

Healing Chronic Illness at Home:
Update - Lyme, Chronic Fatigue Syndrome, and Fibromyalgia Related News

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By Jill Neimark

About 18 months ago I wrote an article with Byron White about my approach to healing lyme disease at home—an approach that applies to many chronic illnesses, infections, and neurological disorders. I have since improved steadily and in small increments, adding in other approaches as well. Although I still have a long road to travel to become the person I was before lyme, herein I offer an update. I hope some of you will be inspired and helped.

I: Oh The Horror

A brief update: Lyme disease felled me in 2000 and life has not been the same since. Although I took a total of six weeks of antibiotics in the very early stages, the drugs did not cure me and I felt so ill on them I chose to shift to alternative medicine. At my worst, I was so sick I could barely get around the neighborhood, had profound, debilitating fatigue, sleep problems, muscle pain, low grade-fevers, crushing migraines, nausea, and a constant feeling of being poisoned and 'buzzy' all over. I also had muscle weakness and burning that made it difficult to stand in line at the post office or a movie.

After being treated with hyperbaric oxygen in two separate clinics, and improving, I slowly relapsed each time. I joined various health newsgroups and one day on a yahoo list called oxyplus I heard about a guy named Lance Brubaker who had recovered from lyme using a home hyperbaric chamber. At his worst, he could not walk 100 feet on his own. He'd built his own in 1994 but now had a portable home chamber and though he is in remission, still uses it regularly. Now he works like the workaholic he always was, and travels all over America and the Caribbean—in the service of alternative medicine and, not surprisingly, portable hyperbaric chambers.

II. Home Hyperbaric: The Foundation

As I've described here before, I got a used home chamber from Lance and it changed my life. I got the large size because I tend to be claustrophobic (there are three sizes, like three beds for Goldilocks). This chamber is portable, FDA approved, and goes to 4.2 psi (pounds per square inch). It pressurizes with air, venting 50 liters every 3 minutes, and I breathe in oxygen using a medical passthrough and a simple plastic mask. Using my chamber, I returned to the land of the living. Although there is debate in the lyme community and clinics about the most beneficial pressure for lyme (a home chamber uses relatively low pressures, whereas clinics tend to treat lyme at 2.4 ata), I'm certain my chamber suppresses the lyme bug and even more importantly, replenishes my entire system. The home chamber pushes 200-400% more oxygen into the tissues. *Borrelia burgdorferi* is oxygen sensitive as it is microaerophilic—it can handle small amounts of oxygen but, for instance, will die in air which contains 21% oxygen.

I think one reason the home chamber helps so much is it counteracts many of the ways borrelia damages the body. Borrelia alters pathways and chemicals in one's neuro-immuno-endocrine system in order to create a hospitable environment for its penetration and survival in all the tissues of your body. Glutamate is often upregulated, leading to sleep disorders and chronic pain and hypersensitivity.

In fact, glutamate upregulation is known to be a serious problem in pain disorders, ALS, perhaps MS and certainly in chronic lyme and fibromyalgia. NMDA receptors are upregulated, correlating with anxiety, panic attacks and sleep problems. Oxygen metabolism is downregulated, leading to a permanent hypoxic state in which all organs suffer. Pro-inflammatory cytokines and molecules called matrix metalloproteinases are upregulated, leading to profound fatigue and damage to blood vessels and cell membranes. All these shifts in our biology are good for the bug and bad for the host (me or you.) And these shifts are common in CFIDS and other infections similar to lyme. Pressure and oxygen can truly offset a lot of the ways chronic infection disables the body.

My chamber usually sits right by my l-shaped desk at a bank of windows where I write. I use it whenever I want, for however long I feel I need it. I lie in my chamber with my ipod turned to a playlist I named "Soothing," and because the pressure and oxygen feel so good, I find it a good place to relax and meditate. With this chamber in my life, I still most definitely live in the shadow of lyme but I function and don't fear disability. It is the life of someone managing a chronic illness while still trying to figure out how to get totally well.

After two years of owning a chamber, it had become as ordinary to me as my morning tea. I had not realized that it was still my liferaft until I discovered that the seam of my chamber had a leak. This is unusual but my chamber had originally been in a clinic and already had many hours of use when I got it. I had to dismantle my chamber and ship it back for repair. I went four weeks without a chamber.

During this time, I began to slowly re-experience lyme symptoms—increasing fatigue and muscle weakness/burning returned, and with it, something that I can only attribute to the bug's hijacking of the nervous system. I alternated between periods of panic and deep sadness. It was as if a protective barrier were slowly being peeled away and I had to look again into the nightmare scenario of full-blown lyme disease. I could feel the bug resurging. Or, more precisely, it was as if my neurological system—which doesn't know the English language, and didn't know that my chamber was out for repair—was signaling very clearly to me that it was being attacked again by the bug.

I had forgotten what active neurological lyme was like. Those with severe lyme often comment they fear they will die, even though they know they won't. My only respite was knowing that my chamber would soon be back, the seam leak sealed by the manufacturer, and I'd soon be lying in it, breathing in oxygen under pressure, and thanking God for my good luck. For me, the hyperbaric chamber is absolutely fundamental in leading a reasonable life with lyme—while I keep looking for ways to completely eradicate the bug.

During this chamber-less time I traveled down to Atlanta, where Lance works with Dr. Rhett Bergeron, one of the more innovative alternative medicine doctors in Georgia. Both Lance and Dr. Bergeron are missionaries for alternative medicine, and extremely kind people. On the morning I was to return to New York, Dr. Bergeron picked me up at my hotel, drove me over to his office, and gave me a session in the portable chamber there, so that I would be fully able to make the trip home with ease. I also met several other lyme patients under his care, one who had traveled from Maryland for treatment. Dr. Bergeron does not use antibiotics for lyme, but a multitude of other anti-infective and cleansing treatments.

Lance has a portable home chamber at home, where he operates a business distributing chambers to doctors and patients. He recently sent a chamber to his parents as a gift when they both fell ill. Over dinner he said to me, "How can you ever repay your parents anyway? And besides, I'm doing it for me, not them. I am the one who will be responsible for their care as they age. The chamber will protect them. They are already feeling much better and using it daily. I still use my chamber frequently, but I

now use my chamber as a stress modulator. I could not keep up this hectic schedule without it. I've traveled four days out of every seven for the last month."

I recently heard from a former lymie named Thomas who was homebound with chronic lyme and had been on antibiotics for two and a half years to no avail. He had been sick for 6 years. He decided to buy a home chamber after he saw my first article. Now, 18 months later, he emails me, "I'm doing better by leaps and bounds. I'm going on lots of vacations, working full-time and commuting 3 hours daily, without taking sick days. For me, the chamber was great. But I also believe it's been the combined effect of ozone sauna and oral hydrogen peroxide that have put me in the right direction. I also began using glutathione and chlorella and they have only added to the success. It's just so nice to be feeling decent and go out with friends instead of living in bed."

III. Hyperbaric and RSD: An Aside

When I told Lance I was going to write about my chamber again, he reminded me that it is effective in other chronic conditions. Lance suggested I give a young woman I'll call Jane Doe a call to hear her extraordinary story. She was a young single mother with two children when she slipped down some stairs at work and ended up with reflex sympathetic dystrophy—a debilitating syndrome in which often one's entire body is in excruciating, chronic pain. He said she'd been cured by the chamber. I'll reproduce her part of my talk with her here:

"RSD is paralyzing, stabbing pain that never stops. This was two years ago. I was in so much pain I threatened suicide in front of my doctor and my parents. I was living by myself in northern California and had to get up each day to stoke the fire to keep it warm. I had to crawl to do it, until I got a wheelchair. I was starting to become incontinent and have cardiac problems. I couldn't hold a fork. One day I put into Google, "RSD cures" and I found out about two people in England who had gone into remission with hyperbaric oxygen. I thought, well, let's give it a go. I was ready to sell everything I owned just to survive.

In the beginning, I went into my chamber three times a day for an hour each time. Within six months I was able to walk and drive again. I remember the first day I was able to drive, and I stood on the street afterwards and I just kept saying to myself, "This is just incredible to just be standing here, a guest in my own body, not in pain, standing by myself in the world." These days I go into my chamber three or four times a week, and just go to sleep in there. It's very relaxing. I'm going back to school to become a medical assistant. I feel nothing but gratitude for the entire experience. I hope my story empowers others."

IV. Glutathione and Gluten

Hyperbaric is my lifeline, but I have since added in other modalities that have helped me. Some are widely available, and others are not but I'd like to mention them all here in case they might help someone.

First of all, I've been reading a lot about glutathione and thinking back on my health history, particularly my maternal lineage. The fingerprints of celiac sensitivity genes are all over my maternal line—as well as genetically weak systems for detoxing heavy metals and other environmental poisons. Finnish scientists are doing most of the pioneering work in celiac disease these days, but let me just note that gluten sensitivity is not always classic—i.e., it is not universally manifested as digestive problems. It can more subtly damage the duodenum and the intestinal villi, skewing the endocrine and nervous systems, and has been linked to a wide range of problems, including neurological and endocrine abnormalities.

I know a prominent psychiatrist and researcher who suffered from uveitis (an eye inflammation), Hashimoto's thyroiditis, and chronic fatigue. She was given a diagnosis of "atypical M.S." In truth, all

she had was celiac sensitivity and once she figured it out for herself and went off all gluten, she recovered perfect health.

In addition, celiac sensitivity genes might only kick in once your body is under the stress of chronic infection. I never ate much wheat, as I knew I was sensitive, but it wasn't until I really researched this subject that I understood that ANY gluten could upregulate the inflammatory response. Eating a little bit of gluten (oh, those croutons won't hurt, now will they?) is akin to eating a little bit of lyme, or a little bit of a virus. Your body will react to the protein in gliadin as if it were an enemy, and mount an inflammatory response. This is not good for you. A doctor friend tells me these genes are actually far more widespread in the population than we realize—probably because grains were a recent introduction in terms of man's evolution.

I stopped gluten entirely and it has been helpful for me. I don't really miss it. I am now known as the French-fries addict. When I'm feeling ambitious, I make my own with organic potatoes. If any of you suspect gluten sensitivity, I'd recommend getting genetic testing. I know of another chronic lymie who is using colloidal silver, hyperbaric oxygen, glyconutrients, and then discovered that some of her M.S. symptoms are due to "gluten ataxia." Genetic testing revealed celiac sensitivity genes. She is now on a gluten free diet and doing better. Anti-gliadin antibodies are truly not diagnostic enough.

In reflecting on the health problems on my mother's side, I had to conclude we all had inborn errors in detoxification. My maternal grandmother suffered from Parkinson's disease; my maternal aunt from trigeminal neuralgia and other health issues. I know from current clinical evidence that glutathione—along with phospholipids—can reverse Parkinson's in some patients. So, I supplement weekly with IV glutathione. I find it helpful.

In addition, I recently heard from another lyme patient who has a home chamber. She began using glutathione daily in a nebulizer and says it is one of the best things she has ever done for herself. It not only got rid of the remnants of pneumonia, it markedly increased her energy. The nebulizer she uses is an Inspiration, which costs only about \$60, and I plan to start using this method daily while still continuing with IV once a week. I have tried nasal glutathione, another popular method, but I did not find it had systemic penetration. Nebulized glutathione, breathed into the lungs, is likely to have systemic penetration—as evidenced by the reports of cystic fibrosis sufferers who not only had improvement in lung function, but in digestion as well, when they used this approach.

For anyone with a chronic illness, a look at celiac sensitivity, and a trial of glutathione supplementation is key, because it is the major detoxifying antioxidant our bodies and liver use. More and more doctors are using glutathione in their chronically ill patients. And when we are sick, we simply cannot manufacture enough on our own to combat the chronic neurotoxins and inflammatory free-radicals we generate.

V. Immune Boosters

In this category, I include something that will not be widely available, as well as something that is. For about a year now I have been getting small amounts of intravenous gamma globulin. It is expensive and not covered by my HMO insurance. I get 5 grams weekly. There has been a noticeable boost in energy since I began using it. I know some lyme patients who are able to get much larger doses because they were originally given a neurological diagnosis (such as M.S., or Guillain-Barre or even peripheral neuropathy) or who have a documentable immune deficiency. I don't have such a diagnosis, so I have to be judicious in my use as it is expensive.

However, there are an increasing number of pioneering immunologists and neurologists who are doing sophisticated testing on lyme patients in order to secure them a diagnosis that will allow IVIG. It is worth looking into. I believe it is helpful because we now know that borrelia can initiate an immune defect that was not previously present, opening the door to other infections as well. Borrelia can downregulate t-cells, natural killer cells, and immune cells called CD-57. In addition, those of us with

certain genetic markers (certain HLA subtypes) tend to have a more sustained inflammatory response to borrelia. IVIG is pooled from 2,000-5,000 donors—helping quiet an overactive yet inefficient immune response.

In addition, a product I have found amazingly helpful, is frozen thymic peptides from Atrium Biotechnologies, a Canadian company. After a bout with cystitis last summer, I'd had a few flare-ups of bladder irritation and pain, and then chronic irritation settled in that was driving me nuts. Repeated urinalysis was negative. Whatever was percolating in my bladder was too low-grade to actually show up as obvious infection on a test—but virulent enough to leave me suffering. Within a week of starting thymus, every other day, my bladder was 90% improved. A box contains 8 vials (a month's worth) and must be kept frozen until you're ready to take it.

I should note that thymus glandulars, which are much cheaper, have never done anything for me at all. This product contains the purified peptides that are highly active. The drying process often involves extreme temperatures that may alter protein structure and functions. In the frozen form, proteins and peptides are kept closer to their natural environment. In addition, taking extracts orally in their liquid form may favor absorption directly into the bloodstream. Note that Thymosin-alpha (one of the thymic peptides in this product) has actually been synthesized and is a drug currently marketed by SciClone Pharmaceuticals in foreign countries for hepatitis and cancer applications.

According to a literature review by James Wilson, Ph.D., the action of thymic peptides is mostly on t-cells such as macrophages, natural killer cells, and both helper and suppressor t-cells. Thymic extracts have been shown to stimulate the production of these cells and enhance their activity. Double blind studies have shown that thymus extracts reduce upper respiratory infections in both children and adults, and one study showed that patients with chronic obstructive pulmonary disease had fewer hospitalizations when taking thymus extract. The extract has even been shown to help patients suffering from tuberculosis, diabetes, herpes simplex, hepatitis, allergies, eczema, rheumatoid arthritis—in fact, a truly wide range of disorders. In sum, it looks like this extract helps the immune system mount a more vigorous and full response to infection.

I really recommend trying this product for anyone who suffers chronic bladder problems (as many lymies do), or any chronic problem associated with CFIDS or immune dysregulation—ear infections, sinus problems, colds, flus, low-grade fevers. This is especially important since as we age, our thymus becomes less effective.

VI. Herbs and Supplements

Fish is full of mercury these days, but fish oil is an important lipid that helps restore cell membranes, which are often disrupted by oxidized and deranged (not crazy, just malformed) fatty acids produced so copiously in chronic infection. I always hated the taste of fish oil capsules so simply avoided them. Now I've discovered the most delicious fish oil and actually crave it. It's made by Pharmax and has an orange flavor. I just take a swig or two every day.

Vitamin A and Vitamin D are important in chronic illness, especially for those of us who live in northern latitudes—or those who are too ill to get enough sun. New research now informs us that 20 minutes of sun daily will prevent 30 cancers for every 1 that it creates...and the key is probably Vitamin D. Vitamin D functions as a hormone and seems protective against many chronic illnesses, including multiple sclerosis. (I bet there is more to the sun's benefits than Vitamin D, however. I suspect the angle of light and the length of the day have important effects on our biorhythms and cycles.

We are products of evolution, just like plants, and we are hard-wired to respond to daily as well as seasonal shifts in sunlight. Vitamin A is an anti-infective and equally important. Since my Pharmax fish oil is pure and has been stripped of Vitamins A and D, I also take Vitamin A and Vitamin D. They are easily absorbed because emulsified, without glycerin or any other fillers. I am not yet sure how much is optimal, so I tend to take the RDA (400 units of D, and 10,000 units of A).

I take Echinacea Purpurea root every day and I take a broad-spectrum digestive enzyme and a high potency bromelain. Most individuals dealing with chronic illness have gut issues and poor digestion.

I get IV magnesium weekly. This is known to help downregulate the upregulated NMDA receptors, easing sleep and anxiety as well as pain. It also is known to be utilized by borrelia, depleting our own stores, so it's best to replace it.

I also take the best probiotic supplement I know of, Custom Probiotics. It's made by a guy named Harry who is a chemist who cured his own digestive disorder by making his own powerful probiotics. Whereas most commercial brands have at most 2 billion organisms per gram, his have 60 billion per gram and sometimes as much as 200 billion. He makes a Custom-6 formula or you can customize your own, which I do. I use three different strains of bifidus which is specific for the large intestine. This product is expensive but it is very potent so requires only a tiny amount daily in a glass of water. Most probiotics contain filler. Harry's product is pure, no fillers at all.

I drink 2-3 cups of decaffeinated green tea daily. There are antibiotic and antiviral polyphenols in green tea. In addition, there are precursors to norepinephrine, as well as theophylline, both of which are stimulants. I also use a special device called Chee Energy invented by retired physician Charles McGee, M.D.. It is an LED (light emitting diode) device that contains infrared, red, blue and white lights (each has different wavelengths) that has pulsing Nogier frequencies programmed into it. These frequencies, developed by a French physician, resonate in harmony with healthy tissue.

LED devices have been studied by NASA and other researchers for use in wound healing. They have even been used to heal mouth ulcers in children treated with radiation for head and neck cancer. They are quite useful for localized pain. However, adding in Nogier frequencies as Dr. McGee has done, really makes this device quite unusual and powerful. I've found that the infrared setting relaxes me and helps me sleep. I also use it on all three settings at once as a kind of acupuncture device to clear blocked meridians, but the device is so powerful on those settings I only do this a few minutes at a time.

Finally, I have returned to meditating with an old friend, music by Hemi-Sync, which utilizes binaural beat technology to help you slip easily into alpha and theta states. I've been using this at night to help me sleep. Hemi-sync technology gently tricks your brain into producing relaxing alpha and theta waves on its own. Sometimes it is hard to get into a peaceful state when you are in a long-term battle with chronic health issues. I use their metamusic series (I myself don't like to be guided by voice), and my favorite has always been Midsummer Night. These CD's must be used with headphones in order to be effective.

VII. Mistakes

Like anyone, I have made a few mistakes along the way. Some were harmless and others were not, and I'll mention them here. First, I've tried healers of various sorts, including distant healers who claim to have cured cancer in just a few sessions. Not one healer has had any effect on my health. It is tempting to indulge in the fantasy that some magically powerful person will render you whole and perfectly healed instantly, but it is probably better not to drain your pocketbook to indulge the fantasy. I also tried a very sincere homeopath, to no effect.

Finally, I tried a microcurrent/rife device from a chiropractor named John Myers, who operates out of Atlanta. He has a very lengthy paper on arthritistrust.org, wherein he lists case after case of cancer and lyme that he has cured when nobody else could. I am always suspicious of such outlandish claims, but I also feel that I should leave no stone unturned. Dr. Myers uses muscle testing (kinesiology) which he dubs 'brain talk', and then programs frequencies into a little battery operated device you wear on your waist. I spoke with two lymies who felt the box had helped them a great deal. He prescribed four hours every other day. After my first four hours, I had muscle weakness, fasciculations, and strange burning sensations that were terrifying and lasted for weeks.

I subsequently learned of another lymie in Florida who had also used the box for four hours (by mistake—she fell asleep with it on) and had such a severe neuromuscular reaction she could not walk for a month. Another lymie, a friend, felt extremely nauseous after 30 minutes with the box and gave up on it. Because I have never had a positive reaction to any electromagnetic or rife device, and because my reaction to this one was alarmingly negative, I will never get near one of these devices again.

The Future

What's on the horizon? I'm working with a prominent Ph.D. in the nutritional field who runs a well-known nutraceutical company, to try and develop a form of allicin that might be taken up into the cells and kill these intracellular infections. Allicin is the perfect pathogen-bomb, but it's unstable, and broken down by stomach acids. So we're working on developing a form that will bypass the current barriers.

I'm soon going to add in another Atrium product, Comitras, that downregulates MMP's, and that one prominent lyme doctor is using for himself and with his patients for this important effect. We know that one way lyme disseminates is by upregulating these inflammatory MMP's, leading to leaky, inflamed cell membranes and blood vessels. For the spirochete, this is pure heaven, as it can easily adhere and penetrate and travel. For the host, it's hell, because it initiates all kinds of complex problems. I will soon be interviewing the alternative M.D. who pioneered this approach for lyme and will post it here on ImmuneSupport.com/

I also recently spoke with Randy Baker, an alternative physician in Santa Cruz, CA, who is using bee venom on lyme patients with only good results for their pain and neurological symptoms. He explained his protocol, which is to inject tiny amounts of venom with procaine in 15 or more spots on the body; and I'm hoping to try it here in the next few months. Bee venom's mellitin has inhibitory effects on the spirochete in vitro, but it also seems to have anti-inflammatory and mood-boosting effects as well. I've known about this for a long time, I just hate shots so have avoided it.

I recently wrote about Dr. Schardt's protocol with diflucan for lyme, but found that I could not tolerate the drug very well. Therefore I am about to get the smallest dose available, in an oral solution, and start taking extremely miniscule amounts, hoping that I can build up tolerance over time. I've also tried experimenting with an unorthodox salt and Vitamin C protocol, but can't report about that yet positively or negatively. I do know some people who it has helped a lot.

In addition, a new book out by a brilliant and very spiritual herbalist, Stephen Buhner, details a brand new approach to lyme disease including some herbs that nobody has thought to try before. Called Healing Lyme, and released by Chelsea Green Publishers, the approach sounds promising. Here's what Stephen Buhner wrote me in an email: "I wrote about lyme because during my speaking and teaching over the past decade it is the one question I am always asked, no matter the topic I am speaking on. And in looking at the disease and literature I was astonished to find that there were no decent texts on the disease at all - which shocked me, given its impact and pervasiveness.

The final deciding factor was that a physician friend who has worked with a lot of lyme patients, asked me to please do a book that could help physicians as well as people with lyme. After reading some thousand journal articles and every book that covered lyme at all, I was pretty astonished to find that virtually no one has an overall picture of the spirochetes's movements through the body, the subtle physiological alterations that occur in the body, why they occur, why the spirochetes actually affect the systems they affect, the transformations they go through to protect themselves, the true effectiveness of antibiotics, just how pervasive the spirochetes are in nature, or how many routes of transmission there really are. For some, of course, antibiotics will work 100%, but never for everyone. The organism is just too smart.

Oddly, the most effective plants for treating lyme tend to be invasive botanicals, especially those that began moving into these ecoregions about the same time the epidemic really got going. The best of

them affect not only the general symptoms of lyme but counteract the biological pathway alterations initiated by the organism. This kind of specificity is really intriguing to me, while antibiotics can only kill (sometimes) the organism, they can do nothing to protect, strengthen, or reverse alterations in subtle biological subsystems of the body. Since my interest is in plant medicines it seemed essential to have a comprehensive text that examined the best plant medicines for the disease." Let's hope that the herbs Stephen Buhner suggests turn out to be effective in helping us treat lyme disease.

If we all come together and share all the information we have, we will all be better for it. I still wish I had never walked in that fateful Connecticut garden 5 years ago, but I also am grateful that I live in a day and age where hyperbaric chambers are available for home use, where gamma globulin and thymus and glutathione are available, where pioneering doctors, pharmacies and companies are coming together to try and heal the epidemic of illnesses that mainstream medicine does not yet understand or know how to cure.

REFERENCES:

For information about or purchase of portable home hyperbaric chambers contact: Lance Brubaker, Net Physician, 678 957 0156

To contact Dr. Rhett Bergeron about his comprehensive approach to lyme disease: 678 990 5401

To buy preservative free glutathione for intravenous or nebulizer use by prescription only: Wellness Pharmacy, (800)227-2627

Reasonably priced nebulizer: <http://www.oxymaster.net> (click on nebulizer)

Custom Probiotics: www.customprobiotics.com

Healing Lyme, by Stephen Buhner: www.chelseagreen.com (book distributor)

HemiSync: www.hemi-sync.com

Chee Energy Device: www.cheeenergy.com.com or contact Dr. Charles McGee 800 442 8029

Bee venom: <http://beevenom.com/> (Michael Simics harvests pure bee venom and has a very good reputation. This allows doctors to use the venom with procaine, rather than having to keep real bees around.)