often helpful, but parasitic infections are often missed by traditional lab testing.

What is the prevalence and role of dental infections?

It is significant in 2-5% of patients and may be an issue in 5-15% in total. Vitamin C is good for gum health, as are sugar-free gums and mints. If a patient has dry mouth, this is one of the first things to address as saliva helps to keep infections down. Dry mouth is often caused by medications such as Elavil. Infection under the gum, known as "periodontal disease", can be a source of chronic inflammation and adds to the total body burden of infection. Ozone therapy can be helpful in dealing with these dental infections.

How important is gluten avoidance?

Gluten is a moderate issue. It is important that we are sure that gluten is an issue when we make the recommendation to take a patient off of all gluten-containing foods. What I find is that when we can address low cortisol levels and resolve bowel infections, food allergies generally resolve. Anti-gliadin antibodies are not as important as anti-transglutaminase antibodies. When the latter are elevated, an elimination diet and treatment with NAET is often appropriate.

Do you look at hypercoagulation?

We don't do Hemex testing as it seems that over 95% of people we have tested have abnormalities. Heparin can be a very effective treatment for about 1/2 of patients but it could be the result of its anti-viral properties as much as its ability to address hypercoagulated blood. Coumadin, for example, thins the blood but does not have the same effect on the patient. Nattokinase has not been helpful in my experience. However, Lubrokinase, Willow bark, and fish oils can be helpful.

Fibromyalgia & Fatigue Centers Newsletter

Patient pamphlets and newsletter are available free of charge to help you find the answers you may need. Simply go to the website:

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Call and speak with a Patient Representative at:

1.866.443.4276

Monday – Friday, 7:30am to 9:00pm CST
Saturday – Sunday, 9:00am to 6:00pm CST

The Shock of Your Life: The Hidden Dangers of IV Lines

by Laura Zeller

Imagine yourself outside on a bright sunny day. You are sitting on your back deck enjoying the outdoors, feeling content and thankful that you have made it this far. You finally received a Lyme disease diagnosis after years of misdiagnosis and a wild goose chase, and the whole confusing and maddening influx of clueless doctors that comes with it. You just got your new PICC line, and you are all set to finally start your IV antibiotics for Lyme disease. You are pretty nervous and overwhelmed at the entire thing, but you are glad to finally be getting the treatment you have needed for months or years.

You do your first 6 weeks of IV antibiotics and everything goes smoothly. You herx pretty hard in the beginning, and that is a normal and expected reaction. All your symptoms get worse, and you even notice some new ones popping up that you never had before. You may feel like you are dying at times because your body is overwhelmed with toxins and killing bacteria.

You keep going with your treatment, taking special care to keep your IV line clean and dry. You hope you won't need it for too much longer, but you are still so sick, you know you will need it for a while longer.

Then one morning you wake up, and flush your IV line with saline, and prepare your IV antibiotic for administration. You've done this hundreds of times by now, so it has become a normal part of your daily routine. Unfortunately, this IV treatment will be different, unlike any other. As you flush the line with saline, you notice your hand starts hurting, and you suddenly feel sick to your stomach. Almost instantaneously, you begin to feel sick all over your body, you start to sweat and you feel funny in the head. A minute goes by, you start to vomit, and you feel like something is taking over your entire body. You grab a thermometer out of your drawer, and much to your alarm, it reads 103.9 degrees! In a panic, you check it again. This time it's measuring off the end limit at 104.7 degrees and climbing.

You start to throw up all over yourself and your heart is racing so fast you cannot catch your breath. Your entire body is shaking violently and you know something terrible is happening. In a panic, you dial 911, and then pass out. The ambulance comes to save you, and they find you near death with a blood pressure of 240/110 and a heart rate of 165. They treat you for shock, and see the IV line sticking out of your arm. You don't know any of this is happening because you are unconscious.

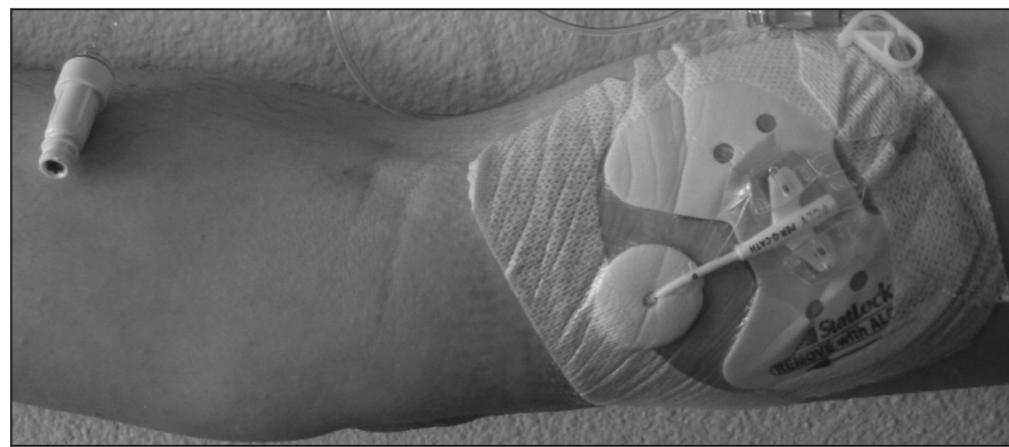
What's happening to you is called septic shock. It's also known as bacteremia, or sepsis. Bacteremias are life-threatening infections of the bloodstream. When bacteria enter a central line (PICC line, chest port, Hickman, Groshong, etc.) they can reproduce in the

line and can cause a fatal blood infection. When this happens, you are referred to as a "septic" patient. Immediate treatment is necessary to save your life. If you become "septic," you will likely be so sick and out of it that you are considered to be in "septic shock". Sepsis can develop as a result of your body's immune system defenses, or from the toxic substances made by the infecting agent (such as a bacteria, virus, or fungus). Many different microbes can cause sepsis. Although bacteria are most commonly the cause, viruses and fungi can also cause sepsis.

To all of you who have IV lines, your doctor may or may not have warned you about the dangers of having a central line. Oftentimes patients are coached on how to administer their IV antibiotics, how to flush the line with saline solution and heparin to prevent clotting of the blood in the line. Most PICC line users know how to change the dressing, how to shower with the PICC line, and how to be gentle with it.

What many patients do not know, is what to do if that line ever gets infected. Most doctors do not routinely explain what to do if you become septic because it would likely scare the patient quite badly. Most vascular surgeons, (the guys who operate on you to insert the central line) also do not explain what to do if it gets infected, when to remove the line, or what to do if it ever leaks, etc.

As a Lyme disease patient, and a two-time septic shock survivor, I am here to share my experience with the dangers of IV lines. This is



only meant to help educate you, and this is not the ranting of some anti-intravenous Lyme victim. Trust me, I am all for aggressive antibiotic therapy and IV, so please try not to get the wrong impression. I am not a doctor, so please do not take any of the following as medical advice. Please follow up with your personal physician and ask your own questions. Please consider these words to be a warning based on a patient's experience. I'm putting this out there to hopefully help save some lives, and arm you with the information about what to do if an emergency ever strikes.

In a nutshell, if you are on IV, or going to be on IV, know the risks in advance. Be prepared. Have your doctor's emergency contact information plugged into your cell phones and on a notepad next to your

home phone. Give your family and caretakers your doctors' phone number, and pager. Inquire in advance if your doctor has a pager, cell phone or answering service, and ask him/her what you should do if you ever have an IV line emergency. Another tip I have to offer is to always do your IV treatments during your doctor's office hours so you can quickly call them if something comes up. It's also a good idea to make sure somebody is home with you, keeping an eye on you while you administer your treatment. At the very least, make sure you have a phone near you when doing your IV. Always go for your routine

"Don't be afraid to encounter risks. It is by taking these chances that we learn to be brave." Be brave, but do it with wisdom.

blood work while you are on IV and be extra careful during all of your social activities. Many of you travel long distances to see your LLMD, sometimes to other states and far from the comfort of your home. Remember, this is the very reason (one of them at least) why your LLMD requires you to have a local physician following your care, so you can call him/her in a situation like this.

Always make sure you keep your IV line clean. Learn how to change your own dressing, and always use sterile tech-

nique, which includes wearing a mask every time. Keep your dressing dry, and do not traumatize or abuse the line in any way by overexerting yourself. If you ever notice a funny feeling during or after an IV infusion, call your doctor. If you ever feel pain all over your body, in the PICC line itself, or on your central line site, then stop the treatment, and call your doctor. If you ever encounter resistance while trying to flush your line, stop! There may be a blood clot in the line, which needs emergency medical treatment. Remember that central lines go directly into your heart, so it is not a wise idea to force the IV into your body. Stop, and think! If you ever notice swelling, discoloration, discharge of pus, bleeding, or oozing from your IV line site, then call your doc-

tor and go to the nearest Emergency room.

If you ever have any of the above problems, plus a sudden fever, shaking chills, sudden pain all over your body, vomiting, etc, then dial 911. You don't have time to drive to the emergency room, so call the ambulance!

Your medical and hospital staff should probably pull out your central line for your own safety. If things are uncertain, and the medical professionals are not sure whether or not you have sepsis, then they should take blood cultures out of the IV line and find out if there are any harmful organisms in your IV line.

Unfortunately, blood cultures take 24-48 hours to grow, so it may be wise for the ER to pull out your IV line, culture the tip of it, and start you on prophylactic sepsis treatment regardless. From what I learned as a patient, blood cultures should always be drawn regardless of whether the line is pulled or not in order to determine which organism is involved, and the resulting appropriate treatment.

When I had sepsis the first time, I had blood cultures drawn both out of the IV line, and a separate set out of my other arm for comparison. Both of the cultures showed a gram negative, very nasty bacteria that would have killed me had I waited and not gotten to the emergency room by ambulance. By the time I reached the ER, I was unconscious and my temperature was 106.7 degrees. Somehow in my delirium I managed to spit out my LLMD's phone number, and the EMT's patched him through. The line was pulled, the tip of

the line cultured, and I was placed on IV Vancomycin to kill the deadly bacteria. The second time, the same thing happened (cause unknown) and IV Cipro® was used. Let's just say that having sepsis was the scariest thing to ever happen to me, and it was absolutely astounding how fast it came on. Be extra careful with your IV lines; know the risks and the dangers and what to do! Each person is different, as is each case. The first time, I had extremely high fever and blood pressure. The second time, on a new Hickman catheter, I had very low blood pressure and fainted, but did again have a high fever and was rushed to the ER by ambulance both times.

Remember that just as there is a risk of not treating Lyme disease or Cancer, there

is equal if not greater risk of using IV therapy.

Severe sepsis is a very serious, life-threatening condition. Simply put, it kills people. If you are a victim of severe sepsis, your organs will likely not receive enough oxygen and they may fail or shut down. When organs shut down, the body cannot function and death is possible. The most important intervention is rapid diagnosis and then prompt and appropriate treatment. For Lyme patients, if you ever have symptoms of sepsis, please do not assume that they are the same thing as a herx reaction. It may seem to you like your body is hurting all over so suddenly that it "must be a herx", and you might be tempted to push through the pain. Bad idea!

According to the Society of Critical Care Medicine, sepsis actually kills more Americans than breast cancer, colorectal cancer, pancreatic cancer and prostate cancer combined. In the U.S., it is estimated to be around 750,000 cases a year. And, mortality is about a third. So, some 250,000-300,000 die every year of sepsis. About half to two-thirds of patients in the ICU die because of severe sepsis.

Now that I have probably scared you all half to death, try to relax. Sepsis is a known risk for anybody with a central IV line, but is the exception, rather than the rule. Over the past 10 years I have emailed and spoken to hundreds of Lyme disease patients who have done IV antibiotics, and had absolutely no problems. I have also talked to a few who have had problems with their lines, such as leaks, bleeding, pain, bruising or blood clots. There have been 4 people that I know of who have gotten severe sepsis. One of the victims was Susan, who is now a good friend of mine. At the time, Susan was just a visitor trying to learn about Lyme disease on the internet. She later told me that if I had not publicly explained my sepsis story on a public internet Lyme disease forum, that she would have had no idea what to do when it happened to her. Sue had read one of my posts, and when she got sepsis herself from an infected Hickman catheter, she recognized the symptoms, knew what to do, and went by ambulance to the ER. She survived, and that is why I decided to write this article as a warning for all of you. If I had to do my Lyme disease treatment all over again, I would still use IV antibiotics without hesitation. Long-term IV antibiotics saved me from a life of disability and pain and brought me back to the land of happiness and healthy, happy living.

In closing, remember this: your health is important, and most of you value it more than anything else in your life. I will leave you with one of my favorite quotes: "Don't be afraid to encounter risks. It is by taking these chances that we learn to be brave." Be brave, but do it with wisdom.

pha

“Impairment” ...cont'd from pg 9

Lyme disease he could consistently shoot 13 to 14 out of 15 free throws from the basketball foul line. Now he averages 3 of 15, and misses some shots by several feet.

Transposition of laterality: The ability to rotate something 180 degrees in your mind. For example, the ability to copy, rather than mirror, the movements of an aerobics instructor facing you.

Left-right orientation: The ability to immediately perceive the difference between left and right. Although this is a part of congenital Gertsman's syndrome or angular gyrus syndrome, acquired left-right confusion is the result of an encephalopathic process. Calculation ability: The ability to perform mathematical calculations without using fingers or calculators. Many LE patients describe an increased error rate with their checkbook.

Fluency of speech: The ability of speech to flow smoothly. This function is dependent upon adequate speed of word retrieval.

Stuttering: The tendency to stutter when speech is begun with certain sounds. Slurred speech: A slurring of words, which can give the appearance of intoxication.

Fluency of written language: The ability to express thoughts

into writing. Handwriting: The ability to write words and sentences clearly.

Imagery

Imagery is a uniquely human trait. It is the ability to create what never was within our minds. When functioning properly, it is a component of human creativity, but when impaired, it can result in psychosis. Imagery functions that can be affected by LE include:

Capacity for visual imagery: The ability to picture something, such as a map, in our head.

Intrusive images: Images that suddenly appear which may be aggressive, horrific, sexual or otherwise.

Hypnagogic hallucinations: The continuation of a dream, even after being fully awake.

Vivid nightmares: A tendency towards nightmares of a vivid Technicolor nature. Illusions: Auditory, visual, tactile and/or olfactory perceptions which are distorted or misperceived.

Hallucinations: Hearing, seeing, feeling and/or smelling something that is not present. In LE, sometimes this takes the form of hearing music or a radio station in the background. Unlike schizophrenic hallucina-

tions, these are accompanied by a clear sensorium, and the patient is aware hallucinations are present.

Depersonalization: A loss of a sense of physical existence.

Derealization: A loss of a sense that the environment is real.

Organizing and Planning

Organizing and planning a response is the most complex mental function, and is dependent upon all the functions already described. These functions, along with attention span and working memory, are referred to as executive functioning. Organizing and planning functions that can be affected by LE include:

Concentration: The ability to focus thought and maintain mental tracking while performing problem solving tasks.

"Brain fog": Described by many LE patients. Although difficult to describe in objective, scientific terms: it is best described as a slowness, weakness, and inaccuracy of thought processes. Prioritizing, organizing, and implementing multiple tasks with effective time management.

Simultasking: The ability to concentrate and be effective while performing multiple simultaneous tasks.

Initiative: The ability to initiate spontaneous thoughts, ideas and actions rather than being apathetic or merely responding to environmental cues.

Abstract reasoning: The capacity for complex problem solving.

Obsessive thoughts: May interfere with productive thought.

Racing thoughts: May interfere with productive thought.

An assessment of each of these areas of functioning is a critical component in the clinical assessment of LE. The cognitive assessment is only a part of the assessment of LE. Other components include the psychiatric assessment, the neurological assessment, a review of somatic symptoms, epidemiological considerations and laboratory testing when indicated. I have gradually developed a structured cognitive assessment which focuses upon the areas mentioned after examining many patients with late stage neuropsychiatric Lyme disease. I have also incorporated concepts from others that have made major contributions in this area, such as Drs. Rissenberg, Niels, Fallon, Freundlich and Bleiwiss. It is difficult to explain exactly how Lyme disease causes cognitive impairments. The variability of these symptoms suggests an episodic release of an endotoxin

or cytokine which may contribute to the cognitive dysfunction. This is an area where considerable research is needed, and is beyond the scope of this article.

The symptoms described are often very difficult for patients to describe, and are difficult for many physicians to understand. As a result, patients with these impairments are sometimes erroneously viewed as being hypochondriacal, psychosomatic, depression, or malingering.

These symptoms are real and must be explained: that cannot be discounted as being imaginary.

There are many treatment strategies. Antibiotics and a number of different psychotropics are helpful to many. I have found Aricept to be helpful in the treatment of "brain fog" and problems with slowness of retrieval.

To those of you who have LE, be realistic about your limitations and the validity of these limitations. Use strong areas to compensate for areas of weakness. Avoid excessive stress which compounds the problem. Be aware that certain tasks challenge many higher level attributes. Maintain hope and retain an effective working relationship with your family, support system and treatment team. *pha*

“Zebras” ...cont'd from pg 7

remained that this had been a partial stroke leaving the patient exhausted and feeling as if he is probably doomed to fall apart. Thus, the first clues occur even before one meets the adult patient in person. They are the hints of desperate fear - even terror, fatigue, road or other rages, extreme marital discord, general irritability, a Tourette's-like tendency to spew abusive words, obsessions, aggression, phobias, compulsions, weakness, memory impairments, and/or weird shifting pains. But they always involve a major PERSONALITY CHANGE. As an example, Lyme-infected adults with strange memory impairments usually were well

known for their efficiency before they developed major cognitive organizational handicaps from their infections and began to avoid the newly stressful tasks and responsibilities.

When the patient is due to be in the office, the doctor frequently will observe the first concrete evidence of brain involvement; typically, most new Lyme patients get very lost on the way to the office, even despite having been given careful directions beforehand. Psychiatrists usually start sessions about on time, but it is not rare that new patients will arrive, lost and frustrated, after the session time is over, and

they may be in a state of fury. They struggle to hide this, but often they are furious because lateness is not their usual style and they can't make sense of why they are not on time. It does not seem fair to them and they are overwhelmed.

So, in the first interview one may get a disconcerting experience with the cognitive problems and the irritability. Often, suggesting to new patients that they need sophisticated testing for TBDs stirs up anger, too. Not so much for the cost, but because they tend to feel that there hasn't been enough attention paid to their over analysis as to why they are there. Some undiagnosed peo-

ple come to see a psychiatrist because, eager to make sense out of their confusing symptoms, they decide they must have arisen in response to the anniversary of a loved one's death long ago, or that they may be reliving an old trauma, or that it is due to marital stresses, or to their doctor-documented hypochondriasis. However, these factors are too simple to explain the plethora of symptoms. Office experience may teach the doctor that any stress can stir up the effects of the spirochete *Borrelia burgdorferi*, the cause of Lyme disease, as well as the infection is able to magnify the old stresses. If the patient proceeds with anti-

microbial treatment, the past trauma fades to greater obscurity.

Of course, it is vital to care about the patients opinions, but it is more important to keep in mind that they are not going to get well until any underlying infections are properly diagnosed and treated as quickly as possible.

Maybe the analogy about hoof beats could be utilized in a positive way. Imagine the impact of Dr. Paul Revere riding on a zebra, carrying an early warning system to arouse the citizenry to be on the alert for a forthcoming assault on their nervous systems by tick-borne infections. *pha*

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The Mitochondrial Component

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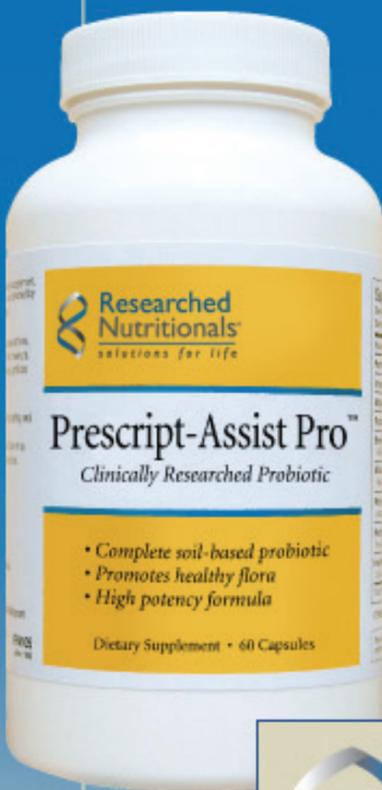


The Immune Component

Most of our patients' immune systems are very weak. In order to provide the nutritional support for a healthy immune system, I recommend Transfer Factor Multi-Immune™. These folks have put a lot of thought into developing a product which promotes healthy natural killer cell function. The combination of transfer factor and the herbal and nutritional base make this an extremely effective product.

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The Gut Component

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