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More Delays in IDSA Lyme Disease Guidelines Revisions

by **Kris Newby**
www.underourskin.com

The Infectious Diseases Society of America (IDSA) has missed its target date of December 31, 2009 for rendering a decision on whether it will rewrite its Lyme disease medical guidelines, which according to a group of leading Lyme disease specialists, “mislead clinicians and result in poor patient care.”

Diana Olson, IDSA VP of Communications, said that the medical evidence review panel, which met over a dozen times in 2009, is aiming to release recommendations “as early as possible in the new year.” If a rewrite is called for, the IDSA revision would be completed in “several months to a year or more”, leaving suffering Lyme patients in treatment purgatory for four years since the scientific integrity of the guidelines was first questioned.

The reevaluation of the IDSA Lyme guidelines was driven by an antitrust investigation led by Connecticut Attorney General Richard Blumenthal. During his 17-month investigation, Blumenthal found substantial conflicts of interest among the 2006 guidelines authors, who held commercial interests in Lyme-related diagnostic tests, vaccines, and insurance. In addition, he found that this panel had suppressed scientific evidence and excluded opposing views.

In December, Senator Chuck Grassley launched an investigation into the conflicts of interest of 33 other medical societies, saying in a press release, “These organizations have a lot of influence over public policy, and people rely on their leadership. There’s a strong case for disclosure and the accountability that results.”

During the 2.7 years since the IDSA Lyme guidelines investigation began, IDSA leadership has shown a consistent lack of concern,

remorse or urgency in correcting possible inaccuracies and biases in the 2006 Lyme guidelines.

As soon as Blumenthal’s investigation was announced, IDSA’s conflict-riddled panel launched a far-reaching campaign to disseminate their 2006 recommendations across the U.S. medical information network through physician continuing education (CME), medical textbooks, infectious disease board certification courses, online resources, and medical school lectures. So, even if the IDSA guidelines are revised immediately, it could take a year or more to remove flawed diagnosis and treatment recommendations from the system.

Furthermore, rather than censuring the guidelines chairman, Gary Wormser, M.D., for violating the IDSA’s conflicts-of-interest policies by holding “a bias regarding the existence of chronic Lyme” and handpicking “a likeminded panel without scrutiny by or formal approval of the IDSA’s oversight committee,” the IDSA leadership awarded Wormser the IDSA’s 2007 Society Citation for being “a bold champion for rational, evidence-based medicine.”

To add insult to injury, three days after the mandated evidence hearing, which according to many observers was an evidence-based victory for Lyme patient advocates, former IDSA president Anne Gershon denied any IDSA wrongdoing, saying, “IDSA’s signing the agreement was not, as [Blumenthal] alleges, an admission of guilt, but an effort to end a fruitless investigation.”

Gershon went on to say, “The notion that the authors had financial conflicts of interest is absurd to anyone who has read the guidelines, which recommend generic tests and a short course of generic drugs.”

Lyme disease policy expert, Lorraine Johnson, J.D., M.B.A., explained why this



At the July 30, 2009 Lyme evidence hearing, ILADs submitted 300 pages of analysis and 1,300 pages of peer-reviewed research contesting the IDSA Lyme Guidelines recommendations.

IDSA statement is misleading: “People in the Lyme disease community know that conflicts of interest were a big issue in the Lyme vaccine. We also know that the narrow disease definitions that suited the vaccine trials the best, hurt patients by denying and delaying diagnosis to patients with Lyme.”

Johnson provided details on the author conflicts in a recent article in the Journal of Medical Ethics:

“The most influential panelists on the IDSA guidelines panel had commercial interests related to Lyme vaccines, diagnostic tests, and insurance. Some of the panelists had been involved in the development of the first Lyme vaccines—had run the clinical trials for these vaccines—vaccines which were withdrawn from the market after patients reported serious neurologic side effects. Some had been sued as part of a class action lawsuit or served as expert witnesses for the vaccine manufacturer. Some of the panelists

acknowledged they owned Lyme diagnostic tests or were working on the second generation of Lyme vaccines, which are still under development.”

In the meantime, as the number of U.S. Lyme cases grows by about 30% per year, Lyme patients are trapped between a broken health care system and biased medical guidelines that are being used by insurance companies to deny treatment.

Here’s to hoping that Senator Grassley and CT Attorney General Blumenthal (who is now running for the Senate) will put some legislative teeth into making “non-profit” medical societies like the IDSA more accountable for patient welfare and less beholden to vaccine and drug manufacturers.

For an overview of the Lyme controversy, watch the UNDER OUR SKIN trailer: <http://underourskin.com/watch.html>. [Breaking news on this story as we went to press. Be sure to catch the next issue!].
pha



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Did this Little Woman have Lyme disease?

by M.M. Drymon



"Is it not meningitis?" were Louisa May Alcott's last words.

"Little Women" is one of the most beloved books that I remember from my childhood. When PBS advertised a television documentary about Louisa May Alcott's life, I was thrilled to be able to watch it. My joy, however, quickly turned to dread when I watched the actress portraying the author run several times through a shrubby, weedy, forested area in a long skirt, albeit, the skirt was tied up a bit. I wanted to reach in to the television and shout at her "watch out for the ticks." If that television special was shot almost anywhere in New England today, the actress was at great risk for becoming infected with Lyme disease. I also wished that I could reach back through the centuries to warn Alcott herself about how risky her daily run could be. Several years ago, in association with a book I was researching, I participated in an experiment that showed with clear results how risky wearing a long skirt in a tick-infested area [Crescent Beach in Cape Elizabeth, Maine] could be. The enlarged flowing cloth profile makes the skirt into a collection flag or magnet for questing ticks, leaving the wearer especially vulnerable to infection. My warnings, however, would be a century and a lifetime of misery too late for Louisa May Alcott.

Born in 1832, Louisa May Alcott was a direct descendant of Samuel Sewall, a judge during the Salem Witchcraft Trials in 1692. For most of her life she resided in Concord, Massachusetts, at a time when the New England landscape was being transformed from an agrarian terrain into the modernized, industrial, and tick-infested world that we know

today. Farms were being abandoned in rocky New England in favor of the easily plowed and fertile soils of the Midwest. Alcott's friend, Henry David Thoreau, wrote about these changes in the famous work that he composed at nearby Walden Pond. The modern reforestation of New England had just begun, bringing with it brushy undergrowth and weedy, neglected patches along with the early foundations of our

When Ian Greaves and Norbert Hirschhorn, experts in mercury poisoning, studied Alcott's symptoms, they found that they didn't add up. Alcott did not have the telltale signals for mercury poisoning or signs of tremor in her handwriting. It seemed to them more like an immune system disorder. They suggested that, based upon her symptoms and a late portrait of her with a rash on her face, Louisa May Alcott suffered

of butterfly rashes on the faces of modern Lyme patients. One patient in Connecticut had such a rash, but it was only after she broke out all over her entire body that Lyme Disease was suspected, diagnosed, and treated. Another patient had a bulls-eye rash on her arm accompanied by a butterfly rash on her cheeks and eventually, a rash that covered most of her body.

There are lessons to be learned from history. An examination of Louisa May Alcott's afflictions may help to bring a spotlight onto modern sufferers of chronic Lyme disease, many of whom live in a medical limbo of pain and despair-their disease denied and their sufferings denigrated. Alcott's symptoms, her frequent interactions with a possibly tick-risky landscape, the scientific findings of extant infections in museum specimens that lived in Massachusetts during her lifetime, and the landscape itself point towards a diagnosis of Lyme borreliosis infection with possible brain involvement. Although she eventually died from a stroke, her suspicion that she suffered from meningitis may not have been very far off the mark.

People who are interested in reading Louisa May Alcott's descriptions of her afflictions should read:

The Journals of Louisa May Alcott [University of Georgia Press:1997]. Edited by Joel Myerson, Daniel Shealy, and Madeleine B. Stern

Resources:

See "Why Women?" on page 150 of *Disguised as the Devil: How Lyme disease created witches and changed History*. A female in a long skirt collected an astounding four times as many Ixodes scapularis ticks as her male counterpart walking in the same area of Crescent Beach, Cape Elizabeth, Maine.

Hirschhorn, Norbert and Greaves, Ian. "Louisa May Alcott: Her Mysterious Illness." *Perspectives in Biology and Medicine*. Volume 50, Number 2, Spring 2007, pp. 243-259.

W.F. Marshall III, S.R. Telford III, P.N. Rhys, B.J. Rutledge, and D. Mathiesen, "Detection of *Borrelia burgdorferi* DNA in museum specimens of *Peromyscus leucopus*," *Journal of Infectious Disease* 170 No.4 (Oct. 1994), 1027-32. *pha*



Grave of American writer Louisa May Alcott, Sleepy Hollow Cemetery, Concord, Mass.

modern suburban landscape. In 1862 Louisa May Alcott contracted typhoid fever while serving as a Civil War Nurse in Washington, D.C. She was treated with calomel, a mercury-laden drug. Her brush with mercury could have left her vulnerable to Lyme infections or re-awakened a pre-existing infection. In subsequent years, when she suffered intermittently from a spectrum of ailments, she attributed them all to mercury poisoning. Alcott's journals and letters are filled with detailed accounts of her suffering: rashes, headaches, profound fatigue, nerve pain, digestive problems. "Sick from too hard work," she wrote in 1867, the year before *Little Women* was published. By 1888, at the age of 55, she wrote "I look about 70, grey & wrinkled & bent & lame."

from the auto immune disease, Systemic Lupus Erythematosus. Another possible diagnosis that needs to be considered is Lyme disease. The late Dr. Paul Lavoie firmly believed that in some people, Lupus or a Lupus-type syndrome was a reaction to an underlying Lyme infection. Modern patients suffering from chronic Lyme often exhibit the Alcott-like symptoms of extreme fatigue, re-occurring rashes, edema, nausea and the joint pain. Some have been diagnosed with Lupus due to elevated Anti-Nuclear Antibodies [ANA] in blood tests but then were subsequently diagnosed and treated for Lyme disease, which cleared up the Lupus-like symptoms in some. The butterfly face rash may be an infrequent symptom of Lyme disease as well as Lupus. There are several documented records

Public Health Alert

The PHA is committed to researching and investigating Lyme Disease and other chronic illnesses in the United States. We have joined our forces with local and nationwide support group leaders. These groups include the chronic illnesses of Multiple Sclerosis, Lou Gehrig's Disease (ALS), Lupus, Chronic Fatigue, Fibromyalgia, Heart Disease, Cancer and various other illnesses of unknown origins.

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

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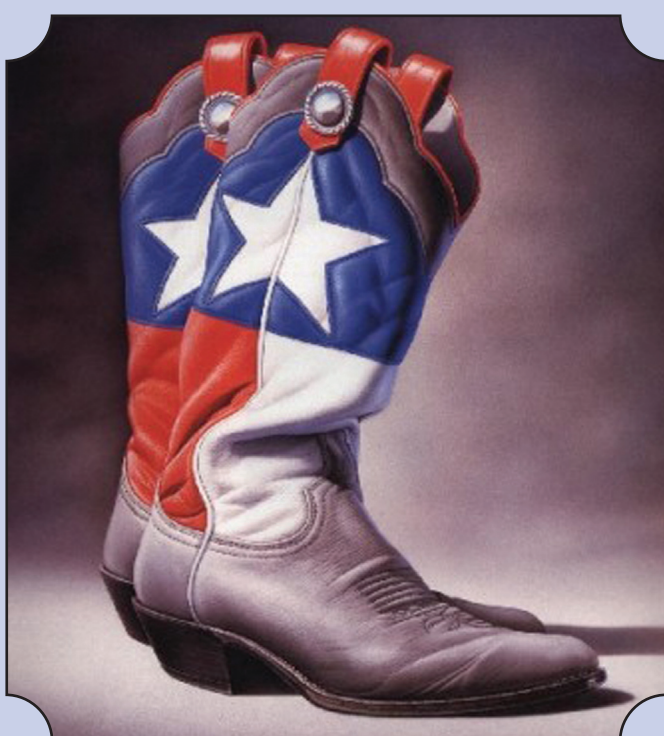
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Under the Eight Ball: a New Film by Timothy Grey Hall



by PJ Langhoff

My father was a professional mechanical engineer, and one of his earlier jobs when he was alive was at the Chicago Bridge and Iron Works in Chicago, Illinois in the early 1960s. When we were young I remember my family driving to visit his mother (my grandmother) who lived on the south side of Chicago. In our endeavor to get to Grandma's, somewhere along the journey from the suburbs to the inner city we would invariably pass by refineries with their large storage tanks full of petroleum and other chemicals. "See those? That is what I used to design," my father would say proudly, pointing to the enormous spherical-shaped tanks as we passed by. As a child, although I would catch a glimpse and regard them with childish curiosity, I could barely appreciate his work let alone the outcome of his designs.

My father would speak just as proudly of his military experience (during the Korean conflict), just as his father and grandfather had served before him; and son and grandson who would follow in service according to family tradition. I always got the feeling when I was younger that Dad knew more than he was willing to talk about, regardless of whether the topic was work or the military. We heard a few references over the years to the "Eight Ball", but I never really bothered to find out what it actually was. I guess I never really thought about the kind of work that my father did when I was growing up, including his work at a division of Rockwell International (a major contractor to the military), at CB&I, or his work on replacement O-rings for the space shuttle program after the January 28, 1986 Challenger disaster where seven astronauts lost their lives. The anniversary of that event looms as I write this so I mention it since engineering (and warfare of a biological kind) are the topics of discussion.

In the 1940s, ex-DuPont scientist and chief of the munitions division of Camp Detrick, (later Fort Detrick) and colleague Harold Batchelor drew up engineering plans for a large metal spherical tank to be constructed. Its intended use was for biological warfare testing of bombs containing microbial agents which were to be exploded in relative safety on site at Camp Detrick instead of elsewhere such as Dugway Proving grounds. The Chicago Bridge and Iron Works received

the contract to fabricate and deliver in 1949, a one-million liter test sphere which would be used for this purpose, called The Eight Ball. The sphere was completed in 1950 and cost three quarters of a million dollars, and weighed about 131 tons according to a source.[1]

When I heard about a new film that was recently released called Under the Eight Ball, the name and its subject matter of Lyme disease spiked my interest. Being somewhat familiar with the design of the sphere thanks to my father and knowing that he passed away but not before exhibiting some very Lyme-like symptoms, I was curious about the film and contacted producers for a preview so that I might write an article about it. Not knowing what to expect perhaps except for the "biowarfare" angle and the topic of Lyme disease, I entered my preview with a curious, open mind.

Directed by Timothy Grey Hall and Breanne Russell, with Justin Blake as producer, this unmistakably relevant film grabs your attention immediately with its edgy music and non-nonsense film work. The story opens with the chronologic story of Tim's sister, award-winning investigative journalist Lori Hall-Steele, who is visibly sick and dealing with an illness of "unknown origin."

While Lori remembers having been bitten in 2006 by a spider when visiting downstate near Detroit, by the time she returned home to Traverse City, she had a hallmark Lyme "bull's-eye" rash and symptoms including a "dropped foot".

Following this, Lori experienced cold and flu-like symptoms, and although she suspected Lyme disease, she was repeatedly told an incredulous phrase that many people hear, which is that "there is no Lyme in Michigan." A menu of diagnoses followed, including Guillain-Barré syndrome, MS, Lupus, Lyme and ALS. Some of Lori's laboratory tests later returned positive for Lyme disease as well as Ehrlichia and Chlamydia; the former which can be fatal by itself.

After a fairly rapid progression of only nine months, Lori was put on a merry-go-round of antibiotics, steroids and immunosuppressive agents that appear to have made her condition far worse and led to complete incapacitation and requiring a ventilator. All along, the words "Lyme disease" seem to fall on deaf ears while a neurologist told her (incredibly coldly) that, "Everyone dies."

Although I am not a violent person, hearing those words made me wish I could reach into the film and grab the medical staff by the shoulders and shake some sense into them. I wanted to shout, "What don't you get? Can't you see how ill this woman is?" The anger that I felt at those provocative words "everyone dies" echoed my own experiences dealing with Lyme disease. It had also been my experience that physicians know very little about the fastest growing vector-borne disease epidemic in the world, and I



Leaving Grand Rapids: Lori Hall-Steele, the director's sister is moved from a hospital to a palliative care facility.

live in Wisconsin, which is endemic for Lyme.

Lori's neurologist's words made me recall a statement my own doctor had made which was "I'm not going to hold your hand every time you think there is something wrong with you." My nearly 100 doctors over a 13-year period in three states all refused to discuss the words "Lyme disease" as well. So I know exactly what Lori and her family were up against although her progression in the illness was far more severe and rapid than many people's I had seen or heard about.

To that end, the film is an incredibly honest, personal portrayal of the last months of this precious woman's life and a desperate search for answers. The film shows that Lori's life was no less meaningful than that of the physicians who contributed to her deteriorating condition. And yet only Lori's friends and family seemed to lend her any credence whatsoever beyond the band aid therapies and medical red tape they were enduring just to make her comfortable in her last days – days which should not have had the outcome they did, had she been properly diagnosed and treated.

I couldn't help but feel incredibly close to Lori and want to speak for her by saying "She has Lyme, you idiots! Lyme disease is real! Give her antibiotics, for God's sake!" as if my efforts would help. If nothing, this film cries "foul" in an honest and justifiable anger that patients with real illness are being ignored and, for lack of better words, "dealt with" because after all, we all die.

The film continues by discussing the history of biowarfare in encapsulation, touching on the microbial pathogens and experimentation which took place inside the eight ball during the 1950s moving forward. There are references to Japan and Lt. General Shiro Ishi's Unit 731 biowarfare facility that was the source of horrific experimentation, including on human subjects. And legitimate questions are asked about the source and purpose of the biological warfare experiments which took place in the United States, where we all live in a sense, under the Eight Ball.

Another segment of the film discusses the chemical companies in Michigan which include Dow and DuPont and their connections with industrial pollutants. It also shows Tim's failed attempts to have the tap water from Lori's home and local sources tested for contaminants. The red tape surrounding water testing in his area is arguable from both sides of the front desk however the response by the public water department appears somewhat skewed. If a concerned citizen brought a water sample forward to be tested, one might expect genuine concern about the possibility of impurities in local supplies. That did not appear to be the case here, as the water board seemed more concerned over proper etiquette than the possibility there might be a legitimate problem.

Tim's approach to filming is admittedly a bit reminiscent of Michael Moore's film "Sicko", (which I liked by the way), but his honesty and aggressiveness are tempered with a legitimate desire to get to the truth of why his sister had to die and what are the origins of Lyme disease. The latter is a question that millions of people the world over are asking but, to date, we have not received any answers.

The worst part about Lori's death is perhaps that the questions remain unanswered. Some of Lori's autopsied tissues remain on ice to date because no laboratory has been found willing to receive and study them in a meaningful manner. And there are no answers either to date about the ramifications of the military's biological warfare testing performed in the Eight Ball at Camp Detrick. In a sense, we are all living under the eight Ball and whatever effects its tests may have brought to the United States.

There are key interviews in the movie, and a metaphorical snow scene that Tim and Breanne said means "something different to each viewer." Since I am an equestrian and I remember a time when I was too sick to ride, I easily related to the physical strength required to do so, and what little I had when I was at my worst neurologically with this illness.

I also felt like the stark

contrast between being able to ride horseback when well, and being reduced to life on a ventilator followed by death were statement enough about the seriousness of this illness. The metaphor, to me, felt like all patients are left to wander aimlessly in the blinding snow of white papers and unrevealed medical knowledge due to politics and secret agendas. Perhaps if we could just see what lies beneath, we could uncover the truths surrounding this disease. Perhaps with films as real as Eight Ball, some of the coldness and secrecy will finally begin to melt away.

Certainly the film asks the hard questions, and Lori and her family deserve to know the answers. While "why" is the loudest question from this film, the best comment for what this film meant to me is simply a "desire for truth".

Naturally the film moved me to tears as I could easily put myself and others I know in Lori's place on the bed. My thoughts were easily "this could have been me". Like Lori, I was also falling down the slippery slope of disability and death until I was fortunate enough to find a physician who believed I had Lyme and agreed to treat me. Many like Lori tragically are not that fortunate, and this leaves their families and friends grasping for answers before it's too late.

And having survived that part of the illness, I feel a kinship with Tim and Breanne and their sense of responsibility to communicate the reality of this illness and also to become spokespersons for those who are suffering because not enough is being done to provide answers. Certainly there are not enough doctors who are able to recognize, diagnose, or treat these patients and there is a serious lack of validation for these patients.

Lori, who gave her willing consent to be filmed throughout this process, is a hero simply because she allowed herself to live and to die on camera, and her story to be told honestly and continued by Tim and Breanne and the rest of the crew involved in the film. I believe their efforts to bring forth this story are well worth the time watching the

"8 Ball" ...cont'd pg 10

Shattered Dreams?



by Linnette R. Mullin

"Keep your chin up! Don't let your illness get you down."
 "Push yourself. Work through the pain. It will make you stronger."
 "How do you keep from killing yourself?"
 "Things have to get done regardless of how you feel. Be responsible and just do it. Don't be lazy."
 "God can heal you. You just need to have enough faith."
 "Moms can't get sick."
 "Get over it, already!"
 I'm sure you've heard at least one of these or similar statements since you've become chronically ill. Unfair as they are, there is no avoiding them. As if our dreams weren't shattered enough, statements such as these can send us into a tailspin.
 So how do we respond? Some choose the positive-thinking path. They decide to live life to the fullest in spite of their circumstances and keep a positive attitude (paying the consequences in private). True happiness, however, cannot be manufactured and I'm sure that many of the "happy" types experience plenty of their own down times...moments when they want to give up and give into the pain, agony, and the limitations created by their ill-

ness.
 Then, there are those who are "oh, woe is me" and can never seem to lift their heads and be thankful for the good moments. No matter how awful life may be for them, I dare say they do experience good moments...moments in which they get a bit of reprieve from intense pain, moments when they get a touch of the rest they need, moments that would make them smile or laugh if they would but recognize them.

Do you fall into one of these categories? Or, maybe you bounce between the two like me. Dealing with chronic illness is like living on an endless emotional rollercoaster. What is the answer to our dilemma? How do we cope? How do we motivate ourselves to keep going? What is it that makes us want to live, to pick ourselves up when we hit those inevitable emotional drops? What is the correct response to our illness, others' responses, and our own shattered dreams?
 In "The God Of All Comfort" devotional book for the chronically ill, Judy Gann answers these questions with sympathy: "Chronic illness smashes schedules - and dreams. From an outing with a friend to a ministry opportunity in China, plans shatter as our rebellious bodies follow their own agendas. "We may reach a point where we refuse to make plans or even dare to dream. Why bother making plans? I'll probably get sick and have to cancel them. The sting of disappointment chips away our fragile hope."
 "Yet, our hope is not in our dreams or in our plans for the future, but in the Lord. He

who knows the end from the beginning is in control and has a purpose far beyond what we can see with our nearsighted vision. The Lord's work in our lives is greater than our dreams. "The Lord is with us as we stand with the pieces of our crumbled dreams scattered about us. As we surrender our dreams and hopes to him, he specializes in fashioning new dreams out of broken ones, in forging something new out of the splintered pieces of our lives." (Go to www.JudyGann.com for book information.)

persevere when life seems impossible.
 My sixteen-year-old son struggles in his dreams for the future. But God has blessed him with incredible insight. Returning home from our latest Lyme check, he said, "One good thing about the Lyme is that it makes me depend more on God instead of depending on my own strength." He's right on! God is our strength, as well as our sanity. Without Him, all hope would be false if not non-existent.

our dreams?
 This past November, I wanted to attend my local writer's conference. It's intense and I didn't know if I would be up to it. I sent in my registration and money, hoping that I would not be disappointed. Not only did God allow me to go, but He blessed my body with the extra energy and stamina I needed to get the most benefit out of the conference. I was so thankful!

Then, New Year's Eve I wanted to attend a gathering for our church at a member's house. I hadn't been able to go for the last several years. Somebody always became ill. Sure enough, my little one came down with one of his Lyme-induced fevers the night before and I couldn't go. I have no idea why God didn't time the fever to come afterward and I was very disappointed. But, I have to submit to His providence and trust that He knows what is best for me, my son, and others affected by the situation.

While one of the hardest things we have to do, trusting God with our hopes, plans, and dreams provides the peace, comfort, and strength we need to persevere through the toughest and most disappointing moments in our lives. Where is your hope? Where is your faith? Have you lain your shattered dreams at the Savior's feet?

~Linnette R Mullin
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**"Perseverance is not a particular distinct grace of itself, but such a virtue as crowns all virtue; it is such a grace as casts a general beauty and glory upon every grace; it is a grace that leads every grace on to perfection."
 ~Thomas Brooks
 1608-1680**

"Many are the plans in the mind of a man, but it is the purpose of the LORD that will stand." Proverbs 19:21 (ESV)
 I admit that sometimes I huff and puff over this verse - usually when there's something I feel I just have to do or something I really want to do. But, most of the time it brings me comfort. As Judy pointed out, it's comforting to know that while my body, my circumstances, my life are often out of my control, they are never out of God's control and He works out His purpose through it all. In fact, this knowledge gives the strength and fortitude to

Mark 12:29-30 (ESV)
 "Trust in the LORD with all your heart, and do not lean on your own understanding." Proverbs 3:5 (ESV)
 "Now faith is the assurance of things hoped for, the conviction of things not seen." Hebrews 11:1 (ESV)
 Faith in God Himself - in who He is - is the only life-giving, hope-fulfilling, dream-making, prayer-answering faith that exists. We are to love God - the Lord Jesus Christ - and trust Him with everything that is in us. Who better to trust than the one who knows all about us - our plans, our hopes,

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The Cost of Compassion



by Joan Vetter

At this time, all eyes and ears are on the terrible crisis in Haiti. How do we live a life of godly compassion for the earthquake victims in Haiti as well as other situations? Let's ask Jesus by going to the scripture where He reveals His heart of compassion and use that for an example of what He expects of His followers.

First, as Jesus was

preaching, teaching and healing every sickness and every disease among the people, he saw the multitudes and He was moved with COMPASSION for them because they were weary and scattered, like sheep having no shepherd. Then He said to His disciples, (we who follow Him), "The harvest truly is plentiful, but the laborers are few. Therefore pray the Lord of the harvest to send out laborers into His harvest." (Matthew 9:35-38) Thus, first of all we can surely pray for laborers to minister both to the spiritual needs of the people in Haiti as well as the physical needs. Most of us can't go ourselves, but we can donate to an organization we trust.

Of course we are told in James 2:15-16 that if a brother or sister is naked and destitute of daily food we're not to just say God bless you, but we are to give them what they need. It's so easy to rationalize this and say we can't help the whole world and just choose not to do

anything. However the Lord guides us by His Holy Spirit to show us specifically where we are to give. We can fall into a ditch on either side - either feeling overwhelmed and constantly condemned that we are not doing enough or hardening our hearts and failing to recognize who we are to reach out to.

Another place where we learn of the compassion of Jesus is in Matthew 18:21-35 where Peter asked Jesus how often he should forgive someone. He told the story of a king who was settling accounts with his servants. One owed him a large amount of money. Since he was not able to pay, the master commanded that he be sold, but he fell down before him and cried out for the Master to have patience with him. His master was moved with COMPASSION, and forgave his debt. But that servant went after someone who owed him far less, demanding violently that he pay up. When the Master discovered this, he

called him a wicked servant, reminding him that he should have shown COMPASSION even as the Master had shown him COMPASSION.

In Luke 7:13 Jesus meets a widow who is about to bury her only son. We are told the Lord had COMPASSION on her and raised her son from the dead. This is not something that happens very often, but it does still happen today.

One of my favorite stories in the Bible is Luke 15:11-32. We are told of a father with two sons. One demanded his inheritance and took off. He spent all his money and ended up feeding pigs. Something of interest here are the words "No one gave him anything."

Perhaps sometimes the mercy of the Lord is to have people withhold help when we are away from where we need to be. Right after this we are told that "he came to himself" by remembering even his father's hired servants have plenty of food. He decided to

return to his father and tell him that he was willing to be as a hired servant. The amazing grace of God is revealed in his return. His father saw him a great way off, which means he had been looking and waiting every day because of his love for the son. When his father saw him he had COMPASSION and ran, fell on his neck and kissed him. That son was restored in full measure as a blessed member of the family. In contrast, the other son sulked at the party given for his brother.

Finally, Peter exhorts us: "Be agreeable, be sympathetic, be loving, be COMPASSIONATE, be humble. That goes for all of you, no exceptions. No retaliation. No sharp-tongued sarcasm. Instead, bless - that's your job, to bless. You'll be a blessing and also get a blessing." (1 Pet. 3:8,9 - The Message Bible)

pha

Can You Be Friends if They Think You are Faking Your Illness?

by Lisa Copen

If you live with an invisible illness, you may find the emotions of coping with people's doubts about it can be harder to manage than the disease itself. Most of us with a chronic illness must eventually accept our condition. In order to live our best life, we need to educate ourselves about the disease and make well-researched decisions about treatment.

Those with illness, however, have no ability to make others accept the illness or even acknowledge it. When our loved ones are skeptical about the existence or seriousness of our disease, it can be devastating. It can wound our self-worth and cause problems in our relationships.

So what is the best way to respond when someone you care about refuses to accept that you really are ill and that your life is changing dramatically because of it? Here are four steps to best cope:

1. Go with it. Though the seriousness of your illness is significant under your roof, it isn't that important to others. And there's no magical conversation you can have with the person that will make him change his mind. The most likely way your friend will accept that your illness is real is by observing you. For example, your invisible illness may begin to have some visible side effects. When he sees you struggle to get up out of a chair, don't comment; just let him take it all in.

2. Grow with it. Use this as an opportunity to reflect on how you perceive other people and what you assume about their abilities. For example, when you're standing in line at the store and feeling wiped out, it is easy to assume "No one else knows how hard this is for me!" Surprisingly, nearly one in two people live with an illness and about 96% of the painful diseases are invisible. So the odds are that there are people who do actually understand how you feel. Also, think about

what situations your friends are experiencing that you don't really understand. Is a friend suffering from a spouse who has had an affair? Do they have a parent who has Alzheimer's? Or have they recently lost a job? All of these events dramatically change one's life and your friends can use your empathy and understanding.

3. Get over it. You may find yourself thinking "No one understands!" so frequently that you are missing out on new friendships. Save yourself the grief and don't obsess over how much people sympathize or if they do it appropriately. Though we would all like a loved one to be able to experience what it would be like to slip inside our skin for twenty-four hours, it's never going to happen. If people around you feel like they can never please you, soon you won't have any relationships left. You cannot change how someone else thinks; you only have control over your own behavior. So make sure your conversations are full of grace.

4. Get on with it. Life is precious and short and no material things in your life can replace friends and family. It is true that the intimacy level in your relationship will not ever be high if your illness is not at least believed to exist. But if you still want a relationship, and it's a healthy one in other ways, it can happen.

The odds are that, in time, your friend will eventually have his own health crisis and have some level of understanding about what you have faced on a daily basis. He may even turn to you for advice. Be supportive and encouraging. Don't say "I told you so."

Go with it. Grow with it. Get over it. Get on with it.

Relationships with those who don't understand the seriousness of your illness can exist. Be positive, accepting him for what he's able to give to the relationship, and have reasonable expectations. Someday, this may prove to be one of your most special friendships.

pha



Lisa Copen is the founder of Rest Ministries, Inc., a Christian organization that serves people who live with chronic illness or pain. She is the editor of HopeKeepers Magazine and author of various books on chronic illness. She has lived with rheumatoid arthritis since 1993.

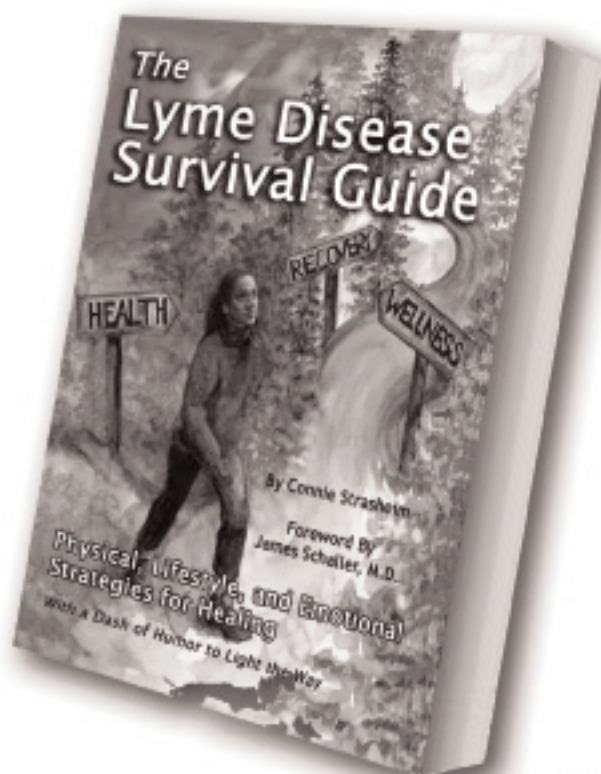


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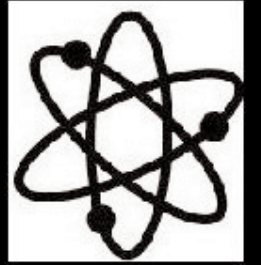
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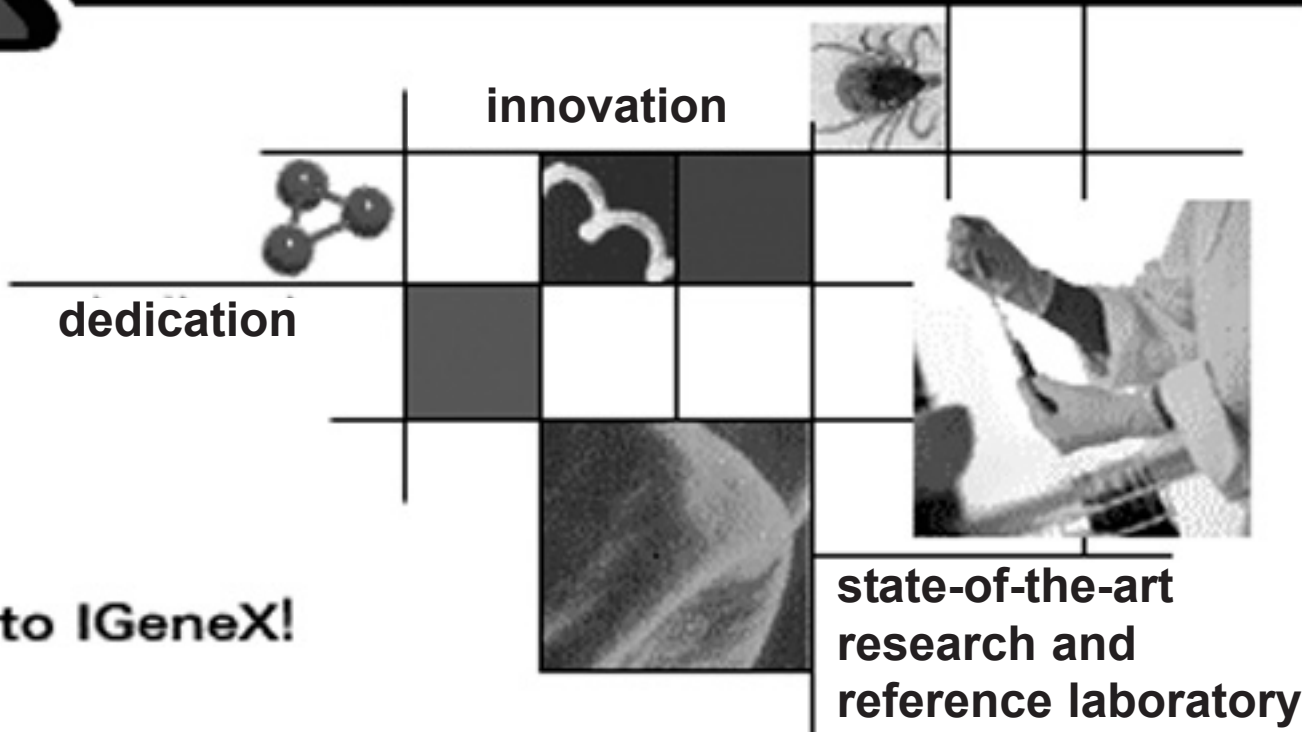
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The Lyme Disease Bacterium: Nothing is Simple

Part 2 in a series



by Dr. Jon Sterngold, M.D.

The bacterial cause of Lyme disease is called *Borrelia burgdorferi*, named after Willy Burgdorfer PhD, the researcher who first identified this germ in 1982. This spirochete, a corkscrew-shaped bacterium, is unique in the known bacterial realm because of the quantity of extra DNA it carries that enables it to evade detection and attack from our immune

systems. It can change its outer protein coat, thus cloaking itself from immune detection. It also can completely change form, becoming a treatment-resistant cyst or by totally shedding its outer coat and entering our own cells to set up shop. Antibiotics generally depend on the activity level of a bacterium; how fast it grows and how often it reproduces. Most of the common bacterial diseases we encounter in medicine are from bugs that reproduce in less than 24 hours. When antibiotics 'hit' the reproductive or active metabolic machinery of these germs, they die. This is why when we treat common illnesses such as pneumonia or urinary infections, people usually get better in a few days. The Lyme bacterium, however, has a reproduction cycle as short as a day but as long as about nine months. During a phase of prolonged inactivity, it is very hard to kill. These are some of the reasons that an established Lyme infec-

tion can be hard to eliminate. Additionally it is thought, and there is real data to support this, that the Lyme bacterium eventually takes up residence, almost certainly with other co-infecting bacteria, in what is called a biofilm community. On a microscopic level, the bacteria clump together in a gel-like secretion where they are insulated from our immune system and circulating antibiotics or antibodies. This is their bunker from which they can still wreak havoc by releasing the neurotoxic products of their metabolic life. It's an evolutionary match - they thrive in a body that they modify to suit their needs. They can suppress our immune systems and alter other vital processes, making us ill, helping them to thrive. They don't tend to kill us, though they sometimes do. It is a parasitic existence.

In addition to symptoms that stem from inflammation of the brain, nerves, heart, blood

vessels, joints, and connective tissue, which the Lyme bacteria cause through multiple mechanisms, we also know that the disease can induce another class of illness called autoimmune disease. Maladies such as lupus, multiple sclerosis, and Lou Gehrig's disease (ALS) can actually be caused by Lyme disease. These diseases are not considered to be curable, but there are many cases in which the autoimmune disease resolves completely when the Lyme disease has been treated - always with long-term, high-dose antibiotics.

Tests to determine whether someone has Lyme disease are very problematic. The common tests measure levels of antibodies we make that are specific to the Lyme bacteria. But, if the bacteria can hide, change form, immunologically 'cloak' itself, and can suppress our ability to make antibodies, a person quite ill with Lyme can have totally negative

tests. What commonly occurs though is that after a year or so of antibiotic use, which can render some of the bacteria into fragments that the immune system can recognize, the tests turn positive. The dilemma is that when someone is looking for a diagnosis, an answer to profound suffering, a physician who relies on initial test results might call it wrong and the patient will have no answer and no effective treatment. This is part of what defines the difference between 'Lyme literate' MDs who understand the problems with testing and treatment challenges versus non-Lyme literate physicians who, for some very compelling reasons, can't or won't manage this disease. The range and depth of this problem is immense and will be discussed in the next article to follow.

pha

2010 Needs a Fearless Conversation About Vaccines



by Barbara Loe Fisher

As the second decade of the 21st century begins, it is clear that the first one saw big changes in the way Americans

think about health and vaccination. A good example is the fact that a majority of Americans "just said no" to getting an H1N1 influenza shot last year. The truth is, most of us just didn't buy the hype about swine flu. Perhaps it is because we are tired of constantly living in fear.

The Decade of Fear

Fear was the unifying emotion that defined the first decade of the 21st century in America. The Decade of Fear began on September 11, 2001, a day of indescribable loss that marked the ending of so much. Among the losses was the end of a civil and substantive conversation about vaccine safety

that had taken shape during the previous two decades but which - after September 11, 2001 - was hijacked by fear.

WMD Allegations Fueled Calls for Smallpox Shots

Within weeks of 9-11, there were frantic warnings by government officials that terrorists had weaponized smallpox and it was necessary to immediately dilute stockpiles of reactive 40-year old smallpox vaccine to make enough to give a smallpox shot to every man, woman and child. Then the allegation that terrorists had hidden weapons of mass destruction to unleash deadly infectious diseases on all of us was used to justify forcing sol-

diers to get multiple doses of reactive experimental anthrax vaccine.

Unprecedented Executive Branch Power

And within weeks of 9-11, a Congress driven by fear quickly passed The Patriot Act followed by the Homeland Security Act. Unprecedented authority was given to the Executive branch of our government, including creation of the third largest federal agency - the Department of Homeland Security. And then public health officials pushed for passage of new Model State Emergency Health Powers Acts to expand the police powers of state health officials whenever a public health emergency is

declared.

Pharma and Public Officials Push Agendas

For three years after 9-11, special interest lobbyists invoked bioterrorism and fear of infectious microorganisms to persuade Congress to pass Bioshield and Pandemic Influenza legislation shielding vaccine manufacturers, doctors and public health officials from all liability when Americans are injured or killed by experimental vaccines or drugs used during a government declared public health emergency.

pha

Around A Rosy



by Virginia T. Sherr, M.D.

First image is that of small children at play. If there are adults involved in the game, they are reduced to the stature of "little" themselves because they have to fall down, too. Such fun! "Ring around a Rosy" is beloved by toddlers because it can be a great equalizer with adults. There is nothing authoritarian about a singing adult flopping on the grass.

This playfulness has a grim history, however. It seems to have originated during the Great Plagues that swept across Europe during the Dark Ages. The "falling down" at the end

had to do with the fact that people were felled by the hundreds of thousands and the "rosy" is said to refer to the way that people tried to protect themselves with flowers, an old-time herbal remedy, perhaps.

Today, the grass upon which the children play may harbor potential for two different kinds of "rings": the telltale bull's-eye ring that may appear in some cases that mark the onset of Lyme disease. And when one looks through a modern microscope deeply into the blood of a child afflicted with babesiosis, another tick-carried plague, the game might be remembered. Set inside the red blood cells there are dark rings -- one form (merozoites) of a microbe that also represents a pestilence. Tiny babesiosis parasites living inside the red cells are making more and more Americans fall down. As in years gone by, people try to protect themselves with herbal and other remedies, not knowing the cause of their symptoms. And as the disease progresses, their on-going energy losses hardly will allow them to stand up or to even think about playing games.

Malaria is a close relative of babesiosis. It is widely



respected and feared--a major, worldwide epidemic that has gained the attention of health professionals globally. In this country, babesiosis similarly is spreading like a ring of fire from the New England states where it was identified into the grass and brush wherever ticks are found. However, state and local Departments of Health, government officials, and most physicians are reluctant to investigate what they imagine to be rare and exotic. Pleas to

Health Departments for dragging to collect and test ticks for the causative *Babesia* protozoan parasite fall on deaf ears in many areas. Babesiosis is not even a reportable disease according to the Center of Disease Control. Thus, multitudes of children, playing innocently in the grass, and their parents as well, are equalized by rings - rings in the rosy red blood cells and those other rings--the ones on skin - the famous bull's eye rings of Lyme

disease.

Fortunately, our second millennial remedies include powerful medications in addition to herbal help but, even so, they are not universal cures. Today's most effective antidote may turn out to be the people who are beginning to find a collective voice to demand medical, governmental and epidemiological interventions before they "all fall down".

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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.

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Conflicted Lymie



by Jennifer Allton
http://jmgarnet76.blogspot.com

Most people wouldn't even realize that I have Lyme Disease unless I told them. It is hard for them to fathom that a PICC line was sustaining my life a year ago. My life appears normal in 2010. God helped me when the quality of

my life was null of fun and normalcy. He gave me the strength to put one foot in front of the other to not only fight for myself, but for others with Lyme Disease. He put people in my path that had a hand in my current state of wellness and for that I am so thankful. In the past year, conflicting emotions run through me as God has finally given me a seemingly ordinary life. Ever feel conflicted?

What's conflicting about that you ask? I find that I am not quite normal and I am not quite a Lymie. I'm in Lymie limbo so to speak. This time of wellness is difficult because most of my friends were in Lyme treatment well before I started treatment and they are still very sick. Some of them are even sicker now than they were then. They call me lucky, blessed and normal. I feel lucky and blessed, but I defi-

nitely do not feel normal.

I feel like my body is the game of Jenga. We're taking pieces from the base and adding them to the top. Each part we pull may or may not be a load-bearing piece. If the wrong component is pulled, I fear that my body will just come crashing down. It is very important to be careful with every single piece and use caution with every move. My inner soul is aching because I don't feel part of my most inner circle anymore. Even though it is probably not true, I think that my Lyme friends feel as if I can't understand what they are going through because I am well.

On the other hand, it is hard to live a normal life because I have lived the Lyme life for so long. There was a point in 2008 where I was at my doctor's office nearly every day. I was getting IV's, picking

up supplements, picking up IV things for home or having an office visit. There are still remnants from that time in my home. I still have an IV pole, specialized PICC line dressings, even the PICC line itself, heparin and saline solutions. The list of what I have from that time in my life goes on and on. Sometimes I just want to throw it all away or give it to others that need it, but then I want reminders of just how far I have come. I need to know how abnormal I was to know how normal I am now.

The other conflicting role is that I became proficient at hiding my physical pains and ailments. I became so good at adapting that sometimes these ailments are hidden from even me. When I finally do complain a bit about a pain here or there, I get a lecture from my friends about how I need to be back in treatment. I immedi-

ately think hateful thoughts towards the spiral bacteria that ruined my life. Then approximately ten seconds later, I pick myself up by the bootstraps. I finally have an immune system and my body is finally doing what it needs to do.

But I still feel conflicted. I am a Lymie that can't be normal and feels somewhat ousted by the Lyme community since I am not complaining about ailments I do have. The "normal" don't desire me to be around when I do complain about my weaknesses and those with Lyme Disease don't want me because I am somewhat normal. Yes, I know that this is all a falsehood created by my own imagination, but it feels somewhat true. Are there others that feel like this too?

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"8 Ball" ...cont'd from pg 3

film. And I believe that the film's impact upon viewers will provide an angle, though difficult to watch at times, that some have not yet had the honor of knowing or understanding. Unless you have personally been touched by Lyme disease, it is difficult to grasp on many levels.

If nothing else, we must continue to talk about Lyme disease so that others might not

have to endure the hell that Lori and her family suffered. While Lyme disease is difficult enough on its own, the other diseases that accompany the infection, the diseases of ignorance, denial, and political agendas, are what viewers of this film will find most perplexing.

Yes, "everyone dies", but medicine is supposed to prevent deaths that can be pre-

vented; and Lori's most likely could have been had she been diagnosed properly and treated earlier.

Tim and Breanne and family's grief and desire for answers are palpable, justified, and pull sharply on the viewer's heart strings. It is difficult to watch someone we love pass on; more so when their death is publicly viewed, and worse, might have been prevented. I

believe that these brave individuals are champions for their honesty and vulnerability which is made so very public so others may learn this illness is not "all in our heads". They are to be applauded and their film watched with appreciation to the attention, openness, and honesty that they bring forth.

The movie premiered December 16, 2009 at the IFC Center in New York. To find

out about screenings in your area, visit: www.undertheeightball.com

Reference

1. Ed Regis. The Biology of Doom. Henry Holt & Company, LLC. 1999 NY.

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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.



Mitochondrial Support

One of the most common complaints among our patients is lack of energy. I became intrigued with **NT Factor Energy™** during a medical conference presentation which showed a 40% reduction in fatigue in eight weeks(1). When I tested my patients on this product, they reported a noticeable improvement in energy. The product's success is due to its ability to deliver a stabilized and absorbable phospholipid complex to promote healthy mitochondrial membrane potential.



Probiotic Support

Prescript-Assist Pro™ is clearly a step above what has been generally available, and I highly recommend it. If you do not have enough good gut flora then you may not only develop GI upset and bad flora overgrowth, but you may also develop food allergies and other ugly stuff. There is nothing more important than a good probiotic. This product was developed to assist you if you are taking antibiotics.



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*These statements have not been evaluated by the Food and Drug Administration. These products are not intended to diagnose, treat, cure or prevent any disease.

(1) Journal of the American Nutraceutical Association 2003; 6(1); 23-28.

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