Public Health Alert


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Farewell Dr B. Thanks for a job well done!

World Renown Lyme Disease
Doctor Retires, Research Begins

by Susan Williams

A major chapter in the history of Lyme Disease will draw to a close this November with the retirement of Dr. Joseph James Burrascano, Jr., a pioneer in the diagnosis and treatment of chronic tick-borne infections.

“Dr. B”, as he is affectionately referred to by his patients, has practiced medicine in East Hampton, New York, for over twenty-five years, and has treated thousands of Lyme patients from all over the world. Considered one of the world’s leading experts on Lyme and associated tick-borne diseases, he is the author of one of the most well-known and widely-followed treatment protocols in the U.S. today.

Dr. Burrascano received the Distinguished Physician Award in 1998. A founding member of the International Lyme and Associated Diseases Society (ILADS), he continues to serve on its board as First Vice President. He also serves on the Medical Advisory Board for the non-profit “Turn The Corner Foundation” (http://www.turnthecorner.org), which is dedicated to the support of research, education, awareness and innovative treatments for Lyme disease and other tick-borne diseases. He has lectured on Lyme both nationally and internationally, and has even addressed Congressional committees and the military on the complexities of Lyme disease. He is published in numerous medical journals and magazines, and has been interviewed frequently for several major television networks and print media.

Yet, in Dr. Burrascano’s eyes, his many outstanding achievements have not filled a large need that still exists. He explained, "I have become more "Burrascano"...cont’d pg 12

Breast Cancer Awareness
Leads to Great Outcomes

by Susan Williams

Breast cancer is the leading cause of death in women between the ages of 40 and 55, and an estimated 212,920 new cases will be diagnosed in American women in 2006 alone. The good news is that when found early, the five-year survival rate is 96%. Over 2 million breast cancer survivors are alive in America today. Breast cancer can strike any woman, but studies have shown that certain lifestyle choices and personal traits, such as genetics, can affect your risk.

Age. Risk increases with age, rising most sharply in the reproductive years from about age 30 onwards. About two-thirds of women who are diagnosed with breast cancer are over age 50.

Family History. If you have a close relative who has been diagnosed with breast cancer, you are at higher risk. A woman does not inherit the disease itself, but inherits the susceptibility to develop the disease. There appear to be clusters of breast cancer that appear in certain families, generally due to two specific susceptibility genes called BRCA-1 and BRCA-2. When these two genes are altered, they result in a much higher risk of breast cancer. There is genetic testing available which will allow a woman to discover whether or not she carries one of the altered genes.

Menstrual History. Other risk factors revolve around a woman’s lifetime exposure to estrogen, which begins at puberty and continues until menopause. Women who began menstruating before age 12 or began menopause after age 55 are at higher risk due to increased estrogen exposure.

Pregnancy. Women who have their first child earlier, generally before age 30, will be at somewhat lower risk. During a woman’s first pregnancy, her breast cells undergo “terminal differentiation” as they prepare to make milk, and the cells lose some of their ability to divide and develop genetic effects. Prolactin, a hormone which aids the breast in creating milk, may increase risk at higher levels. However, a woman’s levels of prolactin become permanently lower after her first pregnancy.

“Breast Cancer”...cont’d page 14
Dear Dr. Burrascano,

Even though you were not our physician, our Lyme specialist used your protocols to cure all four members of my family afflicted with Lyme Disease.

When we got sick in 1996, I could not find anyone in Texas who knew anything about LD, any support group, or anyway to evaluate the medical opinions we received. Your guidelines for diagnosis and treatment, which were published online then, were a blessed lifeline that helped me keep my sanity, especially through my daughter’s severe illness. I will never have enough words to thank you.

Pat Ricks

Dear Dr. Burrascano,

I find an overwhelming need to write to you even though we’ve never met. I live in San Francisco and am a Lyme patient of Ginger Savely, a Nurse practitioner under the supervision of Dr. Raphael Stricker. After one year, $90,000 dollars in insurance monies and appointments with upwards of fifteen Medical Doctors I finally was diagnosed with Lyme Disease. I can’t begin to describe my story, but then you’ve heard my story before.

It’s the all too familiar story with Lyme disease. Endless Doctor visits, countless tests, sleepless nights, loss of credibility. You begin to question your own sanity, others already have. I want you to know Dr. Burrascano that I can’t thank you enough. We haven’t met, we probably never will and I feel an overwhelming bit of gratitude for your dedication to this insidious disease.

Your guidelines will continue to make us well, even if you aren’t at the helm. You gave us hope when others looked the other way. The politics that goes along with this disease is shameful. The CDC should have a man such as yourself running the show, people would be well and this disease would be more than managed.

Thank you for standing your ground with them.

I don’t want to sound bitter, even though at times it’s hard not to be. I consider myself one of the lucky ones. I had the good fortune to live in a city with teaching hospitals giving me access to some of the best specialists in their fields, insurance to cover the year of testing for the disease ravaging my entire body. But in the end it didn’t matter.

What I needed was a Lyme literate physician who would have recognized my symptoms and clinically diagnosed me. A physician like yourself. Thank you for being the physician who made a difference in the treatment of Lyme disease.

Barbara Lavelle
San Francisco, California

Dear Dr. Burrascano,

Thank you for being the Dr who was willing to get aggressive with treating my Lyme disease when all other treatments/practitioners, no matter how well intentioned, had failed to eradicate my Lyme.

Because of your methods of aggressive treatments against an aggressive and tenacious bacteria, (and co-infections) I now have my life back. I never expected to feel this good again, and you gave me a second chance. I wish you the best in your new ventures and efforts. Thank you again.

Sue Cole

The Faith Factor by Joan Blinn

As a mother of thirteen, and in the midst of home schooling seven boys, ages eleven through three, a diagnosis of breast cancer in December in of 2003 changed my life radically. It was an opportunity for God to demonstrate to my family and I, in countless ways, that He is faithful and true.

In the Fall of 2003, I felt impressed to write a song for my husband for his fiftieth birthday, titled “Perfected Concerns”. I gathered all the Scriptures that had been so encouraging in our twenty-eight years of marriage. These were promises that had been our anchors to hold onto in difficult times, including any health challenges we had faced in the past. In preparing the song, the Word became etched in my heart.

In early December, I had an urge, that I believed came from the Lord, to do a topical study about courage and being strong in the Lord. I followed that leading and the next week found the lump. I believe the LORD had prepared me. Corrie Ten Boom wrote’ “Never be afraid to trust an unknown future to a known God.” I made a decision from day one that I would not make fear-based decisions, but prayerful ones, with my hand firmly hanging onto Jesus. I knew in my heart that this illness was for my good and for His glory.

Everyone has battles or storms in their life. The Lord is the God of the storm. The Bible says in Psalm 107:2 that He (the Lord) stirs up the tempest, but He leads us to our desired haven. God is sovereign over every illness, and I knew because of His word that this would work together for my good and the good of my family. He gently led those that have young.

Several years earlier I committed to, “Let my fruit reflect my faith in my Father and His future for me.” I trusted God to calm my anxious heart. It has been a journey of grace. We have experienced an outpouring of love and provision. The body of Christ truly was God’s love with skin on. I have learned that the big “C” is not cancer but Christ. Like Joseph and Job, that which others may have looked on as a disaster has been a door to highest benefit. My soul has found rest in God.

“Faith Factor”...cont’d pg 10
by Susan Williams

Earlier this year, a report came out that identified several soft drinks as containing high levels of benzene. Though steps are being taken to reduce the amount in soft drinks, however, most consumers still have many questions about this issue.

What is it?
Benzene is a colorless, sweet-smelling but flammable liquid. It also happens to be classified by the US Department of Health and Human Services as a human carcinogen, meaning that it can cause cancer. Once used as an additive in gasoline, it is a natural constituent of crude oil and a component of cigarette smoke. (Yum! And we're drinking this stuff!?)

Exposure to benzene can cause many undesirable side effects, including sleepiness, dizziness, rapid heart rate, headaches, tremors, vomiting, confusion, convulsions, unconsciousness and, in extreme cases, even death. Long-term exposure can cause leukemia, as benzene is known to damage bone marrow. It may also cause excessive bleeding and suppression of the immune system.

Why do manufacturers add it to soft drinks? Actually, they can also form. Since fruit-flavored drinks generally contain lots of citric or ascorbic acid, you can expect that these are common culprits for high benzene levels.

Additional components that contribute to this chemical reaction are heat and light, such as storing soft drinks in a warm place.

Does this mean that we should cut the manufacturers some slack? Nice try, but no. As early as 1990, both the manufacturers don't. Benzene can form naturally from two ingredients that are common in some soft drinks -- ascorbic acid and any added benzoate (sodium benzoate, potassium benzoate, and calcium benzoate). If citric or erythorbic acid are used in place of ascorbic acid, benzene would smell as sweet.

"What's In a Name? That which we call a rose by any other name would smell as sweet."
- William Shakespeare

Everything and everyone has a name. Ask a linguistics professor, who studies language, and s/he might tell us that names of inanimate objects like ‘table’ and ‘chair’ are quite arbitrary and could have just as easily been named ‘bunta’ or ‘cooglie’. (I only took one linguistics class in college so I don't have what is considered a 'common' name. I think what most mothers eventually realize is that names go through cycles of what is popular and socially acceptable within that war-zone referred to as a playground. I was relieved as a child, and still as an adult, that my mother did not name me after my great-grandmother…Orvetta (may she rest in peace). Orvetta, to me sounds like a hefty, homely farm girl with a really wide nose and thick calluses on her feet, as does the names Bertha and Gertrude. (To all the Orvettas, Berthas, and Gertrudes out there - I apologize for my narrow-mindedness and childish stereotyping!)

Even to this day, as a level-headed…um, ‘lady’, for me those names still have that connotation in my mind. I'm not sure what their 'official' meanings are as I'm much too lazy to look them up - but I still think of really portly, very plain women, perhaps possessing a bit of a nasty attitude because they've had to combat stupid attitudes such as mine all of their lives. However, as I've aged and expanded my…mind, I also realize the name Donna can also call forth the image of a fat unattractive woman with a nasty attitude, especially after I wake up in the morning and peer into one of the few mirrors I've allowed in our home. Yet all of that is really beside the point.

What I think is truly important is the name given to our various sets of health-related symptoms. To Professor Linguistics, while the names themselves are still quite arbitrary - to the doctor and patient, they certainly are not.

In fact, the name given to a patient's set of symptoms can be a life and death designation.

As mentioned in my other columns, Lyme disease has over 350 symptoms and is called the "Great Imitator" (much like syphilis) because it can mimic over 300 other diseases. Lyme disease has been misdiagnosed as such syndromes as Chronic Fatigue Syndrome, Fibromyalgia, Irritable Bowel Syndrome, Interstitial Cystitis, and such diseases as ALS (Lou Gehrig's disease), Alzheimer's disease, Multiple Sclerosis, Lupus, Rheumatoid Arthritis, and so much more. Many patients with a litany of symptoms spend years searching for a physician willing to name their collection of symptoms.

Most of these 'complicated' patients receive the tried but often untrue definition of "depression" early on in their quest. For many doctors, depression is their first and sometimes finest attempt at a diagnosis. It's a catch all diagnosis meant to pacify the patient and collect the co-pay, thus allowing the dear doc to move on to the next paying customer. While a co-pay with depression myself, it does not explain the entirety of my symptoms and therefore was not the end all diagnosis to solve my problems. In fact, for me I believe the depression to be a secondary syndrome because of the fact that I could find no one brave enough or smart enough to name my collection of symptoms.

"Regan's Ramblings"...cont'd pg 7
Lyme Disease is the fastest spreading vector borne disease in the world. It is becoming obvious that the ticks and other insects which may spread the Lyme bacteria (Borrelia burgdorferi), and other infections, know no boundaries. The ticks which carry Lyme disease and numerous coinfections, are very hardy and their area of habitat is not just limited to New England. Ticks are able to withstand varied climatic conditions.

Numerous patients are being told that the ticks which spread Lyme disease, just do not live in their state and as a result doctors are saying there is very little chance that the patient’s problems could be due to Lyme disease. Many times the coinfections are not even discussed. However, these seem to play just as important of a role in causing disease as the Borrelia. Some researchers feel that perhaps the many different coinfections, such as babesia, erlichia, bartonella, mycoplasma, are just as important as the Borrelia in causing this disease. Those seem to play just as important a role as the Borrelia in causing disease.

So, despite the assertion that Lyme does not exist in certain states, there have been confirmed reports of Lyme disease in just about every state, including Texas. There are no tick border patrols. The incidence of autoimmune diseases and other chronic conditions seems to be escalating in proportion to the Lyme/coinfection epidemic. Many people with Lyme and other coinfections are being misdiagnosed with non-specific labels such as M.S., ALS, Alzheimer’s Disease, Fibromyalgia, Parkinson’s, Lupus, Chronic Fatigue Syndrome, and many others. All of these disease labels only describe the symptoms, not the cause. Most of these disease labels have no known definitive tests, causes or cures, only symptomatic treatments.

Despite the very inaccurate testing, thousands of patients with these labels are being found to test positive for Lyme and the coinfections. Everyone seems to have a unique combination of pathogens. This may account for all the different presentations of the disease complex called Lyme Disease. Currently there is no test in use which can totally rule out Lyme Disease. So, it would seem prudent...especially with the degenerative diseases, to initiate an adequate trial of a single antibiotic...or in some cases a combination of different antibiotics, which would also address the coinfections or different forms of the Lyme spirochete. This brings me to my next topic...Pleomorphism.

It is felt by a growing number of researchers, that one of the reasons for the inaccuracy of testing for Lyme and coinfections, is due to pleomorphism. Pleomorphic organisms are those which change form according to the internal environmental conditions they are faced with. We will use Borrelia burgdorferi as an example. When researching or testing for Lyme, most researchers and lab technicians are trying to identify the corkscrew or spiral shape of the organism, or they are trying to measure the body’s immune reaction to this form of the microbe. The tests are looking for certain proteins which are specific to the spiral shape of the organism. The problem with this is that when the spirochete morphs into the cyst or L form, there are now different proteins associated with this new form of the organism which the old tests can not identify. This would lead to the conclusion that the current testing is missing a whole segment of this microbe’s population in the patient’s body.

Dr. Stephen Phillips, who has been researching Lyme Disease for the past 15 years, shared some of his research with doctors, patients and advocates at a Connecticut conference in 2005. Many doctors feel that spinal taps are the gold standard for diagnosing central nervous system Lyme disease. Phillips tells us that pleomorphism enters into this situation. Phillips said that in one study when the spiral form of Bb was injected into the spinal fluid, there was 100% conversion of Bb from the spiral form to the cystic form. This cyst form of the Lyme microbe is being found in the spinal fluid of M.S. patients.

Phillips strongly suggests that Bb may be one of the causes of M.S. He stated that every feature that we see associated with M.S. can also be found in Lyme disease. Two of the most striking shared diagnostic signs for Lyme and M.S. are brain and cervical cord lesions.

I think the main idea we need to come away with...concerning pleomorphism, is that perhaps we should be probing for the L or cyst forms of Lyme in many of our rapidly emerging diseases.

Another example of a possible crossover or link to Lyme, is with Alzheimer’s Disease. Judith Mikloosy, a Swiss researcher, conducted a study which was published in Neuro Report vol. 4, no. 7 of July 1993. It focused on autopsies of 14 Alzheimer’s brains. It was entitled...Alzheimer’s Disease - A Spirochetosis? The study found that spirochetes were found in the blood, cerebral spinal fluid and brains of 14 Alzheimer’s patients during autopsy. Thirteen age matched control cases were without spirochetes. To summarize, the observations suggested that perhaps several strains of spirochetes, including Bb, are responsible for Alzheimer’s Disease. One would think that researching the role of antibiotics in the treatment of Alzheimer’s would be of primary importance.

Here is a partial list of reasons for misdiagnosis:

1. Inaccurate testing
2. Pleomorphism
3. Doctor’s ignorance of the overall symptom complex of these tick and possibly other insect borne infections. According to the CDC, Lyme Disease is a clinical diagnosis (based on patient’s history and symptoms). Lyme Disease is not just a muscular skeletal disease. It can affect every system of the body and presents with a classic overall symptom complex. Individuals vary in the symptoms they exhibit but the overall picture is most often unmistakable.
4. Coinfections and different strains of spirochetes not being tested for.

In order to end this epidemic of misdiagnosis we need to identify and treat the basic causes of these diseases and conditions. The medical community seems to think that treating inflammation is treating the cause. We want to know, what is causing the inflammation?

Important Links

Dr. Bransfield’s Reason’s for Seronegativity (the reasons why you can test negative and still have Lyme disease.) http://www.mentalhealthandillness.com/seronegativelyme.html.

Lyme Disease can be a persistent infection. (Articles and Studies which back up that fact.) http://www.lymeinfo.net/medical/LDPersistence.pdf

Lyme disease signs and symptoms http://www.timeforlyme.org/TFLWebDone/SignsSymptoms.htm

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I have nasty Lyme arthritis in my knee, and the pads are helping to decrease the swelling and flexibility. It was my Lyme doctor who first told me about the pads...she swears by them! -Satisfied Customer
Medically, Study Found Link Between Genetic Factors & Autism
by Susan Williams

A new study at the University of Washington Medical School and Autism Center has found a link between genetic factors and autism. After nearly a decade of research, scientists at the university have found evidence that six major genes contribute to the development of autism, while up to thirty other genes have a lesser effect on the symptoms of autism. The findings were reported in the August online edition of the journal Molecular Psychiatry.

The study also provides new evidence to support the idea that multiple genes contribute to the development of autism. Scientists believe that individuals who inherit a greater number of these "susceptibility" genes may be more likely to develop a more severe case of autism. Researchers have long suspected that genetics played a significant role in autism, as past clinical studies had found that identical twins, who have the same DNA, demonstrated higher rates of autism than did fraternal twins. Additionally, the researchers found two genetic subtypes of autism: male versus female, and early-onset versus late-onset. The fact that different genes may be responsible for causing autism in boys than in girls may help explain why the condition is more common in boys.

To reach these conclusions, the scientists studied the DNA of 223 families that had at least two children with autism, Pervasive Developmental Disorders, or Asperger's Syndrome, a less-severe form on the autism spectrum. Further study will likely lead to the ability to test infants for those specific genes, which will allow for early intervention before the disease becomes severely debilitating. Researchers hope that this information will lead to a better understanding of the disorder, its diagnosis, and its treatment.

The ongoing research is part of the National Institute of Child Health and Human Development Collaborative Program of Excellence in Autism.

Families who have more than one child of any age with an autism spectrum disorder who are interested in participating in the university's genetics study can call toll free at 1-800-994-9701.

Drink to Your Health
...cont'd from pg 3

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Transcendence in Chronic Illness: Why “Giving In” is Not “Giving Up”

by Ginger Savely

In the book Learning to Fall: The Blessings of an Imperfect Life, Philip Simmons, suffering from Lou Gehrig’s disease, finds that his disability forces him to embrace life more fully. He finds transcendence in stillness, in doing nothing, in letting go of his pre-illness expectations of life. He writes “When we learn to fall, we learn that only by letting go our grip on all that we ordinarily find most precious --- our achievements, our plans, our loved ones, our very selves --- can we find, ultimately, the most profound freedom. In the act of letting go of our lives, we return more fully to them.”

My experience with chronic illness has been that patients go through the traditional stages of grieving that follow all sorts of loss: denial, anger, bargaining, depression, and finally acceptance. The first three stages can last a long time with patients trying to ignore or fight their symptoms, resentful of their limitations and angry with themselves for the inability to carry on in spite of them. Then the depression and despair hits and it becomes difficult to motivate one’s self to do what is necessary to begin to heal. It is when patients arrive at the stage of acceptance of the reality of their situation that healing of the body and the mind begins. This is the time I refer to as “giving in.” It is often signaled by an ability on the part of the patient to see the humor in his shortcomings and a willingness to stop working against the illness and start working with it. A difficult lesson for many of us and even the elderly and disabled can enjoy this type of communion with pets of all kinds at the bedside.

Chronic illness is a challenge that cries out for transcendence, a time when the spiritual self is called upon more than ever, both for coping and for finding meaning in a seemingly cruel and unfair fate. The emptiness felt by those who face a life devoid of meaning in their joys that nourished it before, stimulates the search for new motivation to carry on and sustain hope. Many people with chronic illnesses find that the blessing in their situation is that they have the time and the need to “stop and smell the roses”, discovering that their lives, and often their disease course, are benefited enormously.

For some, the word transcendence conveys an image of religious mystics living blissfully on a mountaintop, having mastered the art of living in another dimension, unattached to and unaware of the physical world. For most of us, this type of lifestyle is not only implausible but unappealing, as there are joys to be found in the material plane as well! For purposes of discussion, let us think of transcendence as a natural “high” - a temporary sense of joy achieved by being totally present in the moment, without worry for the past or care of the future. Most of the time we live very grounded to our physical needs, aware of hunger, thirst, pain, heat, cold, and discomfort of all kinds. During transcendence there is no physical or emotional pain, because for a brief time one’s actual body is out of the focal plane: possibilities are limitless as we enter the playground of the mind.

Achieving transcendence is a personal matter and each of us have different motivators that facilitate this for us - different “distractions” if you will, that allow us to become lost in the moment and elevated to a higher plane. You may or may not know what these are for you, but chances are that while chronically ill, you will need to modify your usual approach due to the limitations of your disease. Sky diving or reading Shakespeare, for example, may be currently out of the question. Meditation, yoga, listening to beautiful music or aromatherapy may be more in line with your diminished capabilities.

For those who are ill and lost in despair and at some point in their lives found solace in a particular religion or church, re-establishing connection may be an answer. For many, organized religion with its comforting rituals and sense of community is one of the best paths to transcendence. For others, the experience needs to be more unstructured, unorthodox and personal.

Spiritual experiences are ubiquitous, if one takes the time to stop and pay attention. I feel blessed to have found spirituality in my profession, as have many others in the serving fields. In fact, the definitive path to transcendence is that of serving others, giving unqualified, unconditional love, helping others by giving joy, comfort and support. Even for the chronically ill there are opportunities to serve. You may not have the stamina to participate in Habitat for Humanity or Meals on Wheels, but there is always someone less fortunate than yourself who can benefit from your reassuring words and calming advice. You will find that the gift you receive is far greater than the gift you give.

Some with chronic disease are lucky enough to have times of remission during which time they are able to engage in physical activities that facilitate a spiritual high. Steven Kotler, a Los Angeles-based journalist in his mid-30s found transcendence in the sport of surfing during his better days while sick with Lyme disease. He tells his story in the book, “West of Jesus: Surfing, Science and the Origin of Belief” (Bloomsbury, June 2006). When I was ill for several years, gentle swimming was my meditation. My daughter, while recovering from a long illness, spoke of “becoming one” with the sea turtles when she swam with them in Hawaii. Others have said the same of swimming with dolphins. In fact, relating to animals is the key for many of us and even the elderly and disabled can enjoy this type of communion with pets of all kinds at the bedside.

The key to dealing with chronic illness is finding a way to lose the SELF. The chronically ill become, understandably, self-obsessed, focusing on every detail as their body betrays them. This self-absorption becomes misinterpreted, to the disadvantage of the patient, by health care providers who are unable to look beyond the patient’s behavior to the precipitating cause. Looking for ways to achieve transcendence is the key, not only for finding grace in a disheartening situation but for letting go and allowing natural restorative energies to flow. Giving in to what is happening to your body, having faith that the best outcome will prevail, is a peaceful way to facilitate healing. Never confuse this with “giving up” because as long as there is the joy of transcendence, there is healing, and hope for better days to come.
When It Comes to Treating and Diagnosing Lyme Disease There are Certain Things You Should Know:

1. The correct diagnosis of this infection can be challenging in many patients.

2. Chronic antibiotic therapy alone is not the answer.

3. Many conditions such as Chronic Fatigue Syndrome, Fibromyalgia, Multiple Sclerosis, Lupus, Parkinson's Disease, Alzheimer's Disease, & ALS; perhaps that would be a risky thing to do?

4. A comprehensive approach using a novel protocol holds the most promise of eradicating this infection and restoring health.

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by Scott Forsgren

One of the challenges that many of us with Lyme disease face is the clear lack of useful diagnostic testing options. For many, finally getting the diagnosis of Lyme disease can be as challenging as finding one's unique path to recovery. Identifying tests that can serve as useful markers of the progression of the illness or as confirmation of a recovery underway is equally difficult. Fortunately, one such option is inexpensive and can even be taken in the privacy of your own home. What is it?

The VCS (Visual Contrast Sensitivity) test is a vision screening test that can be used to identify the potential presence of neurotoxins in the body. These neurotoxins negatively impact the body's neurological functioning and often lead to long-term, biotoxin-induced illnesses. The test has been advocated by Dr. Ritchie C. Shoemaker, MD* in conjunction with the work of H. Kenneth Hudnell, Ph.D. as a screening test which may help determine whether or not one's chronic health problems are caused by biotoxins. The test itself has been around for many years and was used by optometrists in the past for other purposes.

Biotoxins are created from numerous sources. These may include dinoflagellates, cyanobacteria, mold and fungi (Aspergillus, Penicillium, Stachybotrys, and others), ciguatera toxins from seafood, Borrelia burgdorferi (the causative agent implicated in Lyme disease), Babesia microti (a common Lyme co-infection) and others. Once these organisms enter the body, they produce biotoxins which can be a significant factor in the symptoms often seen in chronic illnesses.

The VCS test is a series of 90 patterns, 45 viewed by each eye, which will either have an up/down, tilted right, or tilted left series of lines represented at varying levels of contrast. When each image is displayed, the user then provides their perception of the direction of the pattern. People that have biotoxins or biotoxin-producing organisms and a symptom picture involving multiple body systems, may provide the necessary information to lead one to a diagnosis.

Though the test does not diagnose any specific illness, it is a useful screening tool that may show the potential exposure to neurotoxins. The results may be a signal to discuss further diagnostic options with your practitioner. If the VCS test reveals a deficit, a specific protocol, which may be of value to those with neurotoxin-mediated illnesses, may be appropriate.

If the test is positive, one may wish to consider a number of factors. One of these may be whether or not the genetic ability to remove these biotoxins from the body is present or not. For a number of people that are chronically ill with neurotoxin-mediated illnesses, there may be a genetic component involved. This can also be tested for with an HLA (human leukocyte antigen) panel. The HLA panel can provide additional information into whether or not a person is genetically susceptible to being challenged when it comes to the removal of biotoxins from the body. The results of this testing may also result in further tailoring of one's treatment protocol.

Sadly, many of us do not have this genetic ability to remove these biotoxins from the body. They may continue to circulate uninhibited and keep us feeling unwell. Theoretically, if one could get rid of Borrelia burgdorferi infection with a short course of antibiotics, they may still remain sick for years to come simply due to the result of the biotoxins which will continue to remain in the body until appropriate binding agents are used in an attempt to help remove these toxins from the system. The specific toxin-binding agents are beyond the scope of this article on the VCS test, but further information is available at http://www.chronicneurotoxins.com.

It should also be noted that a NEGATIVE test result does not rule out the possibility of a biotoxin being involved in one's illness. The criteria for a POSITIVE result is set relatively high to avoid false positive results and thus the potential of a false negative result does exist. It is reported that this may be the case 5-10% of the time.

The results may look something like those noted below where the items with a deficit noted are marked with "X".

<table>
<thead>
<tr>
<th>Date</th>
<th>Score</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>August 2005</td>
<td>POSITIVE</td>
<td></td>
</tr>
<tr>
<td>September 2005</td>
<td>POSITIVE</td>
<td></td>
</tr>
<tr>
<td>April 2006</td>
<td>POSITIVE</td>
<td></td>
</tr>
<tr>
<td>September 2006</td>
<td>NEGATIVE</td>
<td></td>
</tr>
</tbody>
</table>

The exact scoring algorithm is proprietary but the key thing for one to consider is simply whether or not or both eyes shows up as "POSITIVE". In that event, a biotoxic-illness might be considered further. For me personally, I have done the test four times and have felt that it provided useful information as to my progress over time. My results have been as follows:

- August 2005: POSITIVE
- September 2005: POSITIVE
- April 2006: POSITIVE
- September 2006: NEGATIVE

The test can be performed online: http://www.chronicneurotoxins.com. Options include one VCS test for $8.95 or 3 VCS tests and treatment protocols for $49.95. It should be noted that it is likely that one will want to take the test several times over the course of treatment as an indicator of progress. Other package options are also available.

* Though there are people that may disagree with Dr. Shoemaker's recent comments on the use of long-term antibiotic treatment for Lyme disease, much of his work has practical application for those of us dealing with the condition. His experience with biotoxins being a major source of symptoms for people with chronic illness appears to be quite sound. Further, I think it is important for patients to consider other potential contributing factors such as mold sensitivity that may be adding to their total body burden. Though I do believe that Lyme disease is a serious condition and may often require long-term therapy, I do appreciate the challenge given to all of us to consider other factors which may be contributing to our illnesses. It is important for us to leave no stone unturned when it comes to recovering our health. Fortunately, with the VCS test, we are offered another chance to consider the possibility that biotoxins may be a part of the puzzle.

Disclaimer: Neither Scott Forsgren nor BetterHealthGuy.com are compensated in any way as a result of the purchase of the testing options mentioned in this article. The article is intended merely to provide information.

Note: Scott Forsgren has battled Lyme disease for the past ten years. He shares his story on his web site at http://www.BetterHealthGuy.com. Scott can also be reached at Scott@BetterHealthGuy.com.
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Faith Factor...cont’d from pg 2

alone. He has and is perfecting that which concerns me. God is my teacher and life is my school. My Redeemer has shown himself to be faithful and true.

Because the Word of God has so sustained me these years since my diagnosis, in December of 2005, I began writing a short topical study entitled "Nourishment for Your Spirit." Just as I am accountable to provide my body with nourishing food, my spirit needs nourishment as well. In Proverbs it states that a man's spirit sustains him in his illness.

Each Month I have shared this "Nourishment for Your Spirit", filled with encouraging Scriptures, at Heartland Health Care, a nursing and long-term care facility, and at a support group I attend called "Health's Angels." I am blessed by sharing the same comfort that the Lord has given me in my time of trial and need. I am "casting my 'Bread' upon the waters", as the Scripture says. I know that God's Word never goes forth void.

If you would like to receive "Nourishment for Your Spirit" in your season of affliction or trial, e-mail me at joanblinn@yahoo.com and I'll put you on our e-mail list. God willing, you will receive it once a month. God will nourish your spirit and sustain you in your illness because He is watching over His Word to perform it and my Redeemer is faithful and true.

He will perfect that which concerns me.
Psalm 138:8

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Special Moments... by Barbara Gerami

Jolyn & Autism: Wouldn’t Trade For the World!

Living with a child with a chronic illness is somewhat tedious. Living with a child with autism with one or more chronic illnesses is usually very hard, beyond tedious. Yet, I would not trade it for the world. Jolyn is 14 years old, came to us just after turning five years old. She has autism, severe chronic asthma, and is deaf.

Autism is a complex developmental disability that usually appears in the first three years of life. Autism impacts the normal development of the brain in the areas of social interaction and communication skills. There are many different levels of autism. Some children, as well as adults, may just sit and rock or spin something. Others may function much better, however, not normal. They can also appear deaf, when in actuality they are just in their own world.

When Jolyn first arrived at our home she flapped her hands as if they were wings, and she ran and screamed most of the time. That went on for at least a year. At the sight of anything new she would go into a severe asthma attack. This is where it is hard, because she doesn't have the verbal skills to tell you that something has scared her, or that she is having trouble breathing, and she ends up in a full-blown asthma attack. One evening in winter, it was snowing here in Texas, I was turning onto our street. It was snowing and it was beautiful. I turned on the bright lights, as we all were amazed at the beauty, except for Jolyn. She made this indescribable sound and shut down. She began turning blue. We always travel with a portable nebulizer, however, sometimes we still end up in the emergency room.

Jolyn is as normal as apple pie, when it comes to being a girl. She loves clothes and loves to shop. It doesn't matter if it is in a store or a catalog. We could be walking in a store and she would be doing her usual chatter, sounding like a lot of 'ts. Once we step into the girls department tower, she comes to life. In full beautiful sentences, she speaks. As she picks a dress off the rack she says in an eloquent accent, "Mom, I just love this dress, isn't it pretty." As soon as we step out of the girls department she goes right back to the chatter, totally not understandable.

A couple of years ago, she was learning to jump rope. She had been practicing at home with her physical therapist, when she accomplished the task. The school was doing a fundraiser at the same time, jump-roping for the heart.

Well, the day came when the highest sellers got recognition. Jolyn was madder than a hornet because she thought she just had to learn how to jump rope and didn't receive recognition. After we figured out why she was so angry, I shared it with her teacher. At the end of the year she gave her a certificate for that event. Jolyn remembered her accomplishment and graciously accepted it.

I have been home schooling my other children for quite a few years now, and really wanted Jolyn at home too, however, I didn't feel I would do her any justice. This past year I started home schooling her. She either wears hearing aids or an auditory trainer. When she was younger, I believe she could hear us most of the time. School personnel insisted that she wear the hearing aids. Now I think she has learned to rely on them. Although she has days that she gives you the same look whether you speak and sign or act it out. She will not function with communication at all on those days. On her good days though, she is learning to read, she is socializing a little bit, and has truly been a joy to have at home. We still have many days that her functioning level is almost zilch, but we deal with them and believe for other good days.

Her brothers don’t tolerate her not playing with them, and they have her at least be in the middle of what they are doing. Slowly, but surely she is getting more involved and has even told them no when she really doesn’t want to interact. That is a major step for a child with autism.

I sleep on the couch close to her room so I can hear her if she is having a problem. Most children with asthma can verbalize or at least make known they are having a problem. Jolyn can’t do that, so I have to listen out for her at all times. Some mornings, as I enter her room, I do wonder if she is alive. She is a wonderful young lady, with difficult problems, yet a blessing in every way. I am honored to be her mom.

Page 10 www.publichealthalert.org Public Health Alert
*I'm From the Government, and I'm Here to Help*

by J. David Kocurek, Ph.D.

President Ronald Reagan coined the title quote, describing the phrase as the most terrifying words in the English language. The quote may have been part tongue-in-check, but it also holds a strong element of truth that we have all observed when well meaning legislators or bureaucrats enact law and make policy to protect the public that ultimately defeats its own purpose.

Texas has become famous for its anti-littering slogan "Don't Mess With Texas" which has evolved to the status of an unofficial state motto, but a more apt description for the current situation regarding Lyme disease in particular and the practice of medicine in general is that Texas is in a nightmare of a mess! By the way, 'nightmare' is not my preferred word choice. Recent reports from patients indicate that only one physician in the state with any Lyme experience is accepting new patients.

As important as the Lyme issue is to me, I now have the perspective that it's only part of a growing problem in all of Texas healthcare, set in motion by a calamity of events that came together over the past four years.

In 2002 and 2003, reporter Doug Swanson wrote a series of articles in the Dallas Morning News that took the Texas State Board of Medical Examiners (at that time) to task for their lax discipline enforcement policy toward physicians that truly required intervention due to impairment or marginal competency. The current Texas Medical Board (TMB) Executive Director, Donald W. Patrick, M.D., J.D., describes this event in his message on the board's website, http://www.tmb.state.tx.us/message.php.

"For many years, the Texas Medical Board had a reputation as a "good ol' boy" network of physicians protecting their own. The era of accountability hit this board right between the eyes in the form of a series by the Dallas Morning News in 2002, which got my attention, the attention of the board members, and the attention of the Legislature. We basically got an ultimatum that made us accountable, or else."

The legislative pressure came from Representatives Ray Allen and Jim Pitts assisted by Austin attorney Joey Longley in his capacity as Director, Sunset Advisory Committee. Thus, a group of slipshod political appointees serving as the state's medical board were transformed into a group of political appointee zealots searching out the least, most inconsequential transgression to prosecute. For the period since the board's June meeting through the end of August, the TMB has taken a record of 99 disciplinary actions and run their budget into the red ink to do so.

While this transformation was being designed, another political hot button issue was brewing. There was a huge campaign to alert the public of the inability of physicians overall, but with emphasis in certain high-risk practice areas to obtain professional liability insurance. Examples of obstetricians and neurosurgeons limiting or even closing their practices were accompanied by stories of skyrocketing rates and insurers leaving the state. Patient quality of care and physician availability was pitted against the greed and excesses of trial lawyers. Plaintiff's attorneys are evil if they are after you. They are champions if you need one.

Sure, there were litigation excesses. Med-mal attorneys, as they are informally known, made generous campaign contributions to the very judges in whose courts they litigated. Cases were filed in the counties, so called legal war zones, which were well known for sympathetic juries and excessive awards. This was a specific problem that could have been handled by targeted legislation and judicial ethics reforms. And, it wasn't an issue isolated to medical cases. But, the attorneys made a perfect protagonist villain for the unfolding drama.

Supporting the leading characters in favor of malpractice reform were the Texas Medical Association, the largest state medical organization in the nation, and the liability insurance industry. If these two groups aren't the most powerful lobbies in the state, they are very close to the top in the power they brandish with the state's administrative branch and the legislature. The process moved swiftly producing the state's 2003 health care liability reforms, which were sold in the interest of public access to affordable, safe healthcare with a media blitz that railed a national election. The final result was the passage of a constitutional amendment that placed caps on exemplary damages that could be awarded to plaintiffs with malpractice claims.

What was never described, to my recollection, is the connection between the increase in the TMB's authority and liability reform. The punishment imposed by exemplary damages, removed by liability reform, was traded in the background negotiations for the increase in TMB power with the intent of maintaining balance. The problem that wasn't considered is that the TMB doesn't answer to anyone, especially the people of Texas, in anything resembling a timely manner. Indeed, legislators and the Governor himself, are prevented by law from any individual intervention in TMB activity. The only path to policy change is through legislative committee action leading to changes in law. That's a time consuming process subject to influence by all the players described. To complicate the matter further, the Texas Occupations Code essentially only enables the TMB; but the board's rules, guidelines and the all important 'community standards of care' that are developed through board action. The TMB has been made a super-agency without accountability when the lack of accountability of a poorly performing agency was the problem set out to be remedied.

Let's tally the winners and losers in all of this mess. The liability insurers loved the fruits of their efforts. Surveys show that rates have been reduced, but I challenge anyone to show that those rates reflect the monies saved by the reduced payouts due to litigation award caps. Physicians, other licensed caregivers and hospital organizations motivated by income thought they were given a free pass. Plaintiff's attorneys received an even worse reputation. Then the TMB went to work and the physician's who thought they were protected didn't know what hit them. Losing a court case can be chalked up as bad luck unless it becomes a habit, but disciplinary action by the TMB can quickly end a physician's career.

And what impact has this had on the patient? I'll speak for myself. I lost in-state access to Lyme treatment, cost for health insurance continues to spiral out of control, reflecting industry charges, and most remarkably local physician fees and hospital costs immediately rose after the reform package took effect. What happened to the promised savings?

Good intentions and reactionary legislation hyped up more than a movie premier all add up to bad law, and that's where our problems with Lyme disease in Texas now reside. Texans, if you don't like the situation, contact your state senators and representatives and clearly express your concerns.

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and more frustrated of late, because I have had to turn away up to ten prospective patients a day - clearly, more Lyme-literate physicians are desperately needed. I feel that my experience with the management of patients with tick-borne illnesses would be better served by my spending more of my time on physician education and on completing my current, very important, research project. I want, once and for all, for the ILADS point of view to be the recognized standard for all professionals. I also wish to remain active in the political realm, as political reform and a more realistic view of our illnesses have to be addressed at the government and public levels."

His success has not come without much opposition and trial. Dr. Burrascano has a great deal of experience in the political and governmental arenas, due to his own legal battles for the right to treat chronic tick-borne illnesses with long-term medical treatments.

There are many who believe that the legal attacks on Dr. Burrascano were begun in retaliation for his public comments against the Department of Health and Human Services’ (DHHS) agencies. "The reasons behind the charges against me are likely a result of my willingness to expose the true status of Lyme research," Dr. Burrascano observed. "Shortly after publicly airing my grievances, I received notice that I was being investigated for medical negligence."

Those grievances were aired at a 1993 Senate committee hearing on Lyme research. Dr. Burrascano received a petition of "many serious improprieties" among NIH and CDC Lyme disease grant recipients, including funding that was being redirected from rheumatologic and arthritic funding that was being redirected to an apparent medical misconduct. The OPMC for attempting to prosecute a medical debate rather than actual medical misconduct. The unjustified OPMC procedures were based on erroneous claims that a mere few weeks of antibiotics were sufficient to effectively cure all cases of Lyme disease, in spite of contra-
dictions by numerous research studies. Many of these attacks on Lyme physicians appear to have been initiated by health insurance companies who want to avoid paying the expenses of long-term medical treatment in spite of their OPMC approval.

The Lyme community quickly responded to the charges against Dr. Burrascano by planning a rally at New York City's Plaza Hotel and hosting letter-writing campaigns, visiting to legislators and contact with media. Hundreds of patients from across the country rallied to Dr. Burrascano's side to show their support and called on legislators to hold public hearings to investigate multi-state harassment of Lyme doctors. Physicians from all over the nation, as well as Switzerland and Germany, signed a petition in support of Dr. Burrascano that was presented to state officials. These fellow physicians referred to Dr. Burrascano as "an international leader in establishing comprehensive medical and ethical standards for the diagnosis and treatment of chronic illness."

The original decision handed down by the hearing panel in November of 2001 not only exonerated Dr. Burrascano from the charges, but also criticized the OPMC for attempting to prosecute a medical debate rather than actual medical misconduct. An excerpt from their decision remarked, "The Hearing Committee recognizes the existence of the current debate within the medical community over issues concerning management of patients with recurrent or long term Lyme disease. This appears to be a highly polarized and politicized conflict, as was demonstrated to this committee by expert testimony from both sides, each supported by numerous medical journal articles, and each emphatic that the opposite position was clearly incorrect. What clearly
did emerge however, was that the Respondent's approach, while certainly a minority viewpoint, is one that is shared by many other physicians. We recognize that the practice of medicine may not always be an exact science, 'issued guidelines' are not regulatory, and patient care is frequently individualized."

The OPMC attempted to file an appeal and, in April of 2002, that appeal was refused by the Administrative Review Board who agreed with all of the findings of the original hearing panel. Dr. Burrascano noted, "Both the Appeals Board and the Hearing Committee favored me and had no problems with my methods in managing Lyme disease. They succinctly stated that it is not the role of the OPMC to pass judgement on what is a scientific debate in the medical community, and how I treat Lyme is not a matter of professional misconduct or competency... They posed no restrictions on my practice, no restrictions on him, the Committee's cases, and, in their written decision, the Committee was quite complimentary."

"I definitely would not have gotten through this if it was not for all the support I received," he continued. "I realize quite clearly that this case represented far more than just me - it represented the truth of Lyme, uncovered the dirty tricks that have been played against Lyme patients and LLMD's (Lyme-literate medical doctors), and helped to focus all of us and propel us into a great, gigantic push for our rights. The bigger goal has been all the positive activity that my case has generated - politically, in the media, and most importantly - we are now a force to reckon with. Truly, we have not gone away, and we never will go away."

"All of us have to really raise the bar now on our reform activities because, until State Medical Boards are revamped, all of this can and will happen again, and anyone, including me, can still be harassed. We must stay focused, remain a single-minded unified force, and move ahead with our efforts to get our knowledge of the truth of Lyme disease to ALL health practitioners so Lyme will be better recognized and treated. Most of all, we cannot let the creeps keep any of us from getting the treatment we need to prevent worsening disability."

Dr. Burrascano assured, "My decision comes at a good time for me personally. I feel well, my prostate cancer seems to be in a remission, and I have not had any bad news from the state Medical Board lately. In other words, this decision has not resulted from any secret problem that I am trying to hide. Rumors will fly, but I say sincerely to all of you that there is no hidden agenda."

Although the news of his retirement has deeply saddened many of his patients and colleagues, there is a tremendous amount of support for Dr. Burrascano in his future endeavors.

"It is the revolutionary work of people like Dr. B which stops me in my tracks. I stand in awe for the compassion he has, the courage he shows for needy people looking for shelter in the rain, and his incredible contributions to science... He deserves more than the support and praise we give him. He deserves for history to record him as one of the great scientists of the late 20th and early 21st centuries."

Sandy Berenbaum, LCSW, is a Lyme-literate psychotherapist in New York who learned about Lyme the hard way. "I went undiagnosed from 1984 to 1990, with severe migraines and psych symp-
toms. I went to at least 5 doctors, including the heads of two NYC headache centers. After being diagnosed in 1990 in Poughkeepsie, I was referred to Dr. B by a doctor friend who was a new patient of his. Dr. Burrascano treated me for the next four years. Despite the Howe's chronic pain, he was always supportive and understanding. His care, compassion, upbeat nature, and hopefulness, were a part of his brilliant diagno-
sis and treatment."

"One year after he first saw me, I 'diagnosed' my first kid with Lyme. He was a 15 year old who was experiencing psychiatric symp-"
toms who came to me for counseling. I recognized Lyme in this young man, and his parents allowed me to point them toward a ‘second opinion’ when their family doc said it wasn’t Lyme. That started my venture into the world of Lyme disease as a professional," Berenbaum recalls. "My point, aside from my love, respect and appreciation for Dr. B, is that his gift to me of restored health led to my gift of my services and expertise to the Lyme community. Each patient that Dr. B (and our other Lyme doctors) treats successfully leads to more good, in and out of the Lyme community. Each patient who is turned away by the ignorant Lyme-denying doctors is another patient, and sometimes whole family, that becomes a burden to society."

Jeanine Phillips, a Lyme patient in New Jersey, declared, "We, as a community, have been blessed by the courage and focused determination that Dr. B. has always displayed with respect to tick-borne diseases and the patients who suffer from them. We can all trust that the same gentleman who has stood up for Lyme patients all these years, and under the most difficult of circumstances, can continue to do this, but in a more elevated manner and in a manner which, in his wisdom, he thinks is best. This news is good news for us all, and we can trust, respect, and support his decision."

Phillips, like so many of Dr. Burrascano’s patients, is searching for a way to express heartfelt thanks to a man who has done so much. "What would be the equivalent of a coast-to-coast standing ovation?" she wondered. "Perhaps a thank-you donation to the nonprofit group that supports his work, the ‘Turn The Corner’ foundation. This is what I am going to do, anyway. I hope to hold a garage sale with other patients in my support group, and the proceeds of the sale will be designated to specifically fund Dr. B’s research. I think this would be a fitting tribute to his work over the years on behalf of ALL Lyme disease patients, not just his own. This would be just a small thank you for a big effort on his part all these years."

Thus, while one chapter in the history of Lyme disease draws to a close, a new and perhaps even more exciting chapter is just beginning.

"I am grateful to all those who have stood behind me over the years, and I will always be thinking of you — that is the point behind my decision," Dr. Burrascano concluded. "I hope that my future efforts on the behalf of the Lyme community will continue to be as fruitful and personal as they already have been."
In The News

Breast Cancer...cont’d pg 1

Oral Contraceptives. Another aspect of estrogen exposure is the use of oral contraceptives over a long period of time. Studies have found that women under the age of 35 who have used birth control pills for 10+ years are at increased risk.

Exercise. Women who exercise regularly four times a week or more are at lower risk, as exercise helps boost the immune system and lower estrogen levels.

Diet. High-fat diets can increase risk. Fat is known to trigger increased levels of estrogen, which leads to tumor growth. Eating a low-fat, nutritious diet with plenty of fruits and vegetables can reduce this risk.

Alcohol. Women who drink regularly several times a week or more have a much higher risk of developing breast cancer. The more alcohol that is consumed, the higher the risk seems to be.

Smoking. A recent study indicated that smoking may increase breast cancer risk, and more studies are underway. However, smoking does decrease an individual's survival rate once diagnosed.

Every woman should follow the recommended guidelines for early detection, regardless of whether she is at high risk or not. Those guidelines include:

Regular Checkups. Every woman should have an annual physical. However, if any unusual symptoms or changes in your breasts occur before your regular checkup, do not hesitate to see the doctor immediately.

Self-Exam. Give yourself a monthly Breast Self-Exam (BSE) beginning at age 20. Your physician can show you how to do this properly, or you can learn how from many reputable websites such as http://www.komen.org. You are looking for any changes in breast tissue, such as changes in size, a lump, dimpling or puckering, or discharge from the nipple. Most breast cancers are detected this way. However, do not panic if you do find a suspicious lump, as eight out of ten breast lumps are not cancerous. Schedule an appointment with your doctor for further evaluation.

Mammograms. Not all lumps are large enough to feel, so a regular mammogram is recommended. The breasts are briefly pressed between two rigid plates to take a low-dose X-ray image. The compression of the breast helps give doctors a clearer picture to examine. Women who find the procedure uncomfortable should schedule the mammogram about a week after their menstrual cycle, as breasts are less tender during that time. Women should have a baseline mammogram by age 40, and additional mammograms every one to two years after that, depending on previous findings. Women 50 and older should have a mammogram every year.

We'd like you to meet some brave women who have experienced breast cancer first-hand and agreed to share their stories with us.

Connie White

Some women may develop breast cancer even if they do not have any known risk factors. Such was the case of Connie White in Greensboro, North Carolina. "Although I had no family history of any cancer, I was diagnosed with Stage 1 Breast Cancer early this year," explained the 50-year old. "It was very early and found on a routine mammogram."

Connie's reaction to the news was somewhat unusual. "From the very first day of diagnosis, I was really pissed off. I had just gotten my life back after having been disabled for a few years from Lyme Disease." Previously working as a rehab consultant, Connie had managed workers' comp and LTD claims for insurance companies. "I was the hired gun, helping them cut people from their benefits. Then after having to deal with the disability system myself, I realized the error of my ways. So when I got well enough, I started self employment as an advocate to help people with their disability claims. I had just gotten that off the ground and then this hit. It was more something in my way of thinking, not really into the 'poor me' thing. I remained in the pissed off mode throughout the whole thing."

Connie underwent a sentinel node biopsy, a new technique used to determine if the cancer has spread to the lymph ducts or nodes without having to do a traditional axillary lymph node dissection. There are many advantages to this newer procedure, such as no need for an overnight hospital stay, fewer side effects, and faster recovery time. While not appropriate for everyone, this procedure is recommended for women like Connie who have early-stage disease and relatively low risk of lymph node involvement. The biopsy showed that Connie's lymph nodes were clear, so she underwent surgery and seven weeks of radiation. "I am okay now, but I made the controversial decision not to take Tamoxifen. I think the stuff is dangerous," Connie acknowledges. "My oncologist is very unhappy I did not follow their advice on Tamoxifen and won't give me other options. Therefore, I seek treatment through a nutritional medicine doctor to prevent a reoccurrence and try to keep my immune system pumped up best I can."

"I wasn't even scared," Connie recalls. "Doctors told me from the start that I was the best case scenario. Thank God for mammograms. I always got mine on time and was glad I did."

Carol Bozman

Carol Bozman, from Baltimore, Maryland, experienced her first symptom in the fall of 2003. "My breast had been hurting, achy, and one day when showering I massaged it - and blood came out of the nipple. I was too scared to tell anyone." She was 55 years old at the time.

"Then one morning that December I woke up with blood on my nightgown. I made myself tell someone so I would be forced to do something about it." Carol was immediately referred to a breast surgeon at a nearby cancer institute. In January 2004, Dr. Kristen Fernandez did a sonogram of Carol's breast and found a lesion. "She told me that I would need to have the milk ducts of my breast removed," Carol recalls. Dr. Fernandez also asked Carol for permission to use a "ductoscope", a tiny camera inserted into the milk ducts to take pictures and help pinpoint the precise location of the lesion.

"Insurance wouldn't pay for the use of the ductoscope because it was a new instrument and not proven yet in the field, so I was a guinea pig," Carol commented, "but Dr. Fernandez ultimately did not charge me for the use of it... and she got some really good pictures, too."

Carol's surgery to remove the lesion went well and she was discharged later that same day. Several days later, she went back for the results. "Dr. Fernandez had a big smile on her face and said I had been given a real gift. The lesion was benign — it was a bleeding papilloma, but was surrounded by atypical ductal hyperplasia which is found with breast cancer. She said during the operation there was a hush in the room when the camera located the lesion because it looked so ominous, so she was very relieved when the pathology report came back."

But when the bandages were removed, Dr. Fernandez's expression turned to shock. "She even took a step back, and said 'I have never seen such a thing!'," Carol remembered. The entire nipple had turned black and subsequently developed a painful infection, which was treated successfully with antibiotics.

Carol's condition is currently being followed every three months by an oncologist. "I did not need radiation or chemotherapy, but I do take Raloxifene to block estrogen. I have lots of bloodwork done. I had a PET scan, which was negative for any other cancer concerns."

"Sometimes I wonder if I should have had a mastectomy, which was an option because I'm in the high risk category. I don't think about it much until my follow-up appointments, and then I get kind of obsessed... wondering if this is going to be the visit that puts me back in the operating room."

"I feel sick to my stomach every time I look at my scar. I bet I'm the only one who can invert their nipple simply by raising their arm," she jokes. "Really, it's no big deal. I feel like one lucky lady. There are so many brave women out there. I almost feel guilty because I was so fortunate to benefit from early detection."

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National Support Groups

National Multiple Sclerosis Association:
www.nmss.org
Alabama
3840 Ridgeway Drive
Birmingham, AL 35209
Phone: (205) 879-8881
Fax: 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
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700 Broadway, Suite 808
Denver, CO 80203-3442
Phone: 303.831.0700
1.800.FIGHT.MS
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455 Abernathy Rd. NE,
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Atlanta , GA 30328
Phone: 404-256-9700
Fax: 1-800-MS-CONNECT
Email: info@msconnection.org
http://www.msconnection.org
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Phone: (407) 487-8880
Fax: info@flmss.org
http://www.nationalmssociety.org/flc
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8111 N. Stadium Drive,
Suite 100
Houston , TX 77054
Phone: 713-526-8967
www.nationalmssociety.org/txh
ALS Association
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315-689-3380
Toll Free for PALS:
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lymediseaseassociation.org/
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Pat Jackson (715) 356-3364
www.pattyknack.com
pattyknack@charter.net
WI * IL * MN
Contact P.J. Langhoff
www.lymeleague.com (US & Can)
www.sewill.org

**Ticktoons**
by Terri Reiser

DFW Lyme Disease Support
www.dfwlyme.com
Meetings held the 3rd
Saturday of each month
Baylor Regional
Medical Center at
Grapevine
1650 West College
Grapevine, TX 76051
(817) 481-1588
in the continuing
education room
For more information:
Donna Reagan
Group Leader
donnareagan@sbcglobal.net

Lyme Disease Support
Groups cont’d
Alabama
Jim Schmidt (334) 358-3206
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913-438-LYME
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www.LDSG.org
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Pat Jackson (715) 356-3364
www.pattyknack.com
pattyknack@charter.net
WI * IL * MN
Contact P.J. Langhoff
www.lymeleague.com (US & Can)
www.sewill.org
A Shot at Better Health
Two New Vaccines Available to the Public

by Susan Williams

Two new vaccines, which will be of interest to large portions of the population, have recently become available to the public. These newly developed vaccines, both developed by pharmaceutical giant Merck & Co., can help protect against shingles infections and most cases of cervical cancer.

Shingles

Shingles is a painful viral infection that is caused by herpes varicella-zoster, the same virus that causes chickenpox. The pain from shingles can be quite severe as the virus infects the nerves in the body. Sufferers also experience a blistering rash which can scar the skin, and some continue to have persistent pain long after the infection clears up. This chronic pain, known as post-herpetic neuralgia, can be debilitating and there is currently no cure.

After a chickenpox infection, the virus becomes dormant and remains in the body. While unknown, it sometimes occurs when a person’s immunity has been reduced or suppressed. This occurs fairly often, and the National Institutes of Health estimates that 500,000 Americans will develop a shingles infection from further attacks, a rare few may have repeated episodes. There is currently no drug that can eliminate the virus completely, although anti-viral drugs may help shorten the duration of a shingles attack. Doctors hope to reduce the numbers of shingles cases thanks to a new vaccine that is now available.

The new vaccine, known as Zostavax, is the result of nearly two decades of research. Zostavax is a live but weakened strain. It is administered subcutaneously as a single shot and is 14 times more potent than the vaccine used against chickenpox. Merck says the new vaccine works by boosting the immune system’s ability to suppress the virus in nerve roots.

The catalog price for Zostavax is $145.35. Zostavax is scheduled for coverage under Medicare’s Part D prescription program, and may already be covered by some health insurance plans.

The new vaccine, known as Gardasil, is expected to cover the cost of the vaccine for children who meet eligibility guidelines. The Gardasil vaccine is recommended for all young females, generally those between the ages of 11 to 26. As the vaccine is most effective when given before contracting the virus, the Advisory Committee on Immunization Practices states that girls can be immunized even as young as 9 years old, at the discretion of their doctors. Some experts are also recommending it for young males, in whom it can help prevent genital warts and possibly penile cancer. Having both sexes vaccinated against HPV would also help to reduce the spread of the disease.

However, it is crucial that some women who have been vaccinated continue to have an annual Pap smear, since the vaccine does not provide protection against HPV. The Advisory Committee on Immunization Practices states that girls can be immunized even as young as 9 years old, at the discretion of their doctors. Some experts are also recommending it for young males, in whom it can help prevent genital warts and possibly penile cancer. Having both sexes vaccinated against HPV would also help to reduce the spread of the disease.

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