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This guide is dedicated to Malea and Sydni and Camp Bad News for teaching me so much and being patient while I learn with them on our journey.



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New Introduction

Purpose

This guide is to offer educational information about Borreliosis, a disease often referred to as Lyme disease. It also covers the many co-infections that can ride on a tick and arrive with Borrelia. In addition, it contains basic supportive information that can help anyone with chronic fatigue, chronic widespread pain and/or brain fog. The following statement by Joseph Burrascano, MD, is often quoted by me when patients ask me why I am bringing up Lyme disease.

Anyone with chronic pain that is widespread, chronic fatigue and brain fog should consider they may have Lyme disease.

My previous versions of this guide included a narrative of my own personal journey that on review rambled quite a bit. So I will briefly just state here that I already felt I had Fibromyalgia and was occasionally very tired and certainly couldn't exercise like I had previously. I often joked that similar to the book "Couch to 5K" but in reverse I could now write the "Ironman to Couch" in 3 years guide. In January of 2012 I broke out with a rash I knew to be Pityriasis rosea. Pityriasis Rosea (PR) was a rash that was of previously unknown cause, but likely viral and you just let it run its course. The few times, I'd seen people experience it before it had lasted 4-8 weeks and was annoying but didn't interfere with their daily lives. However, mine was accompanied by crippling fatigue, swollen lymph nodes, sore throat, hives on top of the skin lesions and abnormal liver enzymes. I researched and found an article published in 2011 that now PR was tied to Herpes Human Virus 6 and could arrive with a "mono-like" illness. Over 10 weeks had already passed and it was still getting worse. So that same article said acyclovir 200 mg 2 tablets 5 times a day for 10 days could shorten the course. It did at least stop the rash but the fatigue and liver inflammation continued.

When I shadowed Dr. Charles Christ in Missouri, I was struck by how many of his LD patients reported reactivation of viruses from the Human Herpesvirus family such as Epstein Barr virus or Cytomegalovirus or Zoster. Therefore, I considered I could have Lyme disease or Borreliosis. Like so many patients with no way of knowing when they were originally exposed, I checked my Western Blot and it was pretty unremarkable with only 1 positive band, but my CD57 cell count was less than 20. (I'll discuss these tests in more detail later). I felt so tired I didn't feel I could even tolerate the antibiotics since many initially get much worse before they got better. So I started supplements first that might help me recover some energy. One was called NT factor. After 6 weeks of that I felt well enough to start an antibiotic and

started doxycycline. Immediately my blurred vision, trouble with lots of floaters and eye twitching resolved. My eye issues became my “pointer” for a need to take antibiotics again.

Since 2013 I have made slow and steady progress by taking antibiotics on and off, other supplements to support adrenals and as well including going gluten-free. I also worked with a therapist for posttraumatic stress disorder from 2010 on as well. Often I’m asked how long will it be before I’m better. That is very hard to say but the LLMD community estimates about 3 years for most patients with chronic borreliosis. Those I’ve seen with known exposure dates that happened in past 3-12 months all get well much faster typically in 3-12 months. (The longer you have it the longer it takes to recover).

So now it’s 2015, I’m still restarting again for exercise and I’m far from the 2008 Ironman finisher I was but I am steadily improving. I really feel so much better every year that I’m sure one of the keys to surviving and then thriving must be resuming regular exercise.

I hope this guide will share what I've learned so far, extracted from others, and also help you understand this process better. A patient recently gave me her “Why can’t I get better? Solving the Mystery of Lyme & Chronic Disease” by Richard I. Horowitz, MD. So often it seems some more information comes my way just when I need it. This book is a NY Times bestseller which is a huge step forward for those combating this disease.

In the appendix I have included additional tools we will use at your office visit to keep us organized and make the best use of our time since this is the MOST complex illness I believe we physicians face at this time. Perhaps, that’s why many don’t want to admit it exists because it certainly can feel like you opened Pandora’s Box when you first start learning about it.

My Medical Training

I started out in undergraduate at Northwestern University as an engineering student but when I decided to go to medical school I switched from Electrical Engineering and Computer Science to Biomedical Engineering with Computer Science applications. I finished that degree and went straight to University of Illinois medical school. Then I did a residency in Internal Medicine but I also was interested in gynecology and psychiatry so after residency I did a fellowship in Women’s Health and got a Master’s in Epidemiology. Epidemiology involved the study of disease trends, public health and conducting research. My Women’s Health focus involved more in depth study of hormonal health and alternative treatments. My fellowship was done at University of Wisconsin, Madison, Illinois.

Dr. Horowitz states in his book that Internists (doctors of Internal Medicine) are uniquely qualified to be the main healthcare providers treating Lyme disease and I agree. He described himself as a medical detective and that is how many have described me as well. I like to solve puzzles and Lyme disease offers a puzzle on the order of Rubik’s cube with a side of the hardest Sudoku. So it has been a very interesting challenge and I’ve by no means mastered it. Having to fight it as well on personal front has at times been a help and a hindrance as you can imagine. You will find however that many doctors that

become experts in certain areas also just happen to have experienced it personally. So as person that has had their share of hormonal chaos and other medical mysteries I have some insight into this area that is unique.

History of Medicine

Modern medicine has made some enormous strides and allopathic and osteopathic doctors (MD and DO) practicing now may have little concept of how far we have come. However, it's important to not lose sight of that journey and to also be aware of shifts in the paradigm of medicine that often lose important knowledge when it's no longer in vogue. I have a great lecture on the History of Medicine I used to do at Midstate College that demonstrates how the pendulum swings back and forth over time and if you wait long enough you'll hear us change our minds back and forth and so on.

Back around the turn of the 19th century into the 20th it was said that the doctor that could treat syphilis successfully was a great doctor. It was actually attributed to Osler, the father of Internal Medicine, who said: 'He who knows syphilis knows medicine'. It was notoriously difficult to diagnose and to treat and was heralded as the Great Imitator. It was transmitted via contact with a sore known as a chancre that occurs on the genitals (pronounced shank-er) or from mother to baby. It caused disease in three stages from sexual transmission with a latency between the stages of months to years.

1st stage was manifested by a hard chancre (skin ulcer) and painless lymph node swelling

2nd stage presented fever, malaise, sore throat, arthralgias, lymphadenopathy, macular popular rash (looked like small target lesions all over the body including the palms of hands and soles of feet), condyloma lata, 'snail track' ulcers in the mouth and on the genitals.

Latent stage was entered then if the syphilis wasn't successfully treated without much in the way of symptoms after 3 to 12 weeks of the 1st two stages and could last less than 2 years to many years.

3rd stage then involved multiple organs including skin, heart and nervous system and presented with gummas (skin lesions), aortitis and aortic regurgitation, meningovascular involvement, general paralysis of the insane and tabes dorsalis (loss of the proprioceptive nerves that caused a very strange characteristic walk that I can demonstrate upon request).

Congenital (mother to baby transmission) syphilis in the early stages could result in stillbirth or failure to thrive, snuffles, skin and membrane lesions like those in secondary syphilis. Later stage stigmata included Hutchinson's triad; tombstone teeth, sabre tibia, other abnormalities of the long bones. Keratitis, uveitis, facial gummas and central nervous system disease.

I had the unbelievable experience of diagnosing secondary syphilis in the emergency department at the University of Arkansas when I was a medical student!

According to Wikipedia:

The name for [syphilis](#) is derived from Fracastoro's 1530 epic poem in three books, *Syphilis sive morbus gallicus* ("Syphilis or The French Disease"), about a shepherd boy named Syphilus who insulted Greek god [Apollo](#)^[5] and was punished by that god with a horrible disease.

However, this was not the poem we learned in medical school to help us remember all that syphilis could do. The poem we learned went as follows:

The Syphilis Poem...

*There was a young man from Black Bay
Who thought syphilis just went away
He believed that a chancre
Was only a canker
That healed in a week and a day.*

*But now he has "acne vulgaris" –
(Or whatever they call it in Paris);
On his skin it has spread
From his feet to his head,
And his friends want to know where his hair is.*

*There's more to his terrible plight;
His pupils won't close in the light
His heart is cavorting,
His wife is aborting,
And he squints through his gun-barrel sight.*

*Arthralgia cuts into his slumber;
His aorta in need of a plumber;
But now he has tabes,
And saber-shinned babies,
While of gummas he has quite a number.*

He's been treated in every known way,

*But his spirochetes grow day by day;
He's developed paresis,
Has long talks with Jesus,
And he thinks he's the Queen of the May*

Syphilis also known as *Treponema pallidum* is a bacterial spirochete that particularly likes connective tissue, the heart and the nervous system (sound familiar)? Yes unfortunately it is the cousin of a spirochete we now face, borrelia, the cause of Lyme Disease.

Borreliosis

When I was first asked by a patient if I had heard of Lyme disease and would I consider testing and treating her for it in 2010. I thought why not? I had no idea that there was such a controversy around Lyme disease. Soon I became aware of the big divide in the US about Borrelia and Lyme disease that interferes with acquiring the latest and best knowledge. However, I had the opportunity to follow Dr. Charles Christ in his clinic in Columbia, Missouri and that helped me get started treating Borreliosis and its friends the co-infections. Then much to my surprise, Dr. Christ started directing the Central Illinois patients that called his office to me and my population grew. It is still just a part of my practice but our integrated-integrative approach fits well with treating Borrelia.

Prior to starting medical practice, I did extra training after medical school and my Internal Medicine residency in Madison, Wisconsin, (tick country by the way). I did a fellowship in Women's Health and part of my fellowship was also doing a master's program in epidemiology, which is very similar to public health. So I have studied articles and research findings for a long time now and have been trained to look at the articles critically and look for bias. It's not enough to have a study about a certain subject but you need multiple studies, an ability to critically analyze the studies for how well designed and orchestrated they are and do they apply to your situation. In many ways, all of our studies are potentially biased if we don't look critically at the design and make absolutely sure we've designed it optimally with respect to bias. This is rarely done by the pharmaceutical industry or the alternative/nutraceutical industry. The former because they aren't interested in proving their therapy works not only well but MUCH better than the placebo. The latter because no one wants to fund the type of research it would take to study nutraceuticals well. In addition, it takes special techniques to study "hands on" therapies such as chiropractic and massage. So all of this adds up to my specialty includes a large focus on hormonal health and alternative treatments, avoiding surgery and even avoiding drugs as much as possible, but using all the above when we have to and also acceptance of our current science limitations in all of these areas and remembering that everyone EVERYONE has an agenda.

So let's start with basic information about borrelia the bacteria responsible for Lyme disease.

1. Lyme disease a form of Borreliosis is transmitted by the bite of a tick and is prevalent in the US and rest of the world.
2. The percentage of people that remember being bit by a tick is less than 50%. The percentage that recall any rash is according to ILADS less than 50% and according to the IDSA 70%. Regardless it's nowhere near 100%.
3. The Center for Disease Control criteria are for surveillance or monitoring of disease progression and spread and only pick up 10% of cases. They were never meant to define everyone that has Lyme disease.
4. The ELISA screening test is also unacceptable due to low sensitivity. It is only 65% sensitive and to qualify as a screening test should be 95% sensitive.

When we don't have reliable testing then we have to make the diagnosis clinically. That means I base my diagnosis on my best clinical judgement, take into account other possibilities and also try to consider what else could cause this array of symptoms. However, if someone presents with seemingly bizarre symptoms, 3 of them are fatigue, widespread pain that moves around and brain fog and the rest all have Lyme disease or Borrelia as a possibility in the differential diagnosis then it makes for a strong possibility.

Like the story I just told you of Syphilis in the 19th century, Borrelia has emerged in the late 20th and now 21st century as the next Great Imitator and worth considering in the differential diagnosis of rheumatologic and neurologic conditions, as well as Chronic Fatigue Syndrome, Fibromyalgia, Somatization Disorder and any difficult-to-diagnose multi-system illness.

In his book, "Why can't I get better? Solving the Mystery of Lyme and Chronic Disease", Dr. Horowitz points out this isn't one problem, this is a combination of overlapping problems with multiple causes that happen in people that have genetic susceptibility and immune system dysfunction. I think this is very important to read again and think about. To put it another way, forget about what states you have lived in or visited. Probably everyone in their lifetime is going to be bit by a tick. Seems silly to think it hasn't happened. But some will go on to develop acute Lyme disease. And some will develop Bartonella. Some will have both. Some will not be able to fight it off due to a lack in their own immune system function and will go on to develop chronic Lyme or chronic borreliosis or combination of multiple chronic infections causing widespread pain, chronic fatigue, and trouble thinking.

Horowitz aptly calls it Multiple System Infectious Disease Syndrome (MSIDS). Dr. Charles Crist calls it "Antibiotic Responsive Illnesses" or Master's disease.* Regardless, most of the patients are felt to have been bit by a tick and then infected with some or all of the species of Borrelia, Bartonella, Ehrlichia, Babesia and other organisms. Dr. Burrascano also describes that Lyme disease can present in three categories: acute, early disseminated, and chronic. Borrelia is a spirochete which is similar to Treponema the organism that causes Syphilis. Syphilis is also characterized by stages and targets similar organs and tissues. Syphilis however is sexually transmitted. Borrelia we feel can go from mother to fetus but is otherwise not transmitted from human to human but comes from a tick bite.

Those that treat Borreliosis do find the sooner treatment is begun the better chance for elimination. So certainly if there is any possibility of acute Borrelia infection I treat a recent tick bite regardless. By the time the test result would return, valuable ground could be lost.

Burrascano defines Chronic Lyme as follows:

1. Illness present for at least a year.
2. Having persistent major neurologic involvement (such as encephalitis/encephalopathy, meningitis, etc.) or active arthritic manifestations (synovitis).
3. Still have active infection with Borrelia or a co-infection, regardless of prior antibiotic therapy.

He points out that after a year of infection the immune system breakdown reaches a clinically significant level and the CD-57 subset of natural killer cells count declines. This immune dysfunction then leads to other co-infections being able to cause pathology. Because the immune system is suppressed, steroids and other immunosuppressive medications are absolutely contraindicated in Lyme. He also recommends extensive nervous system evaluation with neuropsychiatric testing, SPECT and MRI brain scans, CSF analysis when appropriate, and regular input from Lyme aware neurologist and psychiatrists. WHERE one would find these people, insurance to cover this testing and such I have no idea here in the Midwest. But I would love to SPECT scan LD, FMS, CFS, and AD/HD patients if I ever find a way to do it. (Dr. Amen is famous for his SPECT scans of AD/HD and other illnesses. You can find more information about the SPECT scan at <http://www.amenclinics.com/the-science/spect-gallery>.)

So what clinical picture leads me to think of Lyme disease? According to Burrascano, anyone with the classic triad of symptoms for Borreliosis is fatigue (tiredness, exhaustion), musculoskeletal pain (joints, muscle, back, neck, headache), and cognitive problems (memory loss, trouble concentrating, difficulty remembering what you read, depression, disorientation, getting lost). It just so happens these are also the 3 main symptoms of Chronic Fatigue Syndrome and Fibromyalgia Syndrome. But there are over 100 symptoms in the questionnaires that many Lyme Literate doctors use (LLMDs) and it's a great imitator so it's certainly worth considering. I also feel that there is some clues that make me think more Lyme vs. CFS for example. If a person has the triad and strange numbness and tingling on one side of their body and weakness of the left lower leg and ankle drop. Now that sounds like Lyme disease. Lyme often causes neurological deficits that I wouldn't expect to find any with Chronic Fatigue and in Fibromyalgia the neurological symptoms might be present a few days but then they would move to somewhere else. I also feel like Lyme disease has much more in the way of eye complaints. Another clue is someone that always feels better after taking antibiotics or 3 days after starting one feels terrible but the next day they're back to normal. So you hopefully get the idea that I'm looking for a pattern here. However, unlike many other diseases you can't just take a test and say ok it says yes therefore I have it or it says no so I don't. Dr. Horowitz points out that MSIDS frequently has symptoms that come-and-go and are migratory.

My biggest concern is that I feel there is enough uncertainty that we should never just say oh well it's all Lyme disease and stop looking for answers. So I try to remain open to finding another causes as well. Lyme disease is the constellation of symptoms that respond well to antibiotics but often take months, even years to recover. Average recovery is currently 3 years but there are many that take longer. Therefore, we should continue to try and unwind the mystery as much as we can. I'm always willing to accept we could be wrong and your issues may not be Lyme related at all and certainly there has to be many other illnesses that are at the root of chronic fatigue and fibromyalgia. Along with Lyme Disease, I have seen people with the CFS and FMS vastly improve when treated with hormonal help, dietary changes, identifying food allergies and other environmental triggers, safe exercise, herbal and homeopathic remedies, and neuromodulating drugs, chiropractic, physical and massage therapy and more. So I recommend that be an important part of the treatment plan. There are patients that report after taking antibiotics for something else that they felt so much better. That should also make us think Borrelia or another tick borne infection.

* One quick word about seeing Dr. Christ, Dr. Horowitz or other LLMD's. Most don't take insurance as you'll soon find out. The older LLMD's were often kicked off insurance plans for treating tick associated diseases and so many of them had to go to cash based style of practice. I haven't had to do that yet but it could happen depending on how the Affordable Care Act and other changes in medicine change our practice parameters. I like to spend a lot of time with patients and that's generally a much harder style to maintain and stay in the black. Many a great doctor has had to quit practice or work for a hospital to make ends meet so those of us in private practice are a dying breed. Once you are employed by a hospital, it often becomes impossible to have more than 15 minutes slotted per patient and you certainly can expect that your practice would probably have to not include any alternative forms of treatment. So in order to stay afloat we have pretty strict policies about labs and missed appointments. Also since I still take insurance, I don't do phone consults. This may change in future as it's becoming more mainstream but currently most insurance companies don't cover it. The problem with that is often if you are interested in a service not covered by your insurance we like to tell you beforehand so you're prepared (but we can't predict this accurately all the time). There are CPT (procedural codes) for billing you for services and that includes telephone consultation. Many insurance companies not only don't cover phone calls they even claim it's outside of our contract to do so and therefore forbid billing the patient for phone calls. This makes it very difficult to change styles of practice and remain part of the system. Same goes for emails but I will try to work with people that live outside of the Peoria area via email to get us between visits.

Lab Testing

I wish there was a simple test to say yes or no you have Lyme disease. But there is not. But the following tests are still just suggestive not confirmatory for chronic disease. The CDC originally came up with criteria for what is consider a positive Western Blot to identify "surveillance cases." A surveillance case is

someone you are sure has the disease and will be tracked to get a feeling for disease presence in your community and excludes 90% of those that probably have it as well. It was never meant to be necessary to meet the CDC criteria to be diagnosed with Acute or Chronic Lyme disease. How it evolved to that is again beyond me. The diagnosis of Lyme Disease should be made based on clinical presentation first and then laboratory testing to confirm but it doesn't rule it out if negative. This is very frustrating for everyone involved but borrelia is a very unique organism and can't be cultured like most bacteria. There is only one lab in all of North America that reports success culturing it. BUT until more than one lab can do I'm skeptical of them. In order for something to be proven in medicine it has to be repeatable. So the following testing is done to see if at least supports our "presumptive diagnosis". But how you respond to treatment is more helpful than any testing in deciding if we're on the right track.

Lyme IgG/IgM Antibody

This test is used by some doctors as the first line test before they will do the Western Blot. Patients with other spirochetal diseases (syphilis, yaws, pinta, leptospirosis and relapsing fever), infectious mononucleosis or systemic lupus erythematosus may give false positive results. In early infection, a negative result does not exclude infection. If antibody results are "equivocal" or "presumptive positive", confirmatory testing will be done using Western Blot. If reflex testing is performed, additional charges may apply. It has such poor sensitivity and specificity that it is a horrible first line test and I don't even bother doing it. I go straight to the Western Blot.

Western Blot

Many that actively treat Lyme disease recommend doing a Western Blot through IGeneX labs in California. It is well documented that the screening tests (ELISA method or similar) can be negative and the confirmatory test, Western blot positive. Therefore, when the index of suspicion is high it makes sense to go straight to the confirmatory test. The test will cost for just the Western Blot of *Borrelia burgdorferi* is \$200 and IGeneX does not take insurance plans but it may qualify for reimbursement. Conversely, we can do a Western Blot here through HealthLab in the Chicago area that is billed to your insurance as done by us so that it is in network and is therefore covered. The test itself is not run differently and the raw data we obtain is the same. But the interpretation that arrives from the lab will have "positive" or "negative" based on the CDC guidelines. In many diseases not just Lyme disease, criteria are set forth to be used in research to make sure that those included have high probability of having the disease being studied and excluding any false positives. A false positive means the person tested positive for a disease they really don't have. This is done to give the research study a better chance of showing clinical significance because the subjects then will have much more in common and likelihood of similar response. However, guidelines set forth for research for LD by the CDC were not meant to be used to exclude the diagnosis in the clinical setting. But they have since been adopted as such by some groups, the Infectious Disease Society of America is one, and this has led to great misunderstanding of the medical community at large and polarized the groups on both sides.

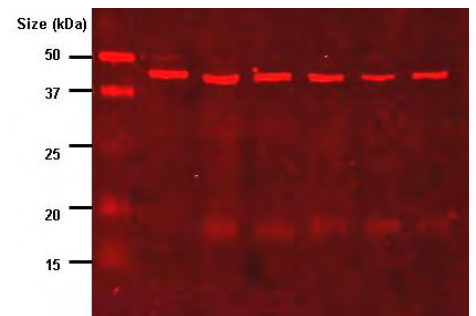
According to a study done by Dr. Charles Crist and presented in 2004, if you have even one positive band on the Western Blot you have a 95% chance of feeling better after antibiotic treatment. Interestingly

one reason that may be the issue in the Midwest is many feel the *Borrelia* here is not burgdorferi and therefore why the Western Blot response may be very weak. Dr. Sam Donta, a full professor of Infectious Disease at Boston University School of Medicine and other physicians have said the same thing. If you have one Borreliosis-associated antibody, they found it is significant.

Very few of us received the Lyme vaccine, in fact, so far I'm the only I know that got the vaccine. I jumped on it the minute it was available and it was pulled just a few months later. Apparently the bands on the Western Blot (31 and 34 kda) that would be positive for someone who received the vaccine were pulled from the Western Blot test and never put back even though very few received it. There are 28 possible bands and the typical Western Blot only reports 13 of them. There is also controversy over which bands are more specific to the organism. Bands 23,31,34,39 and 93 are considered very specific and 18 and 41 are less so. One distinction that IGeneX does that no other labs does is if there is a reaction but not strong enough to say positive or negative they call it indeterminate. The rest of the labs call that negative.

To further explain the Western blot, you need to understand some more about bacteria. Bacteria are one celled organisms but that doesn't mean they're not smart or cunning. The borrelia organism is both. On it's outer surface are various proteins. However, it can shed up to almost 2/3's of it's outer cell wall and associated proteins and roll up into a ball or cyst form. This is called the L-form because it "L"oses part of itself. By doing that it makes it much harder for your immune system to find it. If your immune system doesn't see it then it won't form these antibodies. So this test is only as good as your immune system is at seeing the little stinkers and the longer it exists in you the better hidden it becomes.

As the outer surface proteins (osp) have been discovered, they have been assigned letters, such as outer surface proteins A, B, and C. Again, each band is an antigen complexed (bound together) with an antibody made by the immune system, specifically for that antigen (part) of *Borrelia burgdorferi*. But it's testing for your antibodies by seeing if they will form a complex with the antigens on this gel matrix supplied by the lab. Then they immunofluoresce (show up neon like) as demonstrated to the right. I've add more bands then you often see on a Western Blot but that can be reported by IGeneX.



- 9: cross-reactive for *Borrelia*
- 12: specific for Bb
- 18: An outer surface protein. Highly specific to Lyme (Many LLMD's say if this band alone is positive, you have Lyme)
- 20: cross reactive for *Borrelia*
- 21: unknown
- 22: Possibly a variant of outer surface protein C.
- 23-25: Outer surface protein C (osp C). Specific for Bb
- 28: unknown

- 30: unknown; Possibly a variant of outer surface protein A. Common in European and one Californian strain-Has cross-reactivity with several different types of viruses.
- 31: Outer surface protein A (osp A). Specific for Bb – Has cross-reactivity with several different types of viruses.
- 34: Outer surface protein B (osp B). Specific for Bb.
- 35 : specific for Bb
- 37: specific for Bb. Other labs consider it significant.
- 38: cross-reactive for Bb
- 39: is a major protein of Bb flagellin; specific for Bb. It is the most specific antibody for Borreliosis of all.
- 41: Flagellin protein of all spirochetes; this is usually the first to appear after a spirochete infection but is NOT specific for Lyme.
- 45: Heat shock protein. This helps the bacteria survive fever. The only bacteria in the world that does not have heat shock proteins is Treponema pallidum, the cause of syphilis. Cross reactive for all Borrelia.
- 50: Cross reactive for all Borrelia.
- 55: Cross reactive for all Borrelia.
- 57: Cross reactive for all Borrelia.
- 58: unknown but may be a heat-shock Bb protein
- 60: Heat shock protein. Cross reactive for all Borrelia.
- 66: Heat shock protein. Cross reactive for all bacteria.
- 83: specific antigen for all Lyme bacterium, probably a cytoplasmic membrane.
- 93: unknown, probably the same protein in band 83, just migrates differently in some patients.

The bands most often reported are 18, 23-25, 28, 30, 31, 34, 39, 41, 45, 58, 66 and 83-93. This is true regardless of whether it is IgG or IgM. But again, there is no universal agreement on the significance of these bands.

Band 23 represents a reaction to an outer surface protein C. This protein is "down regulated" while Borrelia is in the tick gut. It becomes expressed when Bb enters the mammalian host. The 41 band represents the flagellum- the tail of the spirochete, and is always expressed. The outer surface protein A, which corresponds to band 31, is "up regulated" in the tick gut and becomes down regulated in the host. It is only expressed- again up regulated in the host after prolonged infection. Therefore, a positive 31 band has been associated with longstanding infection and be a marker for neuroborreliosis. The 34 band, outer surface protein B is also seen later in the course of the disease. Some have postulated that 58 and 66 bands are seen with co-infection. The evidence of these associations is up for debate. Unfortunately, research on the clinical side has not kept up with the bench research which has found out a lot more about Borrelia in past decade.

If we have high suspicion for Borreliosis we can also retest after 4 weeks of doxycycline and off antibiotics 10-14 days. The antibiotic kills the Borrelia which exposes it to your immune system since it can't evade when it's dead and you form antibodies. 36% of the time this can convert a negative or equivocal Western blot to positive by stricter criteria. You can continue to retest and will have more

and more become positive but obviously from a cost-saving perspective this can get costly. After second one is negative you can also go to a Lyme Urine Antigen Test (LUAT). If this test is positive it corresponds to very high likelihood of improvement with antibiotics. This test some feel should be the test of choice.

I recently saw data on the ILADS site saying that having 2 bands positive on the Western Blot was 92% sensitive and 95% specific. If we used the CDC criteria we miss 90% of Lyme cases and the CDC acknowledges that but clinical practice guidelines set forth by IDSA don't and the controversy continues. Dr. Christ felt anyone with even one band had a good chance of responding to antibiotics.

CD57

I also for now use the CD57 count to look for trends in response to treatment. Some patients have a very clear reaction when an antibiotic is started that indicates it's working called Jarisch-Herxheimer reaction. (Many refer to it as Herxing for short). Typically it happens soon after starting new antibiotic and you feel like death warmed over for a few days (like really bad respiratory and/or GI flu). But it should be temporary and only go for 3-4 days. If it continues past that then you will have to stop those antibiotics and go on to next "round" or call for direction. If you do feel much better on certain antibiotics we will continue those as long as you continue to improve. But many times we're not sure if overall it was better, worse, same and then I rely on the CD57.

C4a

This is another marker that was said to be elevated by Lyme infection and lowering of this number was a good indication. However, this one seems to have less reliability than the CD57. It is also involved with lupus and is more helpful in mold illness so I don't use it in Lyme but I do if you have mold issues.

Part of diagnosing MSIDS that is so well demonstrated in Horowitz' book is his categorization of what other diseases it could be for different symptoms and signs and how he eliminates them. So he addressed how to eliminate some of the following at least at this time. But you have to watch for signs of them continually because many of them aren't easy to diagnose either. Or people can have both which we call overlapping diseases. So we also need to consider and rule out the following:

- Rheumatoid Arthritis, Lupus, and other connective tissue and autoimmune diseases
- Thyroid, Adrenal and other hormonal imbalances
- Multiple sclerosis, chronic migraine and other CNS demyelinating processes
- ALS and other neuromuscular attacking diseases

Multi-System Approach

In my mind, regardless if you have Lyme disease or Chronic Fatigue or Fibromyalgia, you clearly have a system that is not functioning as it should. Many people are exposed to Lyme but few get chronic Lyme. Now many may have it and are calling it something else. We now have found that looking at your HLA DR and DQ types may point to whether you're of the 25% of the population that is susceptible to post or chronic Lyme vs mold vs Multisusceptible vs other toxins. But it is well documented that some who have full blown acute Lyme disease receive treatment and have no further sequelae. Some people have mono, Epstein-Barr or Cytomegalovirus infections or other Human Herpesvirus family infections and after that resolves they are fine and others will develop chronic fatigue. Most people with Fibromyalgia have history that it started after a physical trauma such as bad fall or motor vehicle accident. Obviously not everyone that has car accident gets FMS. So what does this tell us? That something goes wrong with our system and leads to not being able to heal as we should. Whether it's an immune system issue or neurological system problem is not known so it makes sense to me that along with treating you for the infections of Lyme we should also do everything we can to look at all of the following areas as defined by Dr. Horowitz (prior I had 7 now I have 16 areas):

1. Treat chronic infections (Bacterial such as Borrelia, Babesia, Bartonella, Ehrlichia, and Mycoplasma; Viral infections such as Herpes family viruses; Yeast, and Parasites)
2. Immune system dysfunction
3. Inflammation
4. Environmental toxins
5. Functional medicine abnormalities with nutritional deficiencies
6. Mitochondrial dysfunction
7. Endocrine abnormalities
8. Neurodegenerative disorders
9. Neuropsychiatric disorders/Trauma work
10. Sleep disorders
11. ANS dysfunction and POTS
12. Allergies, food and environmental
13. Gastrointestinal disorders
14. Liver dysfunction
15. Pain disorders and addiction
16. Lack of exercise and deconditioning

No wonder most doctors want nothing to do with this. We were taught based on a model that most diseases have one cause, you treat that root cause and everything becomes great. Any doctor paying attention and in primary care should see that this doesn't work for very long once you're in practice. So many problems are multifactorial and overlap and then there's the domino effect. I see so many people that it started as one thing going wrong and before they knew it their health was falling apart like the dominoes falling down that were placed in long lines and formations. But don't let that get you down!

not able to work and you're pretty miserable. 9 or 10 and if this was an acute problem you would be headed to the ER. I'm a little suspicious of the persons reporting 9 and 10's all the time. That worries me because most people can't tolerate 9 and 10's if it's pain without going out of their mind. So if you're disabled and not able to work and feel pretty awful every day you should be reporting 7's maybe 8's. If you report 9 and 10's everyday then I have bad news. You're going to run out of scale when it gets worse. So trust me. If you're reporting 9 and 10's all the time you're likely over reporting. But if the person that writes the above diary comes in and has 6's and 7's and one week 9 and 10's I know something terrible is going on and we need a serious intervention. Keep in mind the scale is relative. So try and make your numbers make sense. I take the above patient VERY seriously even though she doesn't report high numbers. I just think she's one of the few that truly appreciates the scale and knows how much worse it could be. There are many of you that will arrive in my office currently flared up and in 6-8 range and I understand that as well.

Ok if you can when you do your lab work bring in your calendar and have someone on staff scan it and send it to me before your appt.

Treat Chronic Infections

ANTIBIOTIC Regimens and Other Treatments based on Horowitz Protocol with some Dr. Christ thrown in (HERBAL REGIMENS AVAILABLE AND TO FOLLOW)

Sign informed consent for several of the treatment options (if *) and unless otherwise noted you continue the antibiotics prescribed 4-6 week minimum. At end of 4-6 weeks, you will need to assess if your symptoms improved, stayed the same or worsened over past 2 weeks. If improved you continue and every 2 weeks reassess. So again we don't worry if you get worse at first that is very common and considered a Herx reaction. But if after first two weeks, you will want to track your symptoms and I recommend tracking just 4 main symptoms. Fatigue, Pain, Brain fog and one other symptoms of your choice, typically your worst symptom other than the main 3.

To combat Borrelia we need to go after it in all its forms and if you follow Dr. Richard Horowitz's thinking you have to do them all at once but if you can't handle that.

For those that don't tolerate antibiotics or have gut issues and want to try a natural route I've highlighted the natural products. For the most up to date ideas for herbal healing of Lyme check out Stephen Harrod Buhner's books and website: <http://buhnerhealinglyme.com/>

CELL WALL FORMS

- Amoxicillin 875 mg 2-3 PO BID with Probenecid* BID with meals
- Augmentin 875 – 1000mg 1-2 PO q 12 hrs
- Ceftin 500 mg 1-2 BID (check peak and trough, 12-15)
- Cedax 400 mg 1-2 times a day
- Omnicef 300 mg 1-2 BID
- Suprax 400 mg 1-2 times a day
- IM Bicillin* 1.2 million units IM 2-4 times a week (some do once a week maintenance)
- IV Rocephin* 2 gm IV q 12-24 hrs pulsed 4-5 times a week or once daily 6 days a week; if have GB also take Actigall 300 mg BID to reduce risk of cholecystitis; also take Baby Asa and fish oil or Xarelto to reduce risk of phlebitis and liver support
- IV Claforan* 2 gm IV q 8-12 hrs
- IV Vancomycin* 1 to 1.25 gm q 12 hrs (anti-histamines pre-dose)
- IV Primaxin* 500 mg IV q 6 hrs
- IV Cleocin* 600 mg IV q 8 hrs or 900 mg IV q 12 hrs
- Resveratrol 40 mg by Source Naturals

CYSTIC FORMS

- Plaquenil 200 mg PO BID
- Grapefruit Seed Extract
- Flagyl* or Tinidazole (contains Flagyl + Tindamax)* dose based on body weight, if doing same time as macrolide take on opposite days:
 - o < 120 lbs 750 mg/day

- 121-150 lbs 1000 mg/day
- >150 lbs 1500 mg/day
- Need B vitamins and anti-yeast for sure
- Azithromycin (per Dr. Christ cyst buster also although not mentioned by Dr. Horowitz)

INTRACELLULAR FORMS

TETRACYCLINES

- Doxycycline* 100 mg 1-2 BID with meals
- Minocycline 50-100 mg BID
- Tetracycline 250-500 mg BID to QID

MACROLIDES (CHECK QTc)

- Azithromycin 250 BID or 500 daily with meals or 2 gm weekly
- Biaxin 250 mg BID or XL 500 mg once daily (children 500 BID)

QUINOLONES (CHECK QTc)

- Ciprofloxacin* 500 mg BID
- Levofloxacin* 500 mg daily
- Moxifloxacin* 400 mg daily
- Factiv 320 mg daily

Consider dosing just 5 days a week to decrease tendinosis plus B vitamins and curcumin to reduce tendinosis

OTHER

- Rifampin 150 to 300 mg BID with meals

If multiple intracellular infections (Borrelia, mycoplasma, chlamydia, Bartonella) do 2 above at a time

BIOFILMS

- **Serrapeptase** 1-2 per day watch in people with sensitivity to fermented products and can't take with Doxy
- **Nattokinase** 1-2 per day, still a product of fermentation but can take this one with Doxy
- **Lumbrokinase** 1-2 per day, an enzyme produced by earthworms so it has to be good!
- Tindamax
- Parazonium
- **Stevia leaf extract** by Nutramedix

Antibiotics, conventional or holistic, can only kill the bacteria when it is exposed. If Borrelia is concealed within a biofilm, antibiotics have no way of penetrating and become ineffective. In order for antibiotics to kill the bacteria that resides within a biofilm, it will require the assistance of a biofilm dissolver.

BARTONELLA (INTRACELLULAR ORGANISM) REGIMENS

- Plaquenil/Doxy/Rifampin/Nystatin
- Plaquenil/Doxy/Zmax/Nystatin

- Plaquenil/Doxy/Levaquin/Nystatin
- Plaquenil/Zmax/Septra
- Plaquenil/Zmax/Rifampin
- Plaquenil/Rifampin/Factive*
- Plaquenil/Rifampin/Factive*/Doxy or Minocin

BABESIA REGIMENS

- Malarone, loading dose is 4 tablets a day x 3, then one twice a day, some may need 2 BID
- Mepron 750 mg 1-2 tsp with high fat meals BID
- Larium* (can't mix with any of the QTc prolonging drugs)
- Artemesia one cap three times daily, if liposomal Artemesia twice a day
- Cryptolepis 1 tsp TID, if sensitive start with ½ tsp
- Neem
- Cleocin 300 mg 2 PO BID-TID/Quinine* 325 mg 2 PO TID
- Coartem*

ANTI-YEAST REGIMENS

- Nystatin 500,000 units 2 caps twice a day
- Diflucan 200 mg every 3rd day (*QTc prolonging)
- Oregano Oil
- Garlic
- GSE

ANTIVIRAL REGIMENS

- Acyclovir 200 mg 2 tabs 5 times a day for 10 days
- Valtrex 1 gram BID
- Famvir
- Valcyte

These can work well for acute viral infections that led to chronic fatigue such as HHV-6 (Pityriasis rosea). But usually immune support and NT factor supplement work better than anti-viral.

LABS WHILE ON ANTIBIOTICS

Oral only every 3-4 months

- CBC, CMP, CD57, thyroid panel, adrenal panel

IV antibiotics every 2-4 weeks

- CBC, CMP or Renal and Liver function panels, CD57
- Thyroid and adrenal every 3 months

BUHNER CORE PROTOCOL this is directly from his website buhnerhealinglyme.com

- Japanese knotweed (*Polygonum cuspidatum*) (Source Naturals Resveratrol with 500mg Polygonum cuspidatum per tablet) - 1-4 tablets 3-4x daily for 8-12 months:

- ☐ Cat's claw (*Uncaria tomentosa*) (Raintree) - 1-4 tablets 3-4x daily for 2-3 months, then 2-3 capsules 3x daily;
- ☐ Eleuthero (*Eleutherococcus senticosus*) (HerbPharm tincture) - 1/2 to 1 tsp upon rising and at lunch;
- ☐ Astragalus (*Astragalus membranaceus*) - 1,000mg daily (not to be used in chronic Lyme) so for most of us that's out.
- ☐ Stephen is now also recommending Ashwagandha (*withania*) to help remedy sleep problems at night and brain fog - 1000 mg at night just before bed. But I disagree I would take only 500 mg at a time otherwise you'll get GI upset and 500 mg is usually enough.

Buhner Co-infections Protocol

BABESIA

Stephen generally recommends the use of a • *Sida acuta*/*Cryptolepis*/ *Alchornea cordifolia* blend for the treatment of babesia these days: ¼-1/2 tsp 3x daily. You could as well do ¼ tsp of each of these three tinctures 3x daily. These three tinctures can be purchased from Woodland Essence. You can also use just one of those herbs; his first choice is *Sida acuta*, second is *Cryptolepis sanguinolenta*. Stephen no longer recommends artemisinin or artemisia for babesia infections. It *can* work, but whatever you are treating, *Sida acuta* will work better, especially for babesia or bartonella.

BARTONELLA

Research is ongoing, this is the most up-to-date protocol:

- ☐ *Sida acuta* tincture (from Woodland Essence or julie@gaianstudies.org) ¼ tsp 3x day for 30 days
- ☐ Hawthorn tincture, same
- ☐ Japanese knotweed, (tincture, same dose (from same sources as *Sida acuta*, above), or capsules from Green Dragon Botanicals 2 capsules 3x daily)
- ☐ EGCG 400mg +/- daily
- ☐ Houttuynia (Yu Xing Cao - 1st Chinese Herbs, powder - use "LYME" code at checkout for 10% off) 1 TBS daily
- ☐ L-arginine 5000 mg daily in divided doses
- ☐ Milk Thistle seed, standardized, 1200 mg daily
All for 30 days.
- ☐ PLEASE NOTE: If you have active herpes, chicken pox, or shingles DO NOT USE L-arginine.

We also recommend from Golden Flower Chinese Herbs a 5 mushroom blend that will boost your immune system and help the CD57 cells thrive and also other cell lines that fight cancer. Only doctors can purchase from this site so we have it on hand in office now 2 ounces for \$25.

Informed Consent about the above treatments

Before starting all these antibiotics it is very important to recognize that this approach is by no means widely agreed upon. In fact, treating MSIDS has been very controversial and even lead to physicians losing their license. It has only been through the outcry of patients and their advocates that some states have now passed laws that a physician can't lose their license for treating Lyme disease. That doesn't mean however, that everyone accepts it as a valid diagnosis and you will invariably encounter other health care professionals that will say that LLMDs are quacks and just trying to make money off of a group of patients that they feel are ill largely due to a psychiatric problem.

I will admit that I can't guarantee many patients that this will be the answer to their problems. But by the time they see me, they have often tried many other approaches and they simply know it's not all in

their head. I have been there and completely understand. I also have noticed throughout my training that the diseases that affect women more than men are often not taken as seriously or blamed on mental health. This type of treatment from physicians (and trust me it happens regardless of the physician gender) is just another indicator of everything that I see that is wrong with medicine and also strikes a personal chord with me. I have been to many doctors during college, medical school, residency and fellowship, and found that very few ever agreed with each other, they certainly didn't listen and the worst of all accused me of somehow bringing all of this on myself. That was unfortunately at a visit after an attempted sexual assault in a hallway. So I am as angry as anyone at how easily we are dismissed.

My practice style is "feminist medicine" but it applies regardless of gender. It simply means that I feel it is my duty to educate you as best as I can and as well as I understand it about whatever is ailing you for certain or just possibly and then help you make what feels like the right decision for yourself. I will try to always inform you of your risks and benefits. I will explain why I am recommending something. But you will always have the option to say "Yeah, sorry, but no thanks." You can also say yes to some and no to other parts. We are partners and we're in this together. I also recognized early on that I couldn't fix everything with a prescription, nor did I want to. I always felt and still do that if I could fix 3 or 4 simple things your health would improve dramatically. Those simple things are good quality sleep, better nutrition avoiding processed, overly refined foods, and eating whole foods, increased water consumption and regular exercise and sunshine. Yes I understand why you're scared to go outside but we can't let the ticks win!

So ever antibiotic or drug in prior list of regimens that had a star * after its name has special considerations as below as outlined in the "Informed Consent" that will accompany your instructions.

2. Immune system dysfunction

- Plaquenil along with killing Borrelia and Babesia also modulates the immune system. That's why it's also used to treat Rheumatoid Arthritis, an overactive immune response that then attacks self.
- Low Dose Naltrexone (LDN) dosed 1.5-4.5 mg usually at bedtime. At the normal dose of 50 mg it is used to reverse opiate overdose. But at this tiny dose it causes a very brief decline in our endorphins (our natural opiates) followed by a prolonged increase in endorphins. Endorphins have a powerful effect over the immune system. Studies are being done around the globe on LDN's usefulness in the treatment of HIV/AIDS, MS, Crohn's disease, Fibromyalgia, and hopefully it can help MSIDS. It's generally obtained from a compounding pharmacy.
- Herx Reduction: Alka Seltzer Gold 2 tabs daily plus 1500-2000 mg of Oral Liposomal Glutathione in addition to the LDN mentioned above.

3. Inflammation

Drugs	Herbals/Supplements
<input type="checkbox"/> Plaquenil	<input type="checkbox"/> Fish oil (EPA/DHA) or just DHA

<input type="checkbox"/> DMARDS <input type="checkbox"/> Macrolides <input type="checkbox"/> Tetracyclines <input type="checkbox"/> NSAIDS, Cox-2 inhibitors <input type="checkbox"/> IV immunoglobulin therapy for severe neuropathy <input type="checkbox"/> IV Glutathione	<input type="checkbox"/> LDN <input type="checkbox"/> Curcumin <input type="checkbox"/> Resveratrol <input type="checkbox"/> Green Tea Extract <input type="checkbox"/> Co Q-10 <input type="checkbox"/> B vitamins (1,2,6, 12 and bioactive folate) <input type="checkbox"/> Alpha lipoic acid <input type="checkbox"/> Magnesium glycinate <input type="checkbox"/> Zinc chelated <input type="checkbox"/> N-Acetyl Cysteine <input type="checkbox"/> Glycine <input type="checkbox"/> Oral Liposomal Glutathione
--	--

4. Environmental toxins

Check urine after DMSA for heavy metals. Often can't address until patient is off antibiotics. Also need to make sure not living in home or working in office with mold problem.

Drugs	Herbals/Supplements
<input type="checkbox"/> DMSA oral <input type="checkbox"/> DMPS ORAL <input type="checkbox"/> D-penicillin-amine <input type="checkbox"/> Transdermal chelation (children) <input type="checkbox"/> IV Chelation EDTA <input type="checkbox"/> EDTA suppositories	<input type="checkbox"/> Chorella <input type="checkbox"/> N-Acetyl Cysteine <input type="checkbox"/> Alpha lipoic acid <input type="checkbox"/> Xymogen for people with methylation issues <input type="checkbox"/> Minerals on non-chelating days necessary

LABS WHEN DOING CHELATION:

- Serum Mg⁺⁺, RBC Mg⁺⁺, Zinc, Copper, Iodine, Selenium (also same labs to check if patient complaining of muscle cramps)

5. Functional medicine abnormalities with nutritional deficiencies

TESTING MAY NEED:

- NutrEval or GI effects by Genova/Metametrix
- B12 panel (B12, Homocysteine, methylmalonic acid, intrinsic factor antibodies)
- Celiac test +/- HLA testing for susceptibility
- 23 and me and then run through Prometheus
- Apo E typing

6. Mitochondrial dysfunction

Commonly seen in patients with multiple chemical sensitivity syndrome. I developed this after moving to new office with new carpets, harsh cleaners used by housekeeping, and incredible stress associated with switching to the EMR. Also an issue in people exposed to mold.

TESTING MAY NEED:

- Quinolinic acid
- Mold neurotoxins (RealTime Labs)
- Home and office mold kits

TREATMENTS:

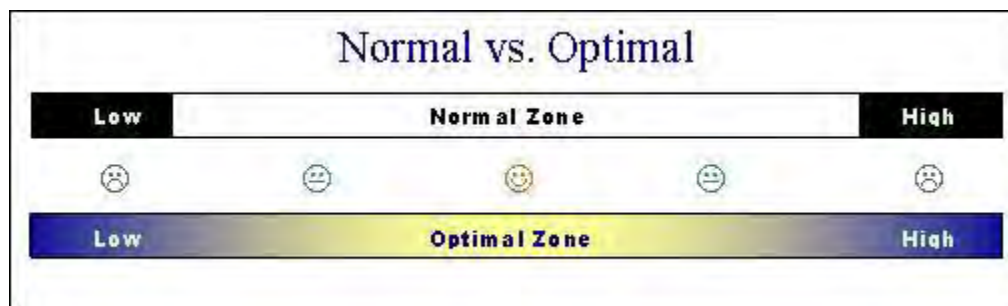
Drugs	Nutritional Supplements	Devices
<ul style="list-style-type: none"> <input type="checkbox"/> Questran <input type="checkbox"/> Wellchol 	<ul style="list-style-type: none"> <input type="checkbox"/> Bentonite Clay <input type="checkbox"/> Charcoal tabs <input type="checkbox"/> Zeolite <input type="checkbox"/> HD oral liposomal Glutathione <input type="checkbox"/> IV Glutathione <input type="checkbox"/> Cruciferous veggies or sulforaphane glucosinalate <input type="checkbox"/> Mg++, NAC, Glycine, ALA <input type="checkbox"/> DIM <input type="checkbox"/> Methylation cofactors <input type="checkbox"/> Phosphatidly choline <input type="checkbox"/> NT factor : B complex or breathe clear <input type="checkbox"/> L-carnitine if no thyroid problems <input type="checkbox"/> Co Q-10 when not on mepron or malarone 	<ul style="list-style-type: none"> <input type="checkbox"/> Infrared sauna <input type="checkbox"/> Regular sauna works too <input type="checkbox"/> Hyperbaric Oxygen chambers <input type="checkbox"/> Rife machine

7. Endocrine abnormalities

Hormonal health

I love hormones and have often said had I to do it all over again I would be an endocrinologist. Hopefully, one that was much more open minded then any of those in our area. So over the years I have treated people with hormonal imbalance more and more aggressively. I will detail some of my goals for optimal function here based on lab results but your history and other symptoms help me as well to target which areas. I also want to clarify, you may have had these tested before and you were told they

were all normal but were they optimal or were they normal for your age? Think of hormones as being Goldilocks, they can't be too high or too low they need to be just right. So just within the normal limits on a lab test may not be optimal and when you have these other issues you need all the help you can get.



Thyroid function

Based on our lab I look for the following ranges to be OPTIMAL:

TSH between 0.5 and 1.5 but for certain < 3.0

free T4 0.8-1.2

free T3 3.2-4.0

total T3 1.2-2.0

reverse T3 < 15

no thyroid antibodies (if you have them then we may have to use more thyroid hormone than most people need)

FT3/RT3 ratio > 20 and TT3/RT3 ratio of 8-10 is normal

Adrenal function

I will start with serum am cortisol, DHEA. I would expect the morning cortisol to be 15-20 and DHEA depends on age but 150-200 is about right for woman in 40's. If either is off then I would like to see a saliva adrenal stress profile. It measure 4 cortisol readings throughout day and DHEA. The correct values is complicated and depends on the curve and ratios so I can't explain that in depth easily here.

Gonadal function

For women that are not on birth control and not post-menopausal I would check the gonadal hormones day 19 of a 28 day cycle if they have any menstrual disorder. If they are on birth control those pills run the show for gonadal function. But testosterone is important too and depending on how its measured women should have level in 30-70 range. Men we are primarily interested in just testosterone levels and above 500 is necessary for them to have normal energy and muscle mass and sexual function.

Pancreatic function

The islet cells of the pancreas secrete hormones that affect our metabolic control of glucose. The three we understand the best now are Insulin, glucagon, and GLP-1. If you have high triglycerides (>150), reduced HDL (good cholesterol) < 40, waist > 35 inches for women and 40 inches for men, elevated blood pressure (>130/85) and elevated fasting insulin (>15) or glucose (>100) then you are developing insulin resistance or Metabolic syndrome. This eventually leads to diabetes but long before you have all the elements it can impair immune function, weight management and other systems.

Pituitary function

Your pituitary gland is not discussed very often but secretes hormones that control all the other glands. That is why it's called the "Master Gland". I used to test it routinely along with growth hormone in my patients with fatigue and/or fibromyalgia. I still do occasionally but I test it much less than before because even when I proved patients had low growth hormone there insurance would only cover treatment 1% of the time. So it was a tremendous amount of work for very little likelihood of being able to pursue that help if needed. However, if times change in that area I would do that again. I can tell from looking at other hormonal systems if there is reason to believe there may also be low functioning of the pituitary.

See the [Hormone Health Guide](#) for more information on this area.

TESTING MAY NEED:

- Thyroid tests: TSH, free T4, free T3, total T3, reverse T3, thyroid antibodies
- Adrenal tests: saliva stress profile (cortisol and DHEA 4 times through day) or serum am (before 8 am) cortisol and DHEA
- Gonadal tests: Estradiol, Progesterone#, Free and Total Testosterone, LH, FSH, DHT^, Sex hormone binding globulin^ (# women only, ^ men only)
- Other hormones: Fasting insulin, IGF-1
- Even more hormones: Leptin? MSH, ADH, VIP, vitamin D is technically a hormone!

8, Neurodegenerative disorders or CNS issues

Lyme can mimic MS so that always needs to be considered. However, it can often be ruled out by history of neurological symptoms and MRI of the brain. Both can have white spots of demyelination but they won't fit the MS pattern in Lyme. Peripheral neuropathies are also common in Lyme as well as muscle disorders and seizure disorders.

TESTING MAYBE NEEDED:

- MRI of brain
- Polysomnography +/- MSLT testing
- EMG/NCV
- Spinal tap if present with meningitis or encephalitis symptoms

- Muscle biopsy
- EEG

Neurological health is often tied to our nutritional health

The brain and peripheral nervous system is an area that we keep learning more and more about but so far to go. Our brain may be the most sensitive organ to good or bad nutrition. Our nerve function is definitely dependent on several nutrients and many of us are deficient in those. The key ones are Vitamin B12 (vegetarians and elderly especially), folate, B6, Magnesium, alpha lipoic acid, and healthy fats found in nuts, avocado, olive oil, and fish. Cruciferous vegetables have been also linked with less cognitive decline in older folks but also less breast cancer. So at a minimum I want to see normal Vitamin B12, folate, homocysteine, methylmalonic acid, and 25 OH Vitamin D levels. But I am exploring a new test called NutrEval that tests every single vitamin, mineral, antioxidant, health fat and metabolic pathway we have. We're still working out the details for that one. And I'll talk more about it in Nutrition. Lyme and FMS are both known to affect the nervous system so it's important that we do what we can to improve it.

9. Neuropsychiatric disorders/Trauma work

I'm amazed by the people who have never seen a counselor or therapist. I have seen many but three of them at different times of life were literally life savers so I worry more about the people that aren't seeing one than those that are. Many therapists employ various techniques to help with recovery from trauma, combatting negative self-talk and stress reduction techniques. In Peoria, I can vouch for the following people personally but they are by no means the only good ones.

Patricia Edwards, Antioch Group, 692-6622, very familiar with Lyme disease, also excellent for trauma work, techniques used EMDR, hypnosis

Brad Post, Chapin and Russell, 681-5850, helped me with assertiveness and is also focused on occupational health, or help when you have a hostile work environment.

Jeanna Fearon. Mindock Counseling, 402-0666, is an art therapist and makes counseling fun! Regardless of your art ability you can benefit from learning another form of self-expression without the pressure to talk at someone. I have found great therapeutic benefits from "doing art." I think it's also super helpful if you have a teen that won't talk or you spouse isn't open to therapy. It's a great way to get them into it without the pressure of talking to a counselor.

10. Sleep disorders

I truly believe that at least Fibromyalgia Syndrome is a sleep disorder. Yet so often we don't get sleep studies on patients with chronic fatigue and pain which doesn't make a lot of sense. I am guilty of not

doing this and it's been because in Peoria I haven't seen sleep doctors willing to address much more than sleep apnea. However, those that show any signs of Narcolepsy or Hyper somnolence could than qualify for a drug called Xyrem that "cured" Fibromyalgia in research studies. The frustrating issue, and part of the reason I then quit doing pharmaceutical research, was that the FDA wouldn't approve for FMS because it could be mixed with alcohol and used as a date rape drugs and because there is so many people with FMS relative to patients with Narcolepsy they feared allowing a wider distribution. Horse pucky I say! However, I also think that more people with FMS probably have verifiable sleep disorders than we previously thought so we should start checking. And if the sleep doctors won't prescribe Xyrem, I have no problem with it and just need the sleep study report showing either Narcolepsy or Hyper somnolence to get it covered. I would even prescribe it without the studies if patients could afford it but it costs \$3000 a month. Yup. That's correct. But if we can get insurance to cover the company that makes it is very generous with lowering the copay to \$35 as long as insurance covers some. So it's worth considering.

Testing Needed:

- Epworth Sleepiness Scale (these are just questionnaires that are in the appendix)
- Fatigue Severity Scale (see appendix)
- Polysomnography
- Multiple Sleep Latency Test

Sleep is in my mind one of the MOST important things a person can do to improve the function of their whole system especially immune system, adrenals, and mental health. We know now that most MSIDS/CFS/FMS patients either do not get enough deep sleep or enough deep or REM sleep. Both are important and recently gadgets have been widespread showing how long you sleep and what percentage of that time you were motionless. I think this is great idea for people that we have no reason to think they have an issue such as sleep apnea or restless legs. It can give you a clue as to whether or not you are getting the amount of sleep you think you are and how much of the time you are actually laying there resting. I thought I slept well and was shocked to find 22 times in a night I was restless. That's just not restorative sleep. Many drugs may interfere with our sleep and we all have changes in sleep patterns with age. So I'm really interested in seeing more sleep studies on people with these issues. I think we may be surprised by how many of us have a sleep disorder.



Sleep is also a behavior, however, and thus is trainable. In order to sleep well you have to also try to train or re-train yourself to sleep. Retraining means you have to make changes that are conducive to getting good rest and do them every single day. These methods are called sleep hygiene and a basic list follows this paragraph. Also the above is fairly inexpensive way to monitor your own sleep at home and

to see how often you get to bed at the same time every night. Yes you need to do that. We've focused a lot on REM but many with fibromyalgia are known to be lacking in that first stage of deep sleep that's typically 20 to 30 minutes in the first two hours of sleep.

Depending on the type of sleep disorder you have treatments fall into a couple categories as well as addressing sleep apnea issues:

Activating Agents

- Provigil or Nuvigil
- Adderall, Adderall XR, Vyvanse
- Ritalin, Focalin, Concerta
- Strattera
- Wellbutrin

Sleep Promoting Agents

- Trazodone
- Lyrical
- Seroquel, Risperidal
- Xyrem
- Ambien or Lunesta
- Amitriptyline
- Gabitril

Alternatives

- 5-HTP 100 mg at bedtime
- Melatonin 3-10 mg
- GABA
- SeriPhos (Phosphatidylserine) especially if cortisol elevated at night
- Valerian root 1,000 to 1500 mg
- L-Theanine

11. ANS dysfunction and POTS

This issue is characterized by low blood pressure and heart racing when going from sitting to standing and that last longer than the usual orthostatic hypotension. Anyone with blood pressure running typically 90/60 or less like myself can have dizziness and their vision fading when they stand up too fast or when stand up out of a hot bath. But if your heart races for the next 10-15 minutes you could have POTS or Postural Orthostatic Tachycardia Syndrome.

Testing to Prove POTS:

- Tilt-table testing

Treatment Options:

- 3 Liters of fluid daily
- 3-4 grams of Iodized Salt daily
- Drugs that may help
 - Florinef 0.1-0.2 mg/d

- Midodrine 2.5 mg TID up to 5-10 mg TID
- Cortef 5 mg daily especially if in phase III Adrenal fatigue
- Catapres 0.1 mg BID or TTS patches
- SSRIs such as Zoloft or Lexapro
- Beta blockers such as Toprol, Carvedilol or Bystolic

12. Allergies, food and environmental

13. Gastrointestinal disorders

14. Liver dysfunction

Chronic fatigue people and especially those that have documented herpetic family viruses often have elevated liver transaminases (SGOT and SGPT). The liver has a big burden to try and help us with detoxification and mutations in our detoxification pathways may also be a big contributor to CFS and chemical sensitivity syndrome. Also some of the antibiotics are hard on the liver and gallbladder like Rocephin.

Treatment:

- Actigall if on IV Rocephin lessens risk of cholecystitis (gallbladder failure)

Supplements:

- N-Acetyl Cysteine (NAC) 600 mg BID
- Milk Thistle PO BID
- Hepa #2 (Traditional Chinese Medicine) 2 BID
- Alpha Lipoic Acid 600 mg BID and Co Q-10 50-100 mg daily

15. Pain disorders and addiction

Consider alternatives to narcotic pain medications whenever possible:

Pain Medications

- Low dose tramadol
- Avoid narcotics long-term if possible
- Anti-inflammatory NSAIDs if can take
- Anti-epileptics
- Antidepressants with pain reducing properties

Alternatives

- Chiropractic
- Physical Therapy
- Specialized Manual Therapy such as Myofascial Release, Manual Lymph Drainage, Neuromuscular Technique, Cranio Sacral
- Essential Oils
- Arnica and other homeopathic treatments
- Topical Analgesics
- Acupuncture

16. Lack of exercise and deconditioning

I often tell people if I could wave a magic wand that would fix your sleep, help you eat more nutritious food, and help you exercise – we wouldn't need anything else and I believe it's true. But the key is you have to recognize your limits before you can move past them. I have had to surrender to the idea that I may not be able to train for an Ironman now or maybe never again but I can increase my exercise VERY SLOWLY and see where I end up. This was a very, very hard lesson for me. I enjoyed the push to be all you can be when it came to exercise. But in this case, I had to accept that the turtle will win the race when it comes to Lyme disease or Chronic Fatigue or Fibromyalgia. We have to guard ever so carefully from having a good day and over doing it. If we took it slow we'd have two good days then three good days then before you know it all good days. So you MUST get moving just a little more than you are now. Don't worry about how much just do a little more every day. Then if you feel bad back off some and start again.

You can also consider doing a F.M.S. evaluation with our physical therapist. But we are also trying to design an easier one for those that are totally deconditioned and I know that's many of us.

A successful exercise regimen EVENTUALLY includes the following:

STRETCHING

CARDIO

WEIGHT RESISTANCE

Yes you need all three. But start with gentle stretching and walking. If you can't walk on the ground try walking in a pool to reduce the impact on your joints. If it hurts to clean the whole house just do one room or even less. BUT do nothing and every day you will be able to do less until eventually you're a heap of flesh and bones and very little muscle and walking to the bathroom will wear you out. You don't want to end up there. It's almost an impossible place to return from. We also must stop the negative

talk and allow ourselves rest or day off when we need it. Do what you can and don't overdo it. It will take trial and error to figure out what that is and only you can figure that out.

Exercise Options:

STRETCH

- Yoga
- Tai Chi
- Chi Gong
- Any stretching program given you by physical medicine team
- Water aerobics
- Calisthenics include cardio and strengthening

CARDIO

- Walk
- Swim
- Walk a lazy river swimming pool
- Run
- Aerobics
- Dance, dance, dance (my favorite that I can do much longer than anything else)

STRENGTHEN

- Resistance Bands
- Little dumbbells and ankle weights (Strong Women, Stay Slim programs)
- Curves
- Nautilus
- Free Weights

I personally rather have pain and muscle soreness and be able to attribute it to the workout I did yesterday than this mysterious pain that comes from nowhere when I did nothing.

Nutrition and Supplements

Again I mentioned already the importance of certain nutrients for nerve function. What about our other systems? Basically everything will work better when our nutrition is good. Some common supplements that benefit both Lyme and Chronic Fatigue are as follows:

NT Factor

NT factor came out of research by Dr. Garth L. Nicolson. He spoke at the 2011 ILADS conference in Toronto and is a Nobel Prize nominated scientist, and President and Chief Scientific Officer of The Institute for Molecular Medicine. He actually was the co-developer of the cell mosaic model of cell membranes in 1972 with Singer. Basically what I'm trying to say is this guy is the real deal. He knows his cell membranes. He became interested in CFS when his wife had it and then his daughter had Gulf War Syndrome after serving there in the military. He feels that there is an infectious cause for most fatigue syndromes, Lyme included. His research has looked at Mycoplasma fermentans being a culprit but it is difficult to track down due to having been altered. His discovery pointed a finger at bioterrorism and led to his losing his tenure at the University he had worked at for years in Texas. (This guy's life is a clear example that conspiracy exists). But he continues to do amazing stuff and publish and he found that a formula of phospholipids (lipid replacement therapy) could restore mitochondrial membrane function and improve fatigue in the following areas;

- Cancer treatment (chemotherapy) associated fatigue
- Chronic Fatigue Syndrome
- Fibromyalgia
- Persian Gulf War Syndrome
- Lyme Disease
- Healthy Aging associated fatigue

From his newsletter: "In a study with severely chronic fatigued patients we found that fatigue was reduced approximately 40.5%, from severe to moderate or mild fatigue, after eight weeks of supplementation with NTFactor®.

In another recent study, moderately and mildly fatigued patients used NTFactor® for 8 or 12 weeks resulting in a 33% or 35.5% reduction in fatigue, respectively. In this clinical trial there was good correspondence between reductions in fatigue and gains in mitochondrial function. After only 8 weeks of NTFactor®, mitochondrial function was significantly improved and after 12 weeks supplementation, mitochondrial function was found to be similar to that of young healthy adults. The latest NTFactor® research indicated that NTFactor® in special formulations can significantly reduce fatigue and increase energy in as little as a week."

This link will take you to the trials done with different NT factor formulas. <http://www.ntfactor.com/clinical-trials/>

I have used it personally after 6 months of fatigue starting with a human herpesvirus-6 infection and woke up 10 days after it started feeling normal. Now I haven't been perfect every day since but that really gave me a big boost forward in returning to a level of function I hadn't had for 2-3 years.

Iodine

We need 150 mcg daily which is what's in 1 ½ tsp of iodized salt.

Magnesium

Magnesium is also recommended for thyroid production and anyone with muscle aches and pains or migraines. It's also good for constipation. Basically everyone probably needs more magnesium. We do a lot of promotion of calcium and ignore the rest of the minerals. But magnesium may be just as important for bone health as well. Calcium tends to be constipating. Magnesium loosens you up. So if you take them together in 2:1 ratio you should tolerate them well. I have also taken both in their citrate form and didn't have trouble with any change in bowel habits.

Adrenal Support Formulas

Most of us fighting Borrelia or fatigue or some horrible virus in the herpes family probably also have adrenal fatigue. Interestingly many of her herbs in the adrenal support formulas just so happen to be also helpful against Borrelia according to Brunner's Fighting Lyme Naturally book see the next list. But these are some of the typical ingredients in adrenal formulas

- Ashwaghandha
- Eleuthro
- Rhodiola
- Panax ginseng
- Skullcap
- Shizandra berry
- Licorice root

Buhner's Protocol

Fighting Lyme Naturally is very helpful although at times a difficult read. According to his website this is his most up to date recommendations. <http://buhnerhealinglyme.com/>

- Japanese knotweed (*Polygonum cuspidatum*) (Source Naturals Resveratrol with 500mg *Polygonum cuspidatum* per tablet) - 1-4 tablets 3-4x daily for 8-12 months;
- Cat's claw (*Uncaria tomentosa*) (Raintree) - 1-4 tablets 3-4x daily for 2-3 months, then 2-3 capsules 3x daily;
- Eleuthero (*Eleutherococcus senticosus*) (HerbPharm tincture) - 1/2 to 1 tsp upon rising and at lunch;
- Astragalus (*Astragalus membranaceus*) - 1,000mg daily (*not to be used in chronic Lyme*)
- Ashwagandha (*withania*) to help remedy sleep problems at night and brain fog - 1000 mg at night just before bed.

CO-INFECTIONS PROTOCOL

BABESIA

- *Sida acuta*/ *Cryptolepis*/ *Alchornea cordifolia* blend: ¼-1/2 tsp 3x daily. You could as well do ¼ tsp of each of these three tinctures 3x daily. (Woodland Essence) see also: Babesia

BARTONELLA

- *Sida acuta* tincture (from Woodland Essence or julie@gaianstudies.org) ¼ tsp 3x day for 30 days
- Hawthorn tincture, same

- Japanese knotweed, (tincture, same dose (from same sources as Sida acuta, above), or capsules from Green Dragon Botanicals 2 capsules 3x daily)
- EGCG 400mg +- daily
- Houttuynia (Yu Xing Cao – 1st Chinese Herbs, powder – use “LYME” code at checkout for 10% off) 1 tbl daily
- L-arginine 5000 mg daily in divided doses
- Milk Thistle seed, standardized, 1200 mg daily
 - All for 30 days.
- PLEASE NOTE: If you have active herpes, chicken pox, or shingles DO NOT USE L-arginine. see also: Bartonella

However, I must report before you run out and try to buy Buhner’s protocol I found many of them very hard to find. Even his website is often listing alternative sources for herbs and they are often only available in bulk or pricey. So if you want to go this route it might be worth working with a traditional Chinese herbalist as that’s where these came from. Then they could probably prepare your supplements for you.

Immune Support

For those that the CD57 report shows immune suppression, Dr. Burrascano recommends supplements that will boost your immune system.

- Reishi Max or some similar mushroom formula like Mushroom Max
- Transfer factor (don’t confuse with NT factor like I did this is different)

Multigenics Chewable (Multi-Vitamins) - I take Women's One A Day Gummy Vitamins

Zinc Food Complex - I have no idea what this is

Lumbrokinase (thick blood/biofilm buster) - I don't believe this is an issue for me

Novoxil - I have no idea what this is

Calm PRT - I have no idea what this is

Kavinace - I have no idea what this is

Teevance (neurotransmitter support by neuroscience) - not sure if this fits me

Burbur Detox - I have no idea what this is

Immuno PRP spray (immune booster) - not sure

Food enzymes before meals to help break down food - I think this is where the Domperidone fits in

Methyl B12 - I have no idea what this is

Transfer Factor Multi Immune - not sure

Ultimate Flora Probiotics - on gummy probiotics

Intestinal Smooth & Build - sounds like Miralax, but not sure

Curcumin (inflammation) - not sure

Inflaymar (inflammation & joint pain) - sounds like Lyrica, but not sure

A tablespoon of honey for immune system daily - could easily be added

A tablespoon of cinnamon for immune system daily - could easily be added

Kidney Maintenance - not sure

Lee Cowden's herbal protocol for Lyme & Babs & Bart



Also uses a Rife machine for treating Lyme & the co-infections - I know that these things are expensive and I highly doubt insurance covers any of it. Before I would even consider buying something like this, I would want to try it and see if it truly made a difference by blood work.

Side note:

For me I was always achy and if I did a lot of computer work my neck and shoulders tightened up since 1998. BUT I was very active and had my daughter at 38 years old. Her birth ended up being pretty traumatic but it all turned out ok in the end. I did lose a lot of blood and had 7 units of blood and ended up in the ICU to give you an idea. I still afterwards resumed my exercise routine and started doing triathlon. Three years later I even trained for and completed the Ironman. But something felt off that year. In the past with increasing mileage I usually lost more weight and became faster at the same time and yet that year I seemed to be increasing in endurance but not much else. I exercised 15 hours a week and while weight loss wasn't a goal it was expected and normal to lose some excess weight and yet my weight never varied more than 2 lbs. Then after the event some short time later I woke up missing the outer third of my eyebrows. I had already noted thinning hair at the temples but this really slapped me in the face because I recognized it immediately as Rinné sign and it happened overnight. I went to bed with full eyebrows and woke up without. I started on thyroid hormone and lost 10 lbs almost immediately and felt better again. But over the past 3 years I kept needing a higher and higher dose and even needing not just T4 (levothyroxine) but also T3 (liothyronine) as well. I learned later this is pretty typical see my Hormone Health guide section about thyroid issues.

I hear over and over from patients with FMS/CFS/LD that they rarely have a good day. Then when they do they are so excited that they try and do a bunch of stuff they're wiped out for days. How could I ever possibly get going with exercise if it always sets me back a week? So I started with gardening. When I started I still had some of the fitness of the ironman (although not what it should have been) and so I could dig all day. I would dig for 8 hours on the weekend double digging the garden that was 15x25 next to our garage. It was pure clay so I collected the leaves from my parents 4 trees across the street, our own from our neighbor's 4 surrounding trees and the neighbor even pitched in their leaves. I dug down one spade deep and then a second spade deep filled it with and turned it over. Well let me tell you next spring did it drain any no! Turns out to amend clay soil you have to replace 2/3's of it with perlite, peat, something else. Those leaves were a drop in the bucket. oh well. So next spring my husband built me raised bed. But I still double dug a second time under just the beds and then lasagna layered would not have to buy enough dirt to fill them. Meanwhile my husband to build a better fence. That was 2009. I'm finally having more energy So this wasn't a fast road.



leaves better sand, BUT so I began 2011.

What else did I do? I also addressed my mental health. I saw a counselor that was fantastic and helped me with post-traumatic stress disorder I had since college. It got revved up when a man broke in our house July 3, 2009 while we were

in bed asleep. Yowza. I had to take some serious medications to restore any semblance of sleep for a while including Seroquel an anti-psychotic of all things. So anyway I digress but it's to show you how far this road has taken me and how winding it has been. So as a natural part of growing this beautiful garden then came the realization great I can grow good food. BUT I'm too tired at the end of the day to cook most of it. So that is where the NT factor came in and I finally tested myself for Lyme. I have no idea where or when I could have been bitten by a tick. I lived in Wisconsin 1996-1998. I did the Ironman in Wisconsin 2008 and went up there for a week of training. But we were riding bikes over the hills around Madison not trekking through the woods so I have no idea. I only had one positive band on the western blot but my CD57 was 44.

Recently in search of more energy I decided to try vegan/vegetarian. Cutting out meat, almost all dairy, still eggs and tons of different vegetables. I finally thanks to NT factor and then adding doxycycline add enough energy to change my diet. This diet obviously required cooking everything and I was already pretty much gluten free since my mom had Celiac Sprue and I'm a chip off the old block. So I had to already feel better to eat better. And that's important to remember you won't be able to do everything you need to do at once but you can't ever stop trying. I especially feel this way about exercise. I really feel that I can beat this and the key will be exercise. The reason I went vegetarian was because I read stories of many athletes in their 40's having a return to great athleticism at an age when may feel as if their body has turned against them. I certainly felt that way. I trained much harder the three years for triathlon than ever before and yet never came close I felt to my level of fitness I achieved when I trained for just the marathon in 1995. Was this just age? I didn't think it should be that different. Besides back then all I ate was junk and I also worked 100 hours in residency. My life was much more balanced now. So Rich Roll's book "Finding Ultra" really inspired me that maybe veganism could restore my ability to recover. I ate that way pretty much from September 2012 until June 2013. And I must say I was doing slowly better and better. I also was taking doxycycline during that time. I stopped it in January for a month and my eye twitch came back so I restarted it. Then I stopped it in June. Then our stepson moved in and brought a whole lot of junk food back to the house so I fell off my healthy diet and within 3 weeks my back was locked up, my mood was bad, my allergies back, my eyes not focusing and well I was headed in the wrong direction again. So I'm obviously working to get back on it. And I'm trying to start a different antibiotic but not going so good either.

Informed Consent

For

Treatment of *Borrelia* and other Co-infections all under the diagnosis of Multi-System Infectious Disease Syndrome per Dr. Horowitz or Antibiotic Responsive Illnesses per Dr. Christ

I, _____ (patient name), have read this document and promise to re-read all the material I was given today. I understand that the treatment of MSIDS is controversial and there are many different protocols. I understand that every time I see a * after a treatment name on the order page that means there are special instructions or precautions to lessen my chance of side effects or adverse outcomes. Dr. Knight has circled the ones below that pertain to your current regimen and will do that every time it changes.

I also understand that it is typical to feel worse in the first two weeks before seeing any improvement and this is called a Jarisch-Herxheimer reaction. If it is severe I should call the office for further instructions and skip my next dose of antibiotics. I may need to start back on a lower dose and work up slowly however if it's a Herx reaction it will go away. If it's a true allergic reaction to the antibiotic or adverse reaction it will get worse. If I'm not sure where it falls I will call the office and may need to be seen right away. If ever I feel my throat is closing, increasing shortness of breath and/or hives that are spreading then I should seek emergency attention or administer an Epi-pen shot.

Once you are asymptomatic for two months and/or your CD57 count is over 126 for 2 months then you can go off antibiotics and switch to the herbal protocol or go off treatment. If you go on herbal protocol and no further relapses for 2 months then you can stop those as well.

In general, Dr. Knight prefers to start with oral medications but she has started IV treatment first when there is significant CNS symptoms or multiple erythema migrans (EM) rashes.

We test for *Borrelia* and other infections but often have to make the diagnosis on the clinical presentation and not the testing because of very low sensitivity and specificity of the current tests. Furthermore, people in the Midwest are often exposed to different strains than typical of the East Coast, Wisconsin and Michigan, so a negative test is not a guarantee of absence of Lyme disease. Lyme refers specifically to the strain of *Borrelia burgdorferi* found on the East Coast and Upper Midwest. We are often treating Master's Disease, a different *Borrelia* strain from a different tick here in Central and Lower Midwest. The same can be said for the co-infections. We also use IV/IM medications when a patient has exhausted all of the oral combinations.

Specific issues with specific antibiotics:

1. Bicillin IM can be very painful but effective. To reduce this use EMLA or Lidocaine cream/patch for one hour prior to the intramuscular injection. Warming the medication to body temperature also helps (carry in a pocket of a shirt or hold in your hands). An ice pack may also be applied 1-2 minutes before injection. Massage area right after and repeat several times for 2-3 minutes.

2. Rocephin IV can quickly turn a good gallbladder bad. To reduce this risk in those with normal gallbladder we add Actigall. If you may have had cholecystitis, we may need to check with a gallbladder sono prior to treatment the current status. Also using baby aspirin and omega-3-fatty acids (fish oil, DHA) can reduce risk of phlebitis. With any PICC line there is a risk of infections and phlebitis that increases the longer it is in so it requires weekly monitoring by a home health nurse. Liver support is a good idea on Rocephin or any IV/IM treatment. Labs also every 2 weeks.
3. IV Claforan can be used for those with gallbladder disease instead of Rocephin. However, it carries a risk of bone marrow suppression. So CBC and CMP needed at least every 2 weeks and possibly weekly if any suspicion of hematological abnormalities.
4. IV Vancomycin can cause "Red man syndrome" which isn't a true allergic reaction however, it can be prevented with anti-histamines. Either Benadryl 25-50 mg PO or IV before each dose or nonsedating antihistamines along with H2 blockers (cetirizine, loratadine or fexofenadine plus zantac, Pepcid).
5. IV Primaxin same labs as above rarely used because have to dose every 6 hours.
6. IV Cleocin is the last one commonly used but it is used the least because Cleocin has the highest propensity to leading to Clostridium dificil infections.
7. Plaquenil is contraindicated in people with psoriasis. It also requires if you take longer than 6 months that you get your eyes examined every 6 months while on it. You will need to bring proof of eye examination to the office in order to get refills.
8. Flagyl and Tindamax can cause an Antabuse type reaction if mixed with alcohol. So you must strictly avoid alcohol when on either of these. They also can make neuropathy and Candida worse so better to skip if either of those a serious problem. They also tend to have the severest Herx reactions so they may need to be pulsed (only take 3 days a week or two weeks on and two off). Using high doses of B vitamins (especially 6 and 12) can reduce risk of neuropathy and decrease the Herx reaction. Nystatin must be taken with them to avoid Candidiasis.
9. Tetracyclines increase photosensitivity so from April through October if you are on one of these, you will be more sensitive to the sun than usual. You want to use at least 45 SPF when outside, avoid direct sun (sun hat and long sleeves). You also must avoid dairy, calcium fortified foods and vitamins with minerals or minerals alone around the time you take them, so 1 hour before 2-3 hours after and don't lie down for an hour after taking to reduce esophagitis.
10. Macrolides can have similar GI effects as Tetracyclines with dairy and minerals. They also can prolong the QTc interval (heart rhythm issue) so we may need to check an ECG and you need to always make sure other doctors and your pharmacist know you are on these to avoid drug-drug interactions. Same goes for Quinolones, Diflucan and Larium; they all can prolong QTc and shouldn't be taken together or with other QTc prolonging drugs unless we monitor ECG to make sure it's not happening.
11. Quinolones can also cause tendinosis, most commonly of the Achilles tendon, with prolonged use. Taking them just 5 out of 7 days a week can reduce this as well as pushing the B vitamins and taking Curcumin.
12. Tetracyclines stain teeth in children so should not be used in children with a few exceptions and avoided if possibly pregnant. Treatment can and should continue during pregnancy so if you are trying to get pregnant let us know so we can adjust your treatment appropriately.
13. Rifampin also interacts with several other drugs on these lists and may require us to check blood levels of the other antibiotics.
14. Biofilms is a new area and there is not agreement on how important this additional treatment is but if you feel your benefits are waning it is probably worth adding one of those enzymes and seeing if you Herx and/or improve. There aren't any studies yet to back up this approach. Some of the antibiotics also break up biofilms. Regular dental care is important to reduce biofilms as well as addressing any other "chronic infections" such as

toenail fungus, jock itch, MRSA colonization, chronic or recurrent sinusitis, gingivitis, tooth decay, chronic prostatitis and persistent UTI's and vaginitis. So any other infections arising while on treatment or issues you had prior need to be dealt with.

15. Any yeast overgrowth or diarrhea needs to be addressed immediately. Anti-bacterials should be stopped. Anti-yeast and probiotics should be stepped up. If diarrhea > 2 days then testing for C. Dif toxin must be done. Call for further directions.
16. Avoid Co Q-10 while taking Malarone or Mepron as it interferes with their efficacy.
17. Cleocin and Quinine not used much anymore because Cleocin higher risk of Clostridium Difcil and Quinine poorly tolerated. Quinine can cause nausea, vomiting, tinnitus, and rashes in up to 50 percent of users.
18. Coartem and Larium can prolong QTc as already mentioned and Larium has possible neuropsychiatric side effects, such as seizures, hallucinations, psychosis, increased depression and paranoia, as well as frequently causing vivid dreams with occasional nausea and dizziness. So it's only used when all else fails. Larium also has very long half-life so only dosed weekly and still in system for up to 15 weeks after stopped.
19. Along with taking antifungals and probiotics, a diet that is low in concentrated sweets is essential to remain yeast free and often improves energy level. William Crook's book "The Yeast Connection" is a great resource for following an anti-yeast diet.
20. Other dietary concerns include Gluten sensitivity, Gluten intolerance, Carbohydrate intolerances and food allergies. These should also be addressed. A good book for doing your own detective work to figure out which foods are bothering you is to read Suzanne Blum's "The Immune System Recovery Plan" was very helpful for me and other patients.

The part that applies to your current regimen is circled above. Please initial the circled parts and sign below that you have read it and understand and have no further questions at this time. You can certainly ask right now if you have any or if later you have questions or concerns please don't hesitate to call or email us*.

_____	___/___/___
Patient	Date
_____	___/___/___
Doctor	Date
_____	___/___/___
Witness	Date

* Email is ok if it's not an emergency and works very well for our nurse Jessica. But neither, Ian or I can check our email when we're in and out of different rooms with patients so we're less reliable. I always see the email within a few days but it's just no guarantee if you need a faster response.

drknight@theknightcenter.com but you may also want to copy tridoc927@gmail.com because sometimes in the afternoon my email hangs up and won't let me send out or receive in. jessica@theknightcenter.com or ian@theknightcenter.com

THE EPWORTH SLEEPINESS SCALE

How likely are you to doze off or fall asleep in the following situations, in contrast to feeling just tired? This refers to your usual way of life in recent times. Even if you have not done some of these things recently try to work out how they would have affected you. Use the following scale to choose the most appropriate number for each situation:

0 = no chance of dozing
1 = slight chance of dozing
2 = moderate chance of dozing
3 = high chance of dozing

SITUATION	CHANCE OF DOZING
Sitting and reading	
Watching TV	
Sitting inactive in a public place (e.g. a theater or a meeting)	
As a passenger in a car for an hour without a break	
Lying down to rest in the afternoon when circumstances permit	
Sitting and talking to someone	
Sitting quietly after a lunch without alcohol	
In a car, while stopped for a few minutes in traffic	

To check your sleepiness score, total the points.

Appendix B

Fatigue Severity Scale (FSS) of Sleep Disorders

The Fatigue Severity Scale (FSS) is a method of evaluating the impact of fatigue on you. The FSS is a short questionnaire that requires you to rate your level of fatigue.

The FSS questionnaire contains nine statements that rate the severity of your fatigue symptoms. Read each statement and circle a number from 1 to 7, based on how accurately it reflects your condition during the past week and the extent to which you agree or disagree that the statement applies to you.

- A low value (e.g., 1) indicates strong disagreement with the statement, whereas a high value (e.g., 7) indicates strong agreement.

• It is important that you circle a number (1 to 7) for every question. FSS Questionnaire							
During the past week, I have found that:	Disagree <-----> Agree						
My motivation is lower when I am fatigued.	1	2	3	4	5	6	7
Exercise brings on my fatigue	1	2	3	4	5	6	7
I am easily fatigued.	1	2	3	4	5	6	7
Fatigue interferes with my physical functioning.	1	2	3	4	5	6	7
Fatigue causes frequent problems for me.	1	2	3	4	5	6	7
My fatigue prevents sustained physical functioning.	1	2	3	4	5	6	7
Fatigue interferes with carrying out certain duties and responsibilities.	1	2	3	4	5	6	7
Fatigue is among my three most disabling symptoms.	1	2	3	4	5	6	7
Fatigue interferes with my work, family, or social life.	1	2	3	4	5	6	7
	Total Score:						

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Scoring your results

Now that you have completed the questionnaire, it is time to score your results and evaluate your level of fatigue. It's simple: Add all the numbers you circled to get your total score.

The Fatigue Severity Scale Key

A total score of less than 36 suggests that you may not be suffering from fatigue.

A total score of 36 or more suggests that you may need further evaluation by a physician.

Appendix C