

Hope to Heal Lyme

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Conference Summary and Notes

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Observations

My general observations from this year's event:

- As always, Char Healy put on a great event. It was well-organized, the content was relevant, and the food was great. Even better, seeing old friends and fellow journeymen and journeywomen has become almost like going to a family reunion.
- Much of the content discussed was similar to previous years. I have seen little change in the past almost two years since I was diagnosed (July 2005). That said, I do think the next 12-18 months will be more significant in terms of the changes in how we diagnose and hopefully treat Lyme disease.
- The most notable take-away message from the conference for me was this: **Babesia and Bartonella are KEY components of chronic Lyme disease.** They are no longer just "co-infections". They may in fact both be much more significant in affecting our state of health than Borrelia has been.
- **Dr. Burrascano** and **Dr. Jemsek** both presented useful content and have both clearly done so much for all of us with Lyme. I also enjoyed having a few moments at breakfast to talk with Dr. Burrascano about some of his current projects.
- **Dr. Mark Garzon** did a fantastic job on the topics of heavy metals and hormones and their impact on those of us recovering from chronic illnesses. In fact, I was so impressed by the group of practitioners that Mark has assembled in the DC area, that I would personally be working with their practice if I were in the area. They have much to offer.
- One of the highlights for me of the event was a presentation by **Amy Derksen ND.** Amy has been one of my practitioners for about 18 months and has brought so much to my recovery. Often, conferences focus on antibiotic treatment of Lyme disease and I was concerned that a presentation on alternative and supportive options may not be well-received. Well, fortunately, I was wrong. People were incredibly open to the information that Dr. Derksen presented. Seeing this gave me hope that people will find their path and that there is a realization that antibiotics are not the entire solution.

Dr. Joseph J. Burrascano - Lyme Disease Diagnosis and Treatment

Dr. Burrascano started with a broad definition of Lyme disease. He described it as "the illness that results from the bite of an infected deer tick". Personally, I felt this definition was both broad and restrictive. I see it as broad given that it clearly suggests that there is much more than *Borrelia burgdorferi* that impacts us when we have chronic Lyme disease. It is restrictive however in that it is my opinion that means of transmission are much more broad than the bite of a deer tick.

Stages of Illness

Three stages of illness were discussed. Dr. B. noted that something happens to the body after about one year of illness and the immune system breaks down. He suggested the following three categories:

- Stage I – Early Lyme – the time before or when symptoms appear. At this stage, the disease can be entirely cured in many cases with appropriate early intervention. It is a mistake to wait for positive blood tests to start treating. By the time the tests turn positive several weeks after being infected, the disease is much more difficult to treat. On top of that, many people will never get a "positive" test result. It is important to be the most aggressive at this stage since this is the stage that may actually be curable. 4-6 weeks of antibiotics generally recommended. Shorter courses result in higher number of failures. Even at this stage, Lyme has spread to many areas of the body including the CNS.
- Stage II - Disseminated – many body systems are involved and the disease becomes more difficult to treat. May be present even if tests are negative. Dr. B. suggested looking for symptoms that move from place to place and vary over time. Treatment at this stage is generally several months or longer.
- Stage III – Chronic Lyme disease – this is defined as one or more years of infection resulting in the breakdown of the immune system. Dr. B. pointed out that this is the stage where serologic (blood) tests are the LEAST reliable given that most of them are looking for immune response to the antigen (infections) and most people in this stage do not have what it takes to mount any such response. At this stage, the treatment has to be aggressive and of long duration.

Testing

Only 17% of people recall a tick bite and only 36% of people develop a characteristic rash. Just over half (50-70%) of people will have a positive ELISA or Western Blot. Dr. B. does not even use the ELISA test. (Personal note: If a doctor suggested running the ELISA as a screening test for Lyme, I would turn and run for the door.)

Lyme has a 4 week regeneration cycle. If you have symptoms, you must be treated at least one month, if not longer, beyond the end of symptoms.

Tests miss 30-50% of cases of Lyme. The ELISA is false positive 5-10% of the time. CSF (spinal tap) is positive only 9% of the time and PCR generally positive 30% of the time or less and this requires being done many times. The Lyme urine antigen capture test has similar positivity rates to the PCR. None of these are good tests.

In terms of symptoms, onset is often gradual starting with fatigue, stiff neck, aches and pains, and headaches. May observe joint pain or arthritic symptoms. The nerves and brain later become involved.

CD57 – lower counts are often observed in people that have been ill longer than one year. The test can reflect the severity of illness. It may be a helpful screening test. It is a good predictor of relapse at cessation of treatment. The following ranges are suggested:

<20 severe
20-60 most common in chronic Lyme disease
> 60 Lyme activity minimal
> 120 Relapse not likely when treatment ends

Dr. B. suggested that testing CD57 about every 3-6 months is appropriate. He noted that it often jumps towards the end of treatment and that it is not a linear improvement in all cases.

(Personal Note: I have found this test to be very useful and it has tracked well with my recovery. I did not do the test at my sickest as I was unaware of it at that time. However, after several months of treatment, my CD57 was 65. It later went to 84. Later to about 130 and most recently to ~160. My personal desire is to see it over 200 before stopping treatment but based on Dr. B's comments, ~160 suggests that stopping antibiotics may soon become a reality!).

Diagnosis

Dr. B. discussed a point system that he devised that can be helpful in determining whether or not someone has Lyme disease. The point system is discussed in his published protocol which is available [here](#).

He pointed out what should be common knowledge by now but sadly is not in the minds of many doctors – that is that Lyme is a CLINICAL diagnosis. The best tests available only help to support a diagnosis. All tests can be negative and Lyme may still be present.

Treatment

For disseminated Lyme, treatment should be continued for at least six weeks beyond resolution of symptoms. Combination therapy is often required. Sicker patients often require 6-12 weeks of IV followed by oral or injectable antibiotics.

Chronic Lyme is much more complex. It is often the stage that is the most difficult to diagnose. The range of presentation of illness is large; from subclinical to debilitating. The infection is very difficult to treat at this stage and may not be curable.

Why are chronic Lyme patients more ill? There are often higher spirochete loads observed as either a result of having been infected longer or as a result of multiple exposures. Borrelia finds compartments in the body where immune surveillance is limited and essentially evades our immune system. Our immune systems become suppressed and numerous other co-infections take up residence.

Many other conditions are often observed in people with chronic Lyme disease. These include:

- Encephalitis – can be observed on scans such as PET and SPECT. Areas of decreased blood flow are present. The scans are not diagnostic but can support that disease is not psychosomatic. Scans can be done over time to show progress.
- Neurotoxins – Borrelia produces neurotoxins. These cause further dysfunction in our nervous systems and increase cytokines which increase inflammation. Neurotoxins can impact hormone receptors. Testing for neurotoxins is done using the VCS (Personal note: I wrote about this test in the Public Health Alert. A link is available on the “My Articles” page on my site.) Cytokine levels can be measured. Tests for insulin resistance are useful. Treatment is with “bile acid sequestrants” such as

cholestyramine. (Personal note: I wrote about the Biotoxin Pathway in a recent edition of the Public Health Alert. That article is also available [here](#)). Hormones find binding sites. These binding sites / receptors are often blocked by toxins. Hormone levels in the blood may look adequate but if the receptors are blocked by neurotoxins, problems result.

- Heavy metals – presence increases symptoms especially neurological. Weakens immune system and results in more severe illness. Metals prevent recovery. Should always be suspected in patients with increased neurological symptoms are patients that are slow to respond to treatments. (Personal note: I think heavy metals are a much more significant issue than most people recognize. Treatment protocols that do not address the presence of metals are often ineffective.) Heavy metals poison our immune system and damage our nervous systems. Over 90% of people that do not respond to treatment have a heavy metal issue.
- Hormonal issues – lack of energy and stamina, loss of libido, exercise intolerance, weight gain, hypersensitive to surroundings/environment
- Neurally mediated hypotension – dehydration, adrenal/pituitary insufficiency. Profound fatigue and often need to lie down. Diagnosed with tilt table test and hormone evaluation.

Approach to Treatment

Must achieve therapeutic levels in the blood. It is critical to measure peak and trough levels. Peak levels should be measured about 1 hour after having taken antibiotics and trough levels 1 hour before next dose.

It is important for the antibiotics chosen to be effective for both extracellular and intracellular infection. This is why it is important to consider combination therapies. Borrelia can survive in both inside and outside of the cells. They must further work on both bodily fluids and in tissues as Borrelia lives in both.

Types of Antibiotics

- Cell-wall agents – must sustain high levels for 72 hours to be effective.
- Doxycycline and macrolides such as Biaxin and Zithromax – Need a spike in blood levels. Taking at one time during the day is better than taking throughout the day. IV is better here to obtain a spike.
- Metronidazole requires sustained level for at least 2 weeks.

Forms of Borrelia

- Spirochete – has a cell wall. Penicillins, cephalosporins, Primaxin, Vancomycin
- L-Forms – has no cell wall. Tetracyclines and Erythromycins.
- Cyst – protected form. Difficult to kill. Use Flagyl, Tinidazole, and possibly Rifampin,

Designing Effective Treatment

Combine antibiotics to target intracellular and extracellular, body fluids and tissues, all three known forms (spirochete, L-form, cyst).

Mechanism of Administration

Oral antibiotics provide slight benefit. IM antibiotics such as Bicillin-LA are more effective than orals. IV is the most effective.

IV is appropriate when: abnormal spinal fluid, synovitis, illness longer than one year, over 60, acute illness in first trimester, acute carditis, other immune deficiency, prior use of steroids, or when other treatments fail.

Typical Regimens

- Oral – Cefuroxime + Biaxin OR Augmentin XR + Ketek
- IM – Bicillin LA + Biaxin
- IV – Rocephin + Ketek OR Vancomycin + Biaxin
- Flagyl can be added to any of the above and is often pulsed.

Treatment Issues

Infection often persists despite treatment. Relapses do occur. Additional treatment is sometimes required. Prolonged treatment is usually required.

Supportive therapies are important. One must look at heavy metals, neurotoxins, hormonal issues.

Blood levels of antibiotics should be confirmed.

May need to rotate regimens though generally suggests to stick with one treatment approach for at least 3 months.

The speed of recovery is tied to the cycle of Borrelia. Stronger drugs do not shorten the treatment time required. Find a program that works and stick to it. Change only when a plateau is reached and symptoms are still present.

Do not cut down doses. When it is time to stop, stop. Cutting down doses may lead to treatment resistance.

Exercise is a MUST. We will not get well without exercise. A light weight or stretch program is suggested. As tolerated, increase. Not exercising reduces chances of recovery and increases chances of relapse. Aerobic exercise may reduce T-cell count more than weight training.

If CD57 not in a reasonable range, cessation of treatment likely will lead to relapse.

Maintenance therapy may be required as the infection is often not cured entirely.

Some signs of continued infection include fevers, synovitis, four-week cycle of symptoms, migrating symptoms, PCR positive results, low CD57.

Co-infections

Bartonella

If there was one message that I took away from this conference it was that Bartonella and Babesia are a MUCH larger part of the problem than we likely ever suspected in the past. I think this will be the big news of the next 12-18 months. (Personal note: Dr. James Schaller has already released a book on Babesia and his upcoming book on Bartonella is likely to change how we think about Lyme disease. It is my current opinion that the co-infection testing from Fry Labs is likely the best available and is appropriate to have performed.)

Co-infections are nearly universal. Symptoms become more vague and overlapping. Tests become less reliable. Patients with co-infections are more ill and more difficult to treat. Standard Lyme treatments does not begin to treat Bartonella, Babesia, viruses, etc. Specific treatments much be used for each of these. Co-infections may be the cause of what is often perceived as treatment-resistant Lyme.

The primary co-infections observed are Bartonella, Babesia, Ehrlichia, Mycoplasma, viruses, and a host of yet to be identified microbes. (Personal note: viruses, and a host of yet to be identified microbes.)

Nematodes have even been found in ticks. What are nematodes? (WORMS!).

Dr. B. refers to Bartonella as BLO or Bartonella-like organisms. He was clear in that **BARTONELLA IS MORE PREVALENT IN TICKS THAN BORRELIA**. He noted that clinically, these appear to be different than the Bartonella that causes Cat Scratch Disease and suggested that they may be Tularemia.

Sadly, testing for Bartonella is also quite poor. Up to 80% of clinically defined cases are missed with blood and PCR tests.

When nervous system / CNS symptoms are out of proportion with the rest of the symptoms, consider Bartonella.

Encephalitis, irritability, anxiety. Insomnia, seizures, gastritis, rashes, tender skin nodules, sore soles of feet, AM fevers, and light night sweats are observed with Bartonella. Nodules on the outside of the thigh or under the arms are often observed,

Treatment of BLO is:

- Levaquin is the drug of choice. 500mg daily with proton pump inhibitor. Tendon damage primary side effect.
- Cell-wall drugs used for Lyme are ineffective though may be synergistic with Levaquin. Remember bartonella is usually intracellular and cell-wall drugs do not reach the intracellular spaces.
- Erythromycins are totally ineffective. These may even inhibit the Levaquin therapy. Biaxin and Zithromax also ineffective.
- Rifampin and Flagyl may be alternative treatments.
- Response to doxycyclines are varied but generally poor.
- Combination therapies may be required.
- Treatment should last 1-3 (or more) months

Babesia

Babesia species are incredibly common and not to be overlooked. Many different species exist – at least 27. There are only tests available for two (Babesia microti and Babesia WA-1 which was recently renamed to Babesia duncani).

The WA-1 strain is more difficult to treat than the microti strain.

Tests are again insensitive and often miss the presence of these organisms.

Babesia, like Borrelia, is immunosuppressive. It renders Lyme more damaging and more difficult to treat.

Blood smears looking for Babesia are generally useful only for acute Babesia infection. In acute infection, 30% of cells may be infected. In chronic, it may be ½ to 1 percent.

Acute infection – abrupt onset, mild to severe, can be fatal.
Chronic infection – symptoms blend with Lyme and are often missed.

Symptoms of acute infection – sweats, high fever, chills, headaches, dark urine, anemia, severe illness.

Serologic tests generally convert within one week but are not always reliable.

Symptoms of chronic infection – marked night sweats which cycle every few days, air hunger, cough, persistent headaches, fatigue, off-balance.

Treatment of Babesia is:

- Babesia is a parasite and thus not treated with antibiotics.
- Babesia can be treated while on antibiotics and other Lyme treatments.
- Clindamycin and quinine are rarely used.
- Mepron 5cc twice daily plus Zithromax 600mg daily for 4-6 months.
- Do not take doxycycline while on Mepron as it lowers effectiveness.
- Malarone – six tablets daily
- Can add Bactrim DS – 2-4 daily.
- Can add metronidazole (Flagyl) 750-1500 mg daily.
- Artemisinin may be helpful but do not take with CoQ-10.

Ehrlichia

Ehrlichia is less common than the other tick-borne infections (Personal note: Aren't I lucky? I got this one too! ☺). As with the others, there are chronic and acute forms of the illness.

Acute generally starts with high fever, muscle pain, headache, low white blood cell (WBC) counts, and elevated liver enzymes.

The chronic form most commonly presents with headaches, muscle soreness.

Can be tested with serological tests, PCR, or smear.

Is generally treated with doxycycline or fluoroquinolones such as Levaquin, or Rifampin for 2-4 weeks.

Rocky Mountain Spotted Fever

From dog tick. Quick onset. Generally has a rash with large spots including the hands and feet. Headache, fever, and body pains. Low WBC, elevated liver enzymes. Can result in death. Responds to doxycycline. (Personal note: I have seen people with RMSF positive tests with no rash presentation.)

Mycoplasma

Mycoplasma becomes a significant issue when the immune system is down from other infections such as Lyme.

Dr. B. suggested that as he looked back through old patient charts, those people that never really got well all had mycoplasma infections.

Antibody tests will often be positive as most people have been exposed at some point in life. PCR is generally the preferred testing approach.

Known as the "Chronic Fatigue" germ or as the causative agent in Gulf War Syndrome.

Generally treated with Doxycycline and fluoroquinolone often with Plaquenil. May need to be treated for months to years.

Cast of Characters Summary

Lyme is a multi-system infection that generally has 4 week cycles. Afternoon fevers are sometimes observed. Illness onset is gradual.

Bartonella is likely when CNS symptoms are out of proportion with remainder of the body. Gastrointestinal issues. Sore soles. Nodules under the skin. Morning fevers. Gradual onset.

Babesia – sweats, fatigue, headaches, air hunger, cough, hypercoagulation, rapid onset, cycles every few days, leads to very severe Lyme symptoms.

Ehrlichia – knife-like headaches, muscle pain, low WBC, elevated liver enzymes, rapid onset.

Treatment With Co-infections

<i>Lyme</i>	<i>Bartonella</i>	<i>Ehrlichia</i>	<i>Babesia</i>
Amoxicillin	Fluoroquinolone	Fluoroquinolone	
Doxycycline		Doxycycline	
Cephalosporin	Cephalosporin		
Macrolide			Macrolide / Mepron
	Rifampin	Rifampin	

Beyond Antibiotics

- Rest must be enforced
- No caffeine
- No alcohol
- No smoking
- High protein, low carb diet
- Vitamins and nutritional support
- Drink plenty of water
- Exercise a MUST
- Never use steroids

Living with Lyme

People DO get better. Do not get discouraged. The first step is to investigate co-infections and associated conditions. It is important not to have “Lyme blinders”.

Network with others in the community to find and see good Lyme doctors.

Keep copies of all test results.

Keep daily diaries and lists of symptoms. Important clues might be later uncovered. (Personal note: Of all the things I did NOT do well, it was keeping a diary and list of symptoms on a regular basis. There have been times that I asked myself “What was I doing 7 months ago

when I felt better or worse than I do now?" and wished I had done this. I suggest doing it.)

For your doctor visit: bring a summary of your condition and any changes, a COMPLETE list of medications and ANY supplements, a list of important questions.

Maximize your chances of recovery: The 1st, 2nd, and 3rd items on this list was COMPLIANCE. Others included medications even if you need to set a clock, vitamins and supplements, exercise, rest, diet and NO alcohol.

Lose the "poor me" attitude. Dr. B. suggested that he can predict those that will recover from their first visit based solely on their attitude. Lose anger towards others. Pursue other interests. Don't become Lyme-obsessed. Enjoy friends and family. Laugh.

Other Notes

The sicker the patient, the less reliable the blood tests.

Main cause of death from Lyme is suicide. (Personal Note: A later presenter pointed out though that suicide also prevents us from recovering from Lyme!).

Steroids should NOT be used. The one exception is if adrenal insufficiency exists, Cortef or other LOW dose steroids may be appropriate to stimulate the adrenals. At these LOW doses, these may support, not diminish, immune function.

For Bicillin-LA, 1.2 million units is about 1000mg. 3-4 shots a week are needed + Probenecid to boost the effect of treatment. There was a study done in Switzerland of 112 patients. The general conclusion was that to get better, at least 1-2 courses of IV were required.

Willy Burgdorfer found nematodes (worms) in ticks.

There is more to the treatment of Lyme than just antibiotics.

Hypercoagulation is not uncommon and is suggested to be related to Babesia.

Alcohol makes Lyme germs more aggressive. Lyme cannot live in an oxygen environment. Smoking reduces oxygen by 10-15%.

Interstitial cystitis – often sees *Borrelia* and *Babesia* in bladder. Ketek often gets there.

Cervical secretions, breast milk, semen etc. – why not looking at these as a diagnostic test? Can do with PCR.

Question from audience - Can you get Lyme from breast feeding since deer hunters eat raw meat and don't seem to get it? Adult digestive tracts may be better able to defend against oral introduction than infants. We believe that transmission via breast milk occurs.

2 doses of Rocephin 4 days a week results in a better outcome than 1 dose 7 days a week.

Lyme suppresses B, T, and NK cells. B suppression results in low Gamma-globulin. If you have low GG, IV GG often helps. GG is a good anti-inflammatory and also heals nervous system damage.

There was some brief discussion about Vitamin D levels being low in people with Lyme. Dr. B. responded that it is the chicken and egg problem. Does one have Vitamin D deficiency which resulted in immune suppression and made it easier to get Lyme or does Lyme itself cause vitamin D levels to decline?

Question from audience – Is there any proven treatment other than antibiotics for those that cannot tolerate them? Dr. B. explained that illness is a balance. We either have to lower germ load or raise our immune system. If you cannot tolerate antibiotics, then you must focus on building the immune system.

Hyperbaric Oxygen (HBOT) + antibiotics results in a better outcome than either alone, BUT it does not address the co-infections well.

Dr. B. talked about his latest project which is the "Lyme and Associated Diseases Registry™". This is a multi-page form that the doctor and patient fill out and then send in. The form asks about symptoms, test results, medications, etc. and then uses a complex computer program to look for trends. Over time, it should help to standardize and optimize treatment for the benefit of patients.

Dr. Kenneth Singleton – Lyme Disease Testing Principles

Dr. Ken Singleton is coming out with a new book on Lyme in October. His web site is www.LymeDoctor.com.

The presentation given by Dr. Singleton was on Lyme Disease testing and focused on defining false negatives and false positives. It discussed the various types of testing available though provided little new information. I am anxious and hopeful that new information will be available in the to-be-released book.

He started with a parable. Essentially it was:

- People in a land were happy
- People got a mysterious illness
- Nothing worked
- Experts tried to study the problem
- Result was the finding that all areas with sickness had cats
- It was believed that cats caused the illness
- All the cats were killed
- People were happy
- The problem got worse
- The cats were not the problem, they were part of the solution
- Cats were the natural enemy of the real problem
- The real problem was rats and fleas

This parable was the true story of the Bubonic Plague. The moral of the story was that bad assumptions lead to bad conclusions which lead to bad actions and policies which lead to human suffering.

After this introduction, the connection was that after 25 years, we still rely on inaccurate blood tests for Lyme. Conventional medical understanding of Lyme is truly medieval.

Doctors generally order an ELISA as a screening test. ELISA stands for Enzyme-Linked Immunosorbent Assay. Blood is placed in a test tube that contains Lyme antigens. If Lyme antibodies are present in the blood, they will stick to the bottom and can be detected via a color test. The test is cheap and has many false positives and negatives.

If the ELISA is positive, a Western Blot is performed. If not, the patient is assumed to be uninfected.

Western Blot is a much more accurate test. It is the most reliable indicator. It looks for specific antibodies (IgG and IgM) to Lyme. It uses a process where the test is evaluated on a specific strip which allows for identification of specific positive or negative bands.

Dr. Singleton suggested that IgM is an early and powerful antibody made by the body against Lyme. He also suggested that it persists in the body until Lyme is under control and generally indicates Lyme activity.

He stated that band 41 + at least one of: 31, 34, 23-25, 39, 83, or 93 are required. The Lymerix vaccine elevates 31 and 34 and thus one may need to know whether or not the patient had the vaccine in order to correctly evaluate the test. Sadly, many WB tests ignore these important bands entirely.

IgG is a later antibody manufactured for future protection against Lyme. May or may not be present with active Lyme. It is a reliable indicator of exposure. Important bands are 18, 23-25, 28, 30, 31, 34, 37, 39, 41, 45, 58, 66, 83, and 93. Lymerix elevates 31 and 34 here also.

Around the discussion of IgM vs. IgG, Dr. Singleton later sent me additional information to further help explain his views and to clarify the general principles of IgM and IgG as compared to the patterns observed around Lyme specifically.

First of all, the comments about immunoglobulins were in the context of my discussion of test accuracy - that is, false positive and false negative test results. I often spend a lot of time in the office explaining why a person tested "negative" in their doctor's office and positive with me. Therefore, I felt it important to help the average patient (many of which don't have much knowledge of the basics) understand the general principles behind testing.

With that as a goal, the discussion of IgM and IgG were broad and general principles, not Lyme-specific principles. As you are well aware, Lyme patients can have any (or no) combination of IgM or IgG at virtually any stage of their disease for a number of reasons, primarily related to the fact that Lyme is such as stealth organism and the individual's immune response may or may not be typical for many reasons.

In the book I go into a lot more detail in terms of application directly to Lyme. But for the record and related to your commentary, here is what I know after over 1200 Lyme patients, numerous ILADS conferences, numerous discussions with Dr. Nick Harris and other ILADS colleagues (including Dr. B and Dr. Ken Liegner), and numerous articles in preparation to write the book:

IgM - is large and powerful (particularly as a participant in, and probably inducer of, the inflammatory process), but is not as specific (not as "tailor-made" as the IgG) and much too big to penetrate into many body tissues. According to Dr. Harris, while we all know that it may or may not be positive at any time in Lyme infection, it generally is a marker for Lyme activity. (And, according to Harris, when positive on initial evaluation and combined with the LDA, is nearly 95% sensitive for detecting active Lyme.) Everyone (even the IDSA group) would agree that some bands (such as 34 and possibly 31) tend to be positive in later untreated Lyme. With treatment, the IgM levels may go up, down, or stay the same. Therefore it is not a good "staging marker" in Lyme (which is the reason that many of us use it for initial diagnosis but don't find it useful to follow serially in chronic LD). But again, in terms of general immunology principles, I think it was important that the average listener know, in the context of my discussion, that generally IgM is the "early antibody" that is involved in acute inflammation.

IgG - is smaller and much more specific for the particular strain involved. It may be positive early or late, and does in fact indicate exposure and not necessarily activity. (Activity is based on clinical findings and not laboratory findings, although CD57 may be somewhat useful in many, but not all, cases.) While the goal of "immunity from future infection" is to have specific IgG antibodies against the invading organism, the variety of strains (combined with Lyme's sneakiness in hiding from the immune system) makes immunity very unlikely. However, everyone agrees (as you well stated) that IgG is an accurate marker for Lyme exposure but not necessarily Lyme immunity.

What are the problems with the Western Blot?

1. The test is often done too early before antibodies are present. It may take six weeks for antibodies to be produced after infection.
2. The patient may have a strain not being tested for by the lab.
3. The lab may have made an error
4. Antibodies are not available because they are all bound up with Lyme organisms as immune complexes.

5. Immune system is too weak to produce antibodies.
6. Antibiotic therapy reduced the number of antibodies.
7. Lyme has changed forms making it less detectable.
8. Lyme finds a way to hide out from the immune system.
9. The test was not designed for diagnosis, but for surveillance. The test is not being used for its original purpose.

Defining terms relevant to testing:

Sensitivity – ability of a test to correctly identify a person with a disease (a 100% sensitive test means no one is missed by the test or there are no false negatives).

Specificity – ability to correctly identify a person not having a disease as not having the disease (a 100% specific test means no one is falsely labeled as having the disease or there are no false positives).

He then went on to explain true positives, true negatives, false positives, false negatives.

He suggests that if you apply the two-tiered (ELISA + WB) approach to testing in a group of people unlikely to have the disease, it grades out well. If you apply to a group that is a higher risk, the performance of this system is “utterly abysmal”. He suggests that this two-tiered approach will miss Lyme in about 40% of cases.

Screen high risk groups with a sensitive Western Blot which includes bands 31, 34, and 83. IGeneX or MDL were the two labs that Dr. Singleton suggested. He noted that Stonybrook Lab will report band 31 and 34 IF the doctor specifically requests. He noted that MDL testing is generally covered better by insurance and also stated that MDL returns an image of the test strip with the bands for review.

Lyme PCR is specific but not sensitive. If positive, it is unlikely to be a false positive.

Immunosciences Multi-peptide ELISA is another option. This also picks up the European strains of Lyme.

When asked about the Bowen test, he stated that it was not specific and that it likely picked up dental spirochetes which many people routinely carry.

Hope to Heal Lyme 2007

Dr. Singleton and his wife Ursuline then gave a presentation on the Lyme diet that they support. I have not attempted to discuss the specifics of the proposed diet here.

Dr. Steven Bock: Road Map for Chronic Lyme Disease

Chronic Lyme Disease Complex is a multi-faceted disease caused by one or more infections that effect immune, endocrine, vascular, and neurological systems. Causes multiple dysfunctions of various organs and results in chronic symptoms including chronic fatigue, fibromyalgia, autoimmune disease, and psychoneuroendocrine immune and energetic dysfunction.

Health is a process. Roadblocks are opportunities for discoveries. Patients lead the way. Trust the process.

Dr. Bock talked about Preconceptions as roadblocks such as personal beliefs, physician education and willingness to work on a team. Specialists can be too narrow.

He reviewed a handful of case studies.

In talking about Lyme, he stated that each case is different. < 30-50% have a rash. <30-50% ever see a bite. Can impact cardiac system, GI, lungs, sinus, skin, eyes, joints.

Chronic Lyme may be undertreated. Diagnosis is often delayed. Often see false negative blood tests. Clinical diagnosis. My personal favorite: Absence of proof is not proof of absence.

Manifestations and Symptoms

Chronic manifestations of Lyme include: nervous system, cardiac, eye, fatigue, cognitive issues, autoimmune disease, sleep issues, depression, headaches, pain and arthritis, sinus issues, fibromyalgia, immune manifestations, neck stiffness, numbness, tingling, dizziness.

Pediatric Lyme - < 30% saw a tick. 20-30% have a rash. Trust mom's intuition. Increase fatigue, decreased energy, sleep disturbance, joint pain, headaches, cognitive issues, memory loss, lower performance at school, outbursts, problems reading and writing, overwhelmed feeling.

Neurological Lyme in children – headaches, visual issues, confused, irritable, stiff neck, fevers, depression, brain fog, fatigue, word finding issues, ADHD, facial weakness, numb extremities, bell's palsy, school phobia.

Psychological symptoms – irritable, depression, anxiety, tics, visual or hearing issues, ADD, OCD, decreased school performance, outbursts.

GI symptoms – nausea, pain, reflux, vomiting.

Presentation in infants – poor muscle tone, irritability, fever, ear and throat problems, joint pains and body aches, developmental issues, cataracts, narrowing of trachea, delayed development, learning disability, psychological issues.

Babesia – intermittent fever, chills in day and sweats at night, causes increase in duration and severity of Lyme symptoms.

Treatment options include:

- Comprehensive diagnosis
- Coinfections
- Treat clinically
- Antibiotics
- Nutritional therapy
- Neurotransmitter precursors
- Probiotics
- Sleep: 5HTP, Melatonin, Herbs
- Physical therapy
- Tutoring
- HBOT
- Ondamed

Dr. Bock talked about diagnosis as those items that show seropositivity (ELISA, 2 tier ELISA/Western Blot, Urine Antigen Capture, C6 Lyme Peptide, Lyme PCR) and those that are considered seronegative (coinfection tests, ECM rash, clinical impression).

He showed the differences in test results of the Western Blot between various labs.

Coinfections

Coinfections discussed were HME/HGE, Babesia, Mycoplasma, Bartonella, and viruses.

HME/HGE (Ehrlichia) – headaches, joint and muscle pain, decreased white blood cells and platelets, increased liver function tests.

Bartonella – Cat scratch disease. Intracellular. Lymphadenopathy. Rash. Diagnosed by antibody tests or PCR. Symptoms include: encephalopathy, ataxia, peripheral neuropathy, myelopathy, radiculopathy. Gastrointestinal, ocular, and cardiac symptoms. In the GI tract can cause bloody stool, abdominal pain, heartburn, gastritis, duodenitis, inflammation, vomiting. Treated with quinolones, Zithromax + Rifampin or Doxycycline + Rifampin.

Babesia cause fever and flu-like symptoms, fatigue, enlarged liver, enlarged spleen, jaundice, petechia (small purplish spots on the skin).

Mycoplasma responsible for chronic fatigue syndrome and fibromyalgia. Intracellular. Immune system impacts. Vascular problems. Autoimmune problems. Neurological and rheumatic diseases. Difficult to treat.

Lab Assessments

- CBC
- Blood chemistry
- ESR
- ANA
- Rheumatoid Factor
- Anticardiolipin antibodies
- Serum Angiotensin Converting Enzyme
- C3 and C4 (complements)
- Lyme ELISA
- Lyme C6 Peptide
- CD57
- Thyroid antibody (TPO)
- VDRL (I think this was STDs)
- Thyroid function
- 25 D and 1,25 D levels
- B&T Cells
- Cytokines
- Immunoglobulins
- Food allergies
- B12 and folic acid levels
- Adrenal tests
- Hormone tests
- Ehrlichia (HME and HGE)
- Babesia antibodies, FISH, PCR
- Bartonella antibodies, PCR

- Mycoplasma antibodies, PCR
- HHV6, EBV, CMV levels
- SPECT scan
- MRI
- ECHO/EKG
- Psychological testing
- Coagulation testing
- RBC minerals
- Heavy metal provocation with EDTA or DMSA

Hypercoagulation is an issue in Lyme. HEMEX ISAC panel as well as other markers considered. Treatment often with heparin, nattokinase.

Nutritional Considerations

Basic: Multivitamins, CoQ10, Rhodiola, Cordyceps, Omega 3, Vitamin C, antioxidants

Minerals and Heavy Metals – EDTA, DMSA, Cilantro, Chlorella, Garlic, NAC, Lipoic Acid.

Immune support – Lyme transfer factors

Injectable or IV – Vitamin C, Glutathione, B12

Immune Dysregulation

Elevated 1,25 D is an inflammatory marker. Treatment may be Marshall protocol.

Mercury pushes towards Th2 dominance. Viruses toward Th2 dominance. 80% of chronic Lyme is high Th2 which would not be good for Transfer Factor use. 20% of chronic Lyme is high Th1. Researched Nutritionals is the transfer factor product used.

Neurotoxin Inflammation

Toxin reaction creates inflammatory cascade. Elevates TNF-Alpha. Elevates anti-cardiolipin antibodies. Changes seen in ACTH, Adrenals, ADH, MSH, Leptin, Cytokine balance, IL-6, IL-10. Elevated C3a, C4a, MMP-9. Abnormal VEGF. Abnormal VCS. Mold may be an issue. Treatment with Actos (inhibits TNF-Alpha) and Cholestyramine. (Personal Note: See my article on Dr. Shoemaker in a recent Public Health Alert that discusses this in more detail.)

Integrative Therapy

Detoxification, herbs, antibiotics, alternative treatments for sleep/fatigue, immune support, fungal sensitivity.

Antibiotic treatment – multiple courses, combinations, longer treatment, rotations, pulsing, treat cyst forms, treat coinfections.

Factors in Illness

Genetics – DR4s, SNPs

Antecedents – trauma, surgery, poor nutrition, stress, disease, viruses, antibiotic use, toxic exposures, allergies. CMV, Mycoplasma, Allergies, Eczema, Dysbiosis, Heavy metals.

Hormone mediators / brain chemicals – changes in cortisol, lower DHEA, lower serotonin/epinephrine, lower melatonin, lower thyroid hormone, low adrenal function, Th1/Th2 imbalances. Neurotransmitter imbalances.

Signs and Symptoms – fatigue, headache, fibromyalgia, joint pain, palpitation, inflammation, sleep problems, hormone problems, GI problems. Autoimmune, palpitations, paresthesias, cognitive issues.

Medical Detoxification

Gastrointestinal, liver, herbal, heavy metals, homeopathic, cholestyramine, phosphatidylcholine

Immune Dysregulation

Transfer factors, Chinese medicine, mushrooms, Qi tonics, vitamins, CoQ10, EFAs, IV C, IV Glutathione.

Anti-inflammatory

EFA, Curcumin, Bosweillin, Olive leaf, Samento

Fatigue

Mitochondrial support – CoQ10, Enada, Provigil, Carnitine, Lipoic Acid
Adrenal stress – Pantothenic acid, B6, C, Licorice, Rhodiola
Qi deficiency / kidney deficiency – Chinese medicine

Fibromyalgia

Trigger point therapy, physical therapy, massage, acupuncture, Chinese medicine, malic acid, magnesium, Elavil, Ondamed

Sleep

Melatonin, 5HTP, Valerian, Comfort Shen, Acupuncture, Ondamed, RX meds

GI Prevention

Probiotics, Saccharomyces boulardii, Flagyl, Vancomycin.

Fungal

Probiotics, Citricidal, Nystatin, Diflucan

Liver

Milk Thistle, NAC, Homeopathics

Cognitive Issues

Ginko, ALC, Vitamin E, Vinpocetine

HPA Axis

Hypothalamus – releasing factors

Pituitary – growth hormone, FSH, LH, ACTH, TSH

Thyroid – T3, T4

Adrenals – catecholamines, cortisol, DHEA, norepinephrine, epinephrine

Hormonal – estrogens, DHEA, testosterone, pregnenelone

Hypothyroidism Symptoms

Low body temperature, cold sensitivity, cannot lose weight, fatigue, dry skin and hair, constipation, mental sluggishness, slow heart rate, depressed immune function, decreased reflexes, hair loss, inability to conceive, menstruation abnormalities

Functional Hypothyroid

Measure basal body temperature, normal thyroid tests, symptoms of low thyroid, TSH can be normal or borderline elevated (0-5.5) - > 2.5 can be functional hypothyroidism, decreased conversion of T4 to T3, mercury toxicity, check TPO (antibodies) for Hashimoto's, check 24 hour urine for iodine after iodine challenge.

Treatment of Hypothyroidism

Synthroid (synthetic T4), Armour (T3 and T4), Thyrolar (synthetic T3 and T4), Cytomel (T3), Nature Thyroid, Thyrotopin, Thyro Forte, Iodine

Low Adrenal Signs

Fatigue, mental sluggishness, weakness, hypotension, lightheadedness, nausea, weight loss, depression, afternoon lull, salt cravings.

Adrenal Testing

Cortisol, Salivary cortisol and DHEA, DHEA-S, Pregnenelone, ACTH, 24 hour urine for corticosteroids

Low Adrenal Treatments

Vitamin C, Pantothenic Acid, B6, Zinc, Tyrosine, Phosphatidyl serine, glandulars, ginseng, eleuthero, licorice, rhodiola, rehmania, ashwaganda, DHEA, pregnenelone, Cortef, AdrenaCalm.

Estrogen Deficiency

Hot flash, night sweats, vaginal dryness, foggy thinking, memory lapse, incontinence, tearful, depressed, sleep problems, palpitations, bone loss, dry skin and hair, headache

Estrogen Excess

Mood swing, tender breasts, water retention, nervous, irritable, anxious, sleep problems, cold body temperature, elevated triglycerides, fibrocystic breasts, uterine fibroids, weight gain in hips, bleeding changes, headaches, heavy periods, breast cancer, low libido, weight gain in waist

Progesterone Deficiency

Candida, fibrocystic breast, hair loss, anxiety, headache, fluid retention, arthritis, endometriosis, stressed easily, sleep problems, weight gain, heavy periods, irritable, cramps, break-thru bleeding, fibroids, PMS, irregular periods, hypothyroid

Testosterone Deficiency

Low libido, vaginal dryness, fatigue, aches and pains, memory lapse, incontinence, palpitations, depressed, sleep disturbance, thin pubic hair, bone loss, decreased muscle mass, thin skin, fibromyalgia

Dysregulation accompanies infection or immune insult when the body attempts to compensate with a struggling immune, hormone, inflammatory, or energetic response. This combined with nutritional deficiencies and detoxification problems leave the body imbalanced and with a myriad of symptoms.

Dr. Bock discussed acupuncture and Chinese medicine. He further discussed energy flow within the body and meridians.

In electromagnetic medicine, human organisms respond to weak signals in specific frequency ranges. Effects can be noted with dilute allergy potencies, homeopathics, electromagnetic waves, acupuncture.

Dr. Bock discussed electromagnetic pulse biofeedback using a device called Ondamed. Uses balancing frequencies to correct blockages, micro-organism frequencies, nutritional frequencies. Can be helpful for sleep, fatigue, well-being, joint pain, fibromyalgia, inflammation, neuropathy, Lyme disease.

Treatment Focus

Evaluation of symptoms, testing, RX, antifungals, probiotics, detoxification, diet, immune and nutritional treatment, hormonal therapy, natural anti-inflammatory, nutrients, acupuncture, Chinese medicine, energetic medicine, Ondamed, homeopathic injections

Diane Wilcox: Chronic Lyme Disease – What It Does to our Work Lives

Diane Wilcox presented on a study she is doing on how chronic Lyme impacts our work lives. More information is available at <http://www.lyme-and-work.blogspot.com/>

Some notables:

- 37% lost more than 100,000 due to Lyme disease
- 71% take 4 or more medications per day
- 84% use nutritional supplements
- 71% use herbal remedies
- 48% had depression
- 45% had Babesia
- 29% had Bartonella
- 15% had Ehrlichia
- 38% took less than 3 month leave from work
- 29% employed full time
- 19% employed part time
- 13% were fired
- 25% permanently disabled
- 28% spent 100K-500K
- 10% spent more than 500K

Chronic Lyme seriously affects the way we learn, think, plan, and make decisions. Executive function in the brain has been impaired

Dr. Joseph Jemsek: Lyme Borreliosis Complex – A Polymicrobial Mediated Immunosuppressive Chronic Illness

Dr. Jemsek started out with references to his current legal situation. He said "I have a gift and I am gonna share it, damnit!". The audience cheered. He even suggested that he was speaking as if Blue Cross was in the room.

First two cases of Lyme were at his clinic in 2001. He has since treated over 2000 people.

Polymicrobial players include:

- Babesia – AMERICA'S MALARIA
- Bartonella
- Ehrlichia/Anaplasma
- Borrelia
- Others

Polymicrobial nature of syndrome fits concept of "disease process". There is an alphabet soup of pathogens involved in Lyme.

Lyme Borreliosis Complex (LBC) represents an acquired immunodeficiency. Associated with wide range of co-morbidities. Multiple clinical patterns. Life altering without spontaneous remission.

Eventually, we will discard the term "Lyme disease" as it is poorly descriptive, politically inflammatory. The name Acquired Immune Deficiency Syndrome is already taken!

Success is about gaining and maintaining immunologic control. Multiple infections require sophisticated antimicrobials. The "pathenogenic hierarchy" or "ringleaders" not fully identified. Borrelia, Babesia, and Bartonella clearly ringleaders. Life stressors or other physical illnesses trigger relapse.

The controversy over Lyme is insanity. Sad reflection of society's disregard for a devastating health issue. Whether there is a conspiracy remains to be seen. Power, Ego, Money. We are in the midst of a pandemic. The storm has arrived.

Babesia

Fever and chills. Sweats with exertion or night sweats. Random sweats. Refractory headache. Refractory inflammatory joint disease. Enlargement of spleen and liver.

Protozoa. Human pathogen. More than 100 species. *B. microti*, *divergens*, WA-1, CA-1, MO-1, and *duncani* all infect humans.

Intracellular. Found in blood. > 30 cases from blood transfusion since 2001. High replication rate in humans.

Broad range of presentation from asymptomatic to severe. Fever, malaise, fatigue, chills, sweats, headaches, myalgias, enlarged spleen, arthralgias.

Severity related to age and host immunocompetency. Most severe infection when spleen previously removed or host is immunocompromised.

If you treat Babesia and you are still sick, it is probably still Babesia. Joint pains get better when treating Babesia.

Bartonella

Endothelial disease, multiple skin manifestations, enlarged lymph nodes, esophageal and gastric ulcers, bony exostosis, refractory cognitive issues, history of abnormal SPECT scan. More ubiquitous. Bumps on fingers which look like bone are Bartonella.

Bartonella – 9 species infect humans. 50-70% prevalence in European study. 4 species found in dust mites. Found in flea feces. Bartonella likely affects the brain. It is “silent corrosion”. Vasculitis and Neuropathy.

Ehrlichia

HME – Monocytic. HGE – Granulocytic - now called Anaplasma. Infects leukocytes.

Borrelia

Lyme is a superbug. Syphilis is the dumb cousin. Patents in 1988. 132 lipoprotein genes in *Borrelia* vs. 22 in syphilis. Perhaps the most complex bacteria known.

Persistence via:

Immune suppression

Innate – complement inhibition, induction of anti-inflammatory cytokines, tolerization of monocytes

Adaptive – induction of anti-inflammatory cytokines, tolerization of lymphocytes, complement inhibition, immune complex sequestration

Immune evasion

Phase and antigenic variation – gene conversion, variable expression of antigens

Physical seclusion – intracellular, extracellular, cysts, immunologically privileged sites

Borrelia wins! *Borrelia* destroys WBC – not the other way around.

Lyme bacteria love brain tissue. Causes memory loss, mood disorders, lack of concentration, sleep issues, anxiety, word retrieval difficulties, headaches

Symptoms of LBC – fever, tick bite, flu-like symptoms, severe fatigue, rash, headache, muscle and joint pain, Bell's palsy, meningitis, encephalitis, cognitive deficits, mood, sleep issues.

An internal medicine doctor averages 7 minutes with a patient – not enough time for a complex issue such as LBC.

Life Forms of Borrelia

Life forms of *Borrelia* – blebs and vesicles, L-forms, membrane derived cysts, motile helical spirochetes. Spirochetes found intracellular and extracellular. Found in tissues and fluids. Skin, heart, brain, CSF,

lymphatic tissues, spleen, kidney, muscle, blood, synovial fluids. Blebs are antigenic decoys shed by spirochetes intended to spend "immune capital". L-forms can form under antibiotic pressure. Lack a cell wall. Osmotically fragile. Survive beta-lactam treatments. Reform a cell wall when turning back into spirochete. Might be a transitional form to cyst. Cyst – reduced metabolic activity. Formed under environmental stress including antibiotics, pH, oxidation, heat. Found intracellular and extracellular spaces. Reproduce inside the cyst. Survive longer than a spirochete.

Other Microbes

Mycoplasma – Dr. Garth Nicholson

Chlamydia – Dr. Charles Stratton

EBV – Dr. Dagmar Hulinska

HHV6 – Dr. Joseph Brewer

Mycoplasma – lack a cell wall. Over 100 species. Lack metabolic pathways such as energy production and synthesis of cell components. Depend on host for nutrients. Chronic fatigue and Gulf war germ. Associated with Bell's Palsy and Fibromyalgia. Treat with doxycycline, fluoroquinolone, and add Plaquenil. Not clear if it is opportunistic, commensal, or primary player.

Chlamydia – implicated in heart disease. Role more fundamental in chronic illness. Not culturable generally. Chlamydia trachomatis and Borrelia found in synovial fluids of people with arthritis.

EBV – herpes virus. 90% of world is infected. Causes mononucleosis. Can be reactivated with stressor. Borrelia and EBV shown to cause severe neurological disease in one study.

HHV6 – herpes virus. 90% of world is infected. Most neuroinvasive of herpes viruses. Reactivation associated with epilepsy and neurological problems. Often found in MS.

Trigger mechanism for LBC is something that causes "tipping point". Could be biologic, environmental, hormonal, physical or psychological. Once the tipping point is reached, the patient is an immunological prisoner of LBC for life. Without intervention, matters only get worse.

Babesia and Borrelia together cause IL-10 and IL-13 to decrease – these are anti-inflammatory. Arthritic symptoms increase. Severity of myocarditis increased.

Ehrlichia and Borrelia together cause increased load of both organisms. Decrease in IL-12, IFN- γ , TNF-alpha, IL-2 and increase in IL-4 and IL-6.

Study done with Borrelia and HGE infection showed that patient is less able to fight Borrelia when HGE is present. Increases ability of Borrelia to penetrate CNS. Increases endothelial cell barrier exposure to Borrelia.

Immunosuppressive pathogens – Borrelia, Bartonella, Ehrlichia (HGE)
Additive or Promoting – Borrelia, Bartonella, Ehrlichia (HME and HGE), Babesia.

Treatment

Know the ELF – Essential Life Functions

Learn your Poems:

Pain

Other – family support, access to treatment

Endocrine/metabolic

Mood/psychiatric

Sleep

Comforting POEMS make the ELF happy.

We don't treat many chronic illnesses with one drug.

Therapy must address:

Bb multiple forms and locations

Major co-infections

Sequence and combinations that make sense

Immunological blockade by Babesia:

Babesia upregulates Borrelia

Address Babesia early

Clinical responses varied

Adequate duration is key. Serious Babesia infections may require 12-16 weeks of treatment.

Assume herxheimer effect only with Borrelia. Bactericidal lysis and release of lipoproteins or through cyst lysis.

Continued effects with new RX combinations implies purging of Bb strains not previously eradicated.

Chances for “immunologic control” increased when purging with focus on blocking co-infections like Babesia.

Clinical Babesia co-infections not reliably detected by labs. Extreme diversity. Follow the sweats.

Bartonella is a major player in endothelial disease. Major contributor to CNS disease. More pervasive and insidious than Babesia.

Babesia Treatment:

Oral – combination of macrolide, doxycycline, Mepron or Malarone and/or Artemisinin.

IV – Clindamycin and Zithromax plus oral Mepron/Malarone and Artemisinin.

Ehrlichia/Anaplasma/Chlamydia/Mycoplasma – in theory covered with other therapies

Bartonella Treatment:

Oral – Sulfa, TMP-Sulfa, Levaquin, Rifabutin

IV – Levaquin, TMP-Sulfa pulsed – alternative Rifabutin

Maintenance program consists of core combination RX, periodic imidazole, progressive extension of holiday periods until goal of 1 week per month reached. Every other day dosing for core is acceptable.

Maintenance – Every 4 week pulsing with three days of combination RX. Prominent herxheimer on maintenance is a bad sign. Once past “induction”, 18-24 month maintenance program. Best measure is response to intense life stressors.

Summary

Immunologic control is the goal with therapy.

Babesia is America’s malaria. Must be accounted for in all cases of advanced LBC.

Advanced disease will require extended therapy.

Combination, pulsed, sequential antimicrobial therapy protocols are effective.

Assumption – three key pathogen groups – Borrelia, Babesia, Bartonella.

Creating an RX approach based on these three pathogens has resulted in strong results.

Be thankful – what if there was no effective therapy? What if antibiotics were not useful? What if there was no active research?

The time for change is near – LBC is too big, too hurtful, and too obvious.

Other Notes

May start using Valtrex for HHV6.

He believes that much of the herx reaction is a cytokine response more so than a neurotoxin.

Follow the sweats when following Babesia treatment. Artemisinin or Mepron that cause sweating is a sign of Babesia.

Resistance to Artemisinin develops if used as a monotherapy.

Does not generally use beta-lactam drugs.

750mg Mepron twice daily or 2 teaspoons twice a day in some cases. 3 days a week. Malarone + Zithromax or Ketek 3 days a week for 3 weeks with 1 week off. Amoxicillin plus Zithromax for pregnant mother from second trimester.

Good balance takes 18 months AFTER getting well.

Biaxin, mino, Rocephin may be neuroprotective.

Jemsek did not believe that there is a concern with doing HBOT if the patient has Babesia as some have suggested.

Mark Garzon: Heavy Metal Toxicity and Lyme Disease

Classification of Lyme patients:

- Exposure to Bb and co-infections with no symptoms
- Exposure to Bb and co-infections with symptoms caused by Lyme and co-infections
- Exposure to Bb and co-infections whose symptoms are caused by something else
- Exposure to Bb and co-infections whose symptoms are caused by Lyme, co-infections, AND something else.

What is something else?

- Hypothyroidism
- Adrenal dysfunction
- Viral infection
- Gastrointestinal dysbiosis (yeast, fungus, mold, parasites)
- Mold allergy/toxicity
- Autoimmune diseases
- Depression/emotional disturbances
- Toxicity (especially neurotoxins)

Fat soluble toxins – neurotoxins are fat soluble, Dr. Shoemaker, every cell in the body including nerve cells have a cell membrane containing fat. Most common neurotoxins are: Bb toxins, yeast/fungal toxins, mold, heavy metals (mercury, lead, arsenic).

Neurotoxins pass right through myelin sheath as well. Mercury destroys myelin sheath.

If you have had mercury/silver fillings, you probably have mercury neurotoxicity.

Symptoms of heavy metals and Lyme are nearly identical. If you are not getting better with Lyme treatment, think about heavy metals.

Like Lyme, heavy metals is a controversial topic – ignorance and lack of adequate diagnostic tests. Medical texts all use blood (serum) as diagnostic criteria for heavy metals. Heavy metals are fat soluble and therefore pass into and through cells – they are NOT in the blood. Blood tests are only good for acute ingestion.

Dr. Garzon reviewed some tests from Doctor's Data and also talked about the Urinary Porphyrin profile. Heme synthesis is disrupted by heavy metals and can be evaluated with the Porphyrin test.

The gold standard is a provocation test where the patient is given a chelating agent or a binding agent and then the urine or stool are checked for metals. Chelating agents: EDTA, DMPS, DMSA, Penicillamine.

Remove the sources of heavy metals if possible. Replace amalgams with porcelain or gold using a dentist experienced in heavy metal removal.

Avoid thimerisol in adult vaccinations. Test well water. Reduce fish.

Heavy metal toxicity – EDTA, DMPS, DMSA, Penicillamine. IV Glutathione and Vitamin C can be helpful. Skin IR sauna, clay baths, detox foot pads. Oral detoxification agents include: Metal Free, NDF, chlorella, oral EDTA, Lipoic Acid, Detox-Max, NCD.

If the dentist is not wearing a gas mask to remove your mercury, they are likely not protecting themselves or you.

DMPS is a good option for mercury and arsenic. EDTA is better for lead.

Mark Garzon: Bio-Identical Hormone Replacement for Lyme Disease

Hormones are messengers sent from one part of the body that have an effect on another part of the body. They have influence over physical, emotional, and mental health.

Hormones decrease with age. Bio-identical hormone replacement has become a popular anti-aging treatment. Can be used to treat symptoms of Lyme disease. Dr. Shoemaker believes that neurotoxins impact the hypothalamus and pituitary glands which are the master hormone organs in the brain.

Fatigue, insomnia, brain fog, digestive problems can all be helped with hormone replacement. First step is to test levels. Checking thyroid and steroid hormones is a minimum. Steroid hormones are cortisol, DHEA, progesterone, estrogen, and testosterone.

Cortisol is the most important and is an adrenal hormone. Has many functions including anti-inflammatory. Lyme disease is an inflammatory process so a person with Lyme needs to make more cortisol to deal with inflammation.

These increase need for cortisol:

- Emotional stress
- Infections
- Autoimmune illness
- Allergies
- Acute and chronic pain
- Toxicity (chemical, heavy metals)

At first, adrenals will produce high levels of cortisol. With chronic stress, the adrenals cannot maintain a high level of cortisol production and leads to adrenal stress/fatigue and cortisol levels begin to drop.

Symptoms of adrenal fatigue:

- Chronic fatigue
- Digestive problems
- Constipation
- Brittle hair or nails
- Insomnia
- Inability to handle stress
- Depression
- Memory loss
- Brain fog
- Mood swings
- Irritability
- Poor immune function
- Bloating / fluid retention
- Hypoglycemia
- Dizziness when standing
- Impotence
- Low libido
- Menstrual problems

Adrenal fatigue has downstream effects on sex hormones. When under inflammation or stress, progesterone is moved to the cortisol pathway. This leads to imbalance of progesterone and estrogen and results in estrogen dominance. Estrogen dominance causes uterine

fibroids, fibrocystic breasts, and can lead to breast cancer. Progesterone should be about 100 times estradiol or you are estrogen dominant. If progesterone is higher than testosterone, you can have erectile dysfunction.

Testosterone can be shunted to the cortisol pathway as well.

Different cortisol patterns can suggest different disease states such as parasites, hypoglycemia, and insomnia.

High AM cortisol levels consistent with parasitic infection. Then drop after first morning test. Drop of more than ½ from 8am to noon, suggests parasites.

4am cortisol can be higher due to hypoglycemia.

Dr. Garzon uses a bio-identical hormone cream that is created for each person uniquely. It has a liposomal delivery system.

Yam based progesterone or soy based estrogen is used in hormone creams.

Tribulus used in the cream, not testosterone. Do not use cortisol or testosterone in the cream.

Mercury is fat soluble. Lyme patients that diet can expose themselves to more mercury. Mercury and lead together have a much more dangerous impact than either alone.

Sun Chlorella – high doses – 550 mg caps – 4 caps 3 times a day BEFORE meals.

Often uses a drainage remedy – German homeopathics

Clifford Research tests for compatibility of dental materials.

DMPS best provocation test but DMSA may be better for long-term therapy. Single dose vials of vaccines may be less likely to have mercury than larger vials.

Amy Derksen, ND: Using Alternative Methods to Help Guide Lyme Treatment

Presentation from Amy Derksen, ND can be found [here](#).

This presentation is one that I was most excited about. Amy Derksen is one of my personal doctors and I resonate very strongly with her work. I was so pleased to see the strong positive response that the audience gave to her discussion.

I am not summarizing it in detail here as the presentation is available above and provides all the details.

Some notes:

Brown spots in iris can be heavy metals.
Weight in the mid-section can be high cortisol.
Very important to support the kidneys while using DMPS.

Carol Fisch: Introducing a New Antigen Test by Flow Cytometry to Detect *Borrelia Burgdoferi*, the Bacteria that Causes Lyme Disease

Key points:

- Passed state inspection on first attempt with no recommendations or corrections
- One of a kind test
- Immune Fluorescence testing using Flow Cytometer
- Identifies Bb including cysts
- Can count the number of Bb in 50,000 cells in one minutes
- Test result reported as a percentage of counted cells
- Results of 0.02 – negative, 0.03 – borderline and 0.04 – positive
- Results in 72 hours
- Covered by insurance and Medicare
- Can be ordered from Europe
- www.CentralFloridaResearch.com

Rita Losee, RN: When Life Gives You Lyme, Make Lymeonade

Rita is a motivational speaker that herself has Lyme. She was a very uplifting speaker.

The "Secret": 1) Ask for what you want 2) You believe that you will get it 3) You allow it to happen.

Ask from a place that is already mine – thank you for whatever you want rather than I would like

What you think about and talk about comes about.

Invest energy and time into what it would be to be completely and totally healthy again.

Institute of Heartmath – evidence of immune-suppression for six hours after 5 minutes of angry thought.

Happy thought – immune function went up for six hours. Everyday – do everything you can to make yourself feel good. Use imagination. Visualization.

Don't use "I am a Lymie" – be something positive.

Sarah Fletcher, MD: Our Journey

Dr. Fletcher shared her own personal story with Lyme.

Before Lyme – she had dental amalgams, IBS, 3 pneumonias, yeast infections, depression, fibromyalgia, fish allergy, rheumatoid arthritis

Holmes is hired – Dr. Leila Zackrison. Removed wheat from diet. Treated trichinella. High ELISA, + WB, + urine antigen. Milk, chocolate, soy allergies.

Treated with orals and IM Bicillin which stabilized but neurological symptoms followed. Urinary and fecal incontinence, bad imbalance, brain fog, choking on saliva and food, night sweats, ulnar neuritis.

Hope to Heal Lyme 2007

Did 9 months of Rocephin and relapsed after 2 weeks.

Had gallbladder removed to see if she improved. PCR + in gallbladder after 9 months of Rocephin. Organs like gallbladder cannot be cleared of infection in many cases.

Identified Babesia and ureaplasma.

Started working less, amalgams removed, chelation started, weight training. Tapeworm, C. Difficile.

Still working on her recovery from Lyme.